

# Children With Acquired Brain Injuries: The Transition from Hospital to Community



Vancouver, British Columbia, Canada

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# Introduction

This manual is about children and adolescents who have recently sustained an acquired brain injury. It is written for hospital, community rehabilitation, and school professionals to facilitate the transition of these children from hospital to home, community, and school. It focuses on the time from discharge to the next few months thereafter.

The severity of a child's brain injury is often described as mild, moderate, or severe. This manual focuses on children who have sustained moderate or severe injuries, and who are beginning to regain many of their previous abilities, such as walking and talking, in the hospital or soon after returning home. For the purposes of this manual, we have not included children with mild brain injuries or those with catastrophic injuries (who remain in a vegetative or minimally conscious state and have severe physical impairments). The term "children" is used throughout the manual to mean children and adolescents of all ages.

## Why This Manual Was Written

Injuries are the leading cause of death and disability in children and adolescents (Medical Research and Training Center in Rehabilitation and Childhood Trauma, 1993). Although brain injury registry data has not been compiled in British Columbia, it is estimated that approximately 150 to 250 children and adolescents sustain a moderate to severe traumatic brain injury in BC every year. In addition, other children and adolescents sustain brain injuries from non-traumatic causes such as strokes and anoxic injuries.

There is still a widely held misconception that children recover better from brain injuries than do adults. While children who have sustained even a severe brain injury generally recover well physically, they are not spared cognitive and psychosocial problems. These children are at high risk for significant long-term social, educational, and vocational difficulties (Lehr & Savage, 1990, Asikainen, 1998).

Most children are not referred to rehabilitation centres from hospital. Those who are discharged directly home are often not linked with the needed support services in their community. They often return to their previous activities and school too quickly after discharge. Their difficulties may not be attributed to their recent brain injury.

The U.S. National Pediatric Trauma Registry studied 24,000 children and adolescents with traumatic brain injury, and concluded:

*“The majority of children with traumatic brain injury, and functional limitations due to the injury, return home at time of discharge from acute care with limited referral to potentially beneficial services”* (DiScala, Osberg, & Savage, 1997).

These were children who were known to have functional limitations in bathing, dressing, and walking as a result of their brain injury.

Some parents may report feeling that they were not adequately informed about community rehabilitation and school services upon discharge. Parents may have limited understanding of their child’s brain injury and of how to best provide assistance. They may be unprepared and lack the confidence or skills needed to help their child upon the return home.

Children and adolescents with a recent acquired brain injury need to be identified and linked with appropriate support services. Their families should also be linked with professionals who can provide them with the information and support they need. This manual will help professionals make these important links to community support services and help prepare for the road ahead.

## **How This Manual is Organized**

This manual is organized into five chapters.

Chapter 1, *Acquired Brain Injury*, provides general background information about pediatric acquired brain injury and its effect on development and learning.

Chapter 2, *Family Issues*, discusses family needs and experiences during the early stages after the injury. Suggestions for family support and assistance are also included.

Chapter 3, *Hospital Discharge*, provides a step-by-step process to link these children with the appropriate rehabilitation and support services in their community. A series of family handouts is also included.

Chapter 4, *Returning to School*, provides a step-by-step guide for integrating these children back into the school setting with the appropriate level of support.

Chapter 5, *Rehabilitation*, provides information about interdisciplinary assessment of children with acquired brain injuries. Some general rehabilitation goals and strategies for these children are also discussed.

Most chapters include a *Future Considerations* section that discusses some of the issues that may arise over the long term. Recommended reference materials can be found in the Appendix at the end of each chapter.

In writing the manual, we spoke to rehabilitation and school professionals in both rural and urban areas of BC to identify information they would like included. Their feedback was very valuable during the manual's conception, and we trust that this manual reflects their wishes and meets their needs. We hope this manual will be a useful and practical tool to help rehabilitation professionals in communities across BC.

## **Would Families Benefit from Reading This Manual?**

As noted, this manual is written for professionals. However, since the first printing, a number of parents have told us the information in this manual is very useful and recommended that we make it available to other families of children with acquired brain injuries.



## Chapter

# 1

# Acquired Brain Injuries in Children

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## Chapter Overview

**Who is this chapter for?** Rehabilitation and school professionals.

**Who is this chapter about?** Children who have recently sustained a moderate to severe brain injury and who are beginning to regain previous skills such as walking and talking.

**What is this chapter about?** Acquired brain injuries in children, including key concepts and terms used in the following chapters.

**C**hildren and adolescents are especially vulnerable to ongoing disability following a moderate to severe brain injury. The effect of an injury to a young, developing brain is different from an injury to a mature, adult brain. Injury to the immature brain can affect not only the child's current abilities, but also the child's capacity to continue to develop and learn. While precise figures are not available, the majority of children and adolescents with a moderate to severe brain injury can expect to experience some form of lasting disability (Krause, 1994).

This has important implications for rehabilitation planning. There is no cure for a brain injury. However, early implementation of appropriate supports and services can significantly decrease complications often associated with brain injury, such as academic and social-behavioural problems (Ylvisaker, 1998).

In this chapter we provide a general introduction to acquired brain injury, highlighting issues important to early planning. We begin with an overview of the uninjured brain. We then describe what happens when the brain is injured, the kinds of problems that may be seen following the injury, and issues concerning recovery and outcome. The following questions are addressed:

*How is the normal brain organized? How does it work?*

*How does the young, developing brain differ from the mature, adult brain?*

*What is an acquired brain injury?*

*What are common problems children experience following a brain injury?*

*What do we know about recovery in children?*

## Structure and Function of the Brain

The brain serves as the control centre for most of the body's functions. It is a highly interconnected and complex organ. The brain activity underlying any organized behaviour involves an extensive network of nerve cells. Higher-level brain functions, such as attention, memory, and walking, are mediated by complex interactive systems that involve many different regions of the brain. A functional system can be disturbed by injury to any one or more of a large number of areas, and will be disrupted differently depending on the specific region injured.

This section provides a simplified description of the organization and structure of the normal brain. We start with the smallest unit, the nerve cell, then move to the larger anatomical divisions of the brain. A brief discussion of some of the developmental changes in the young brain is included.

## The Nerve Cell

The brain is comprised of billions of nerve cells called *neurons*. Neurons are the basic building blocks of the nervous system. They are the “communicator” cells. Neurons carry information to and from the brain and interconnect the various regions within the brain. Fibres that extend from the nerve cell bodies (*dendrites* and *axons*) receive and transmit information in a relay fashion: electrical impulses pass through the neuron, and are then chemically transmitted from one cell to another. A whitish sheath of fatty tissue called *myelin* surrounds the axon and enables the cell to carry impulses more efficiently.

## Basic Organization of the Brain

The brain can be described in terms of three basic divisions: the brainstem, the cerebellum, and the cerebral hemispheres (see the diagram on page 1-4). Each of these parts has diverse underlying structures and functions. We start with the brain regions that deal with the most basic aspects of human function, such as breathing and consciousness, and end with brain regions that deal with the most complex and subtle aspects of human thought and behaviour.

### Brainstem

The *brainstem* interconnects the spinal cord and the cerebral hemispheres. The brainstem includes the *reticular activating system* (RAS), a network of cells involved in the control of arousal (sleep/wakefulness) and the ability to maintain attention. Brain injuries that involve the RAS typically result in a decrease or loss of consciousness.

The lower part of the brainstem controls basic functions essential to life, including breathing, heart rate, and blood pressure. It contains relay centres for vision, hearing, touch, taste, balance, and chewing and swallowing.

The upper part of the brainstem is important for integrating and relaying information related to sensations and movement, and for controlling hunger, thirst, sleep, hormonal secretions, and temperature regulation. Structures in the brainstem are also closely associated with the *limbic system*, which is of primary importance in the regulation and expression of emotions.

### Cerebellum

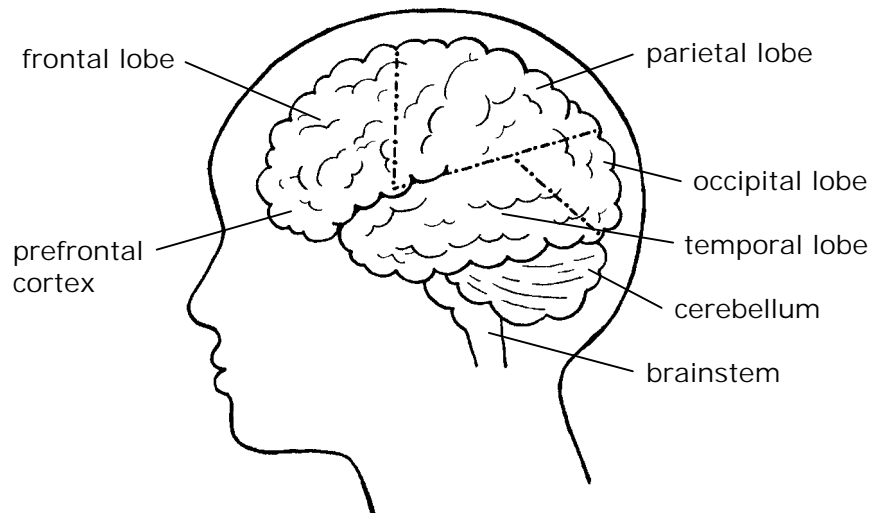
The *cerebellum*, which is attached to the lower part of the brainstem, is primarily involved with balance, refined movements, and muscle tone. Injury to the cerebellum can result in impairments such as tremor, weakness, and impaired gait or speech. Recent research indicates that the cerebellum also plays a role in some cognitive abilities.

## Cerebral Hemispheres

The two *cerebral hemispheres*, which constitute about five-sixths of the mass of the brain, are involved with more complex and integrated brain functions. They are composed of an outer layer of grey matter, the *cerebral cortex*, underlying white matter, the myelin-covered nerve fibres, and subcortical structures, the *basal ganglia*. The two hemispheres are connected by the *corpus callosum*, a wide band of nerve fibres.

**Basal Ganglia** – The basal ganglia, located in the central part of each cerebral hemisphere, play an important role in sensory-motor control and contribute to higher-order cognitive functions. Basal ganglia injuries commonly result in movement disorders. They can also disrupt aspects of cognitive function and personality.

**Lobes** – Each hemisphere of the brain can be divided into four lobes.



- **Occipital Lobes** – The *occipital lobes* are involved in processing and understanding visual information. Damage to the occipital lobes can impair visual awareness and recognition.
- **Temporal Lobes** – The *temporal lobes* are important for memory and auditory processing, including language comprehension. Damage to the temporal lobes can result in specific memory impairments and difficulty understanding spoken language. The temporal lobes are closely interconnected with the limbic system and the frontal lobes, and play a critical role in the integration and regulation of emotion, motivation, and behaviour. They are also involved in music perception and the sense of smell.
- **Parietal Lobes** – The *parietal lobes* are involved in body sensation (the *somatosensory* functions), including touch, pressure, temperature, and position awareness.



The parietal lobes are also involved in more complex perceptual and cognitive skills. They are responsible for the integration of visual, auditory, and somatosensory information, which provides a multi-sensory experience of the external world.

Injury to the parietal lobes can result in disorders of language, reading, writing, arithmetic, recognition of visual and tactile information, body image, and spatial abilities. Parietal injuries can result in different motor planning (*dyspraxic*) disorders, including difficulty carrying out dressing, drawing, and constructional activities. Parietal injuries can also result in a disorder of selective attention, or specific inattention for information on one side of space, usually the left.

- **Frontal Lobes** – The *frontal lobes* contain the motor areas and the large *prefrontal* regions. The motor areas are involved in movement and in organizing the sequence of body movements. Injury to the motor areas can result in weakness or paralysis, and can disrupt complex motor acts such as speech production.

The prefrontal regions are commonly referred to as the “executive centres” of the brain. They are involved in the most subtle and complex aspects of human behaviour. The prefrontal areas are richly interconnected with all the major sensory and motor systems. They integrate and regulate all components of behaviour at the highest level. Common difficulties following frontal lobe injury include problems planning, monitoring, and modifying activities. Prefrontal injuries can disrupt mental flexibility, abstract thinking, self-awareness, judgment, social skills, emotional regulation, attention, organization, and memory function. Changes in personality are often seen after injury to these regions.

### Differences in Left/Right Brain Function

There are important differences in the function of the two cerebral hemispheres. For example, in most people, the left side of the brain has primary responsibility for language, verbal memory, and logical, sequential analysis. The right side is better suited for more holistic, nonsequential information processing and is dominant for spatial-perceptual-constructional tasks. This dominance arrangement is sometimes incomplete or reversed.

Each side of the brain is either responsible for, or plays a dominant role in, sensory and motor function in the opposite side of the body. For example, using the right hand is a left-sided brain function. Injury to the left motor or somatosensory areas can result in a right-sided paralysis or sensory loss. This left/right arrangement is more complicated for vision and hearing.

## The Brain's Blood Supply

The brain is maintained by a complex system of blood vessels. To operate normally, the brain requires a constant supply of oxygen and glucose, which are transported via the bloodstream. Impairment of the blood supply is one of the most common causes of injury to the brain. Even brief interruptions in blood flow can result in brain dysfunction.

## Protection of the Brain

The brain is normally supported and protected from injury in the following four ways:

- The brain is enclosed in the skull, which generally serves a protective function. However, in a traumatic head injury, the fragile brain tissue, which has a consistency somewhat softer than jello, can be injured when it is jarred against the rough inner surface of the skull.
- The brain is protected by three membranes between the skull and brain. The outermost layer protects the brain from excessive movement, but this protection breaks down when the movements are violent.
- The brain is normally cushioned from shock by *cerebro-spinal fluid* (CSF). This fluid is produced within four hollow internal chambers within the brain, called *ventricles*. The CSF circulates from the ventricles out onto the surface of the brain and down alongside the spinal cord. Sometimes an injury to the brain results in obstruction of the flow of CSF, leading to dangerous fluid build-up (*hydrocephalus*) and pressure on the brain tissue.
- The brain is normally protected from many chemical substances circulating in the rest of the body by a *blood-brain barrier*. This barrier can break down when the brain is injured, resulting in leakage of toxic substances into the brain tissue.



*Children are not  
little adults.*

## The Developing Brain

The developing brain is very different from the adult brain. The brain weighs just under one pound at birth, and continues to grow rapidly, reaching 80 percent of its adult weight of approximately three pounds by about age four.

Much of the brain's growth is due to an increase in the size, complexity, and *myelination* (development of the myelin sheath around the neuronal axon) of nerve cells after birth. We are born with all the neurons in the brain that we are ever going to have. The neurons in the brain are not replaced if injured. However, after birth, the neurons continue to mature and form additional fibre connections into adulthood. Myelination is critical for the efficient functioning of the nerve cell. It begins before birth and continues until age 20 or later. The *prefrontal cortex* is relatively late to mature; this appears to be related to the development of more abstract and complex thinking abilities.

As the brain increases in size, there is an ongoing functional organization of the nervous system that reflects both its genetic blueprint and the influence of environmental stimulation. Damage to the young brain can disrupt the development of this complex structural and functional organization.

From birth to age two, the child's brain is particularly vulnerable to traumatic injury. The young brain tissue is less myelinated and therefore of a softer consistency, making it more susceptible to injury when the head is jarred. The child's large head size in relation to the body and weaker neck muscles both make the child more susceptible to injury. The skull offers less protection because it is pliable at birth and does not become solid until after age one; the front portion of the skull may not harden completely until age two.

In children, the cognitive deficits associated with injuries that involve specific areas of the brain are broadly similar to those found in adolescents and adults, but they tend to be less marked and less differentiated. Infants and preschoolers, in whom cognitive skills are developing rapidly, are at greater risk for generalized cognitive impairment.

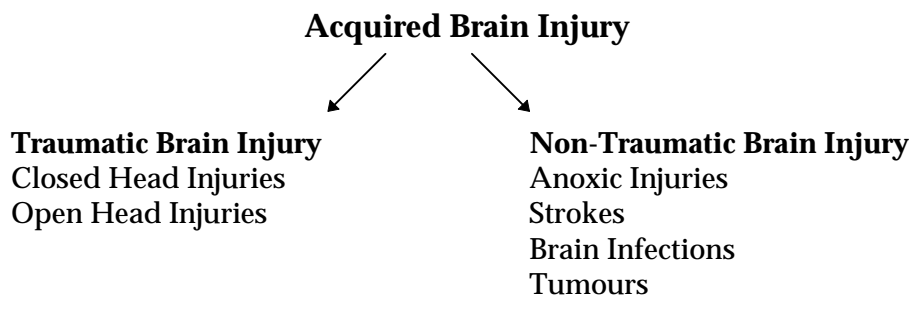
As the brain matures, the relationship between specific (*focal*) injuries and the pattern of cognitive and behavioural problems becomes more pronounced and predictable. The brains of older adolescents are more structurally similar to adult brains, and the relationship between the site of damage and behavioural consequences is more direct and reliable in comparison to younger children. However, a brain injury in adolescence can disrupt the final stages of brain maturation and organization, and comes at a time when individuals are facing major developmental challenges (adapted from Begali, 1992, Lehr and Savage, 1990).

# Acquired Brain Injuries

An *acquired brain injury* is an injury to the brain that has occurred since birth. The term *acquired brain injury* does not refer to brain injuries that are congenital or brain injuries induced by birth trauma (adapted from the U.S. Brain Injury Association, 1997 as cited in BC Brain Injury Association, 1997).

The brain can be injured in many different ways. The effects of these injuries are unique, and depend on a complex set of variables related to the injury and to the individual child or adolescent. An acquired brain injury may result in subtle to profound impairments in many areas, including physical, cognitive, and social abilities.

There are two broad categories of acquired brain injuries (ABI): traumatic and non-traumatic.



Adapted from Savage, 1993 as cited in Blosser & DePompei, 1994.

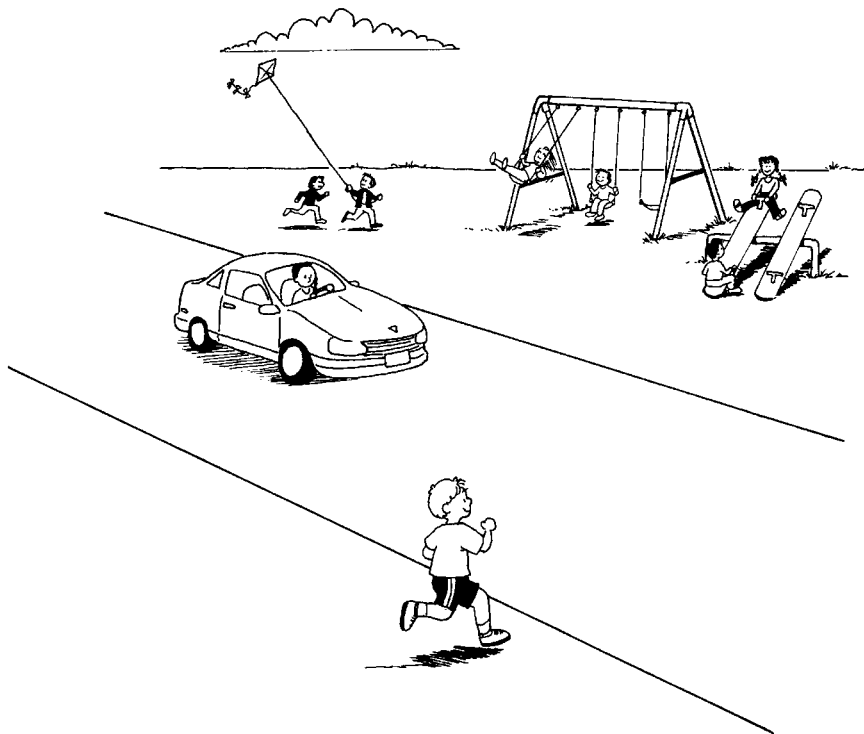
## Traumatic Brain Injury

*“A traumatic brain injury is an insult to the brain caused by an external physical force. The injury may produce a diminished or altered state of consciousness, resulting in an impairment of cognitive abilities or physical functioning. These impairments may be temporary or permanent and may cause partial or total functional disability or psychosocial maladjustment”*

(U.S. Brain Injury Association, 1986 as cited in BC Brain Injury Association, 1997).

Causes of traumatic brain injuries in children and adolescents include motor vehicle accidents, falls, and assault. The most common causes of traumatic brain injury tend to vary with the severity of the injury and the age or developmental level of the child. The number of boys injured is roughly twice that of girls.

In children, falls account for the majority of traumatic brain injury hospitalizations, but most of these injuries are mild. Motor vehicle accidents account for the majority of severe injuries. In infants, physical abuse has been reported as the most frequent cause of injury. As children become older and more involved in recreational activities, sports-related injuries become more common. During adolescence, the rate of traumatic brain injury increases dramatically. The number of severe injuries sustained between ages 15 and 19 is estimated to be equal to the number sustained in all the previous 14 years combined (Lehr & Savage, 1990, Ylvisaker, 1997, Blosser & DePompei, 1994).



A traumatic brain injury generally occurs when the head is struck or when it strikes a hard object (for example, the dashboard of a car) and the brain is pitched around inside the skull. The brain can also be injured without the head being struck—for example, in cases of whiplash or violent shaking.

This type of brain injury results from the sudden starting and stopping movements of the head and the brain itself (often referred to as *acceleration/deceleration forces*). The initial force to the head causes direct injury to the brain (*primary injury*). As the head quickly moves, the brain follows the movement of the head and gets pulled and twisted, resulting in injury to the nerve cells. Bruising and lacerations to the brain tissue and resultant bleeding may occur.

Further injury to the brain can also occur in the minutes and hours following the injury (*secondary injury*). There may be swelling of brain tissue, pooling of blood, lack of blood flow to parts of the brain, and biochemical changes affecting nerve cell function.

The rotational and shearing forces involved in traumatic brain injuries typically result in a common pattern of damage. This includes widespread injury to the nerve cells and blood vessels throughout the brain (*diffuse injury*) and bruising in the prefrontal and anterior temporal areas. Other injuries to specific areas of the brain (*localized* or *focal injury*) may also occur.

Depending on the cause, traumatic injuries may involve bruising or skin lacerations, facial fractures, broken teeth, and other soft tissue injuries. The skull may also be fractured. Most skull fractures heal without intervention. In some cases, a penetrating injury occurs in which the fracture is depressed, resulting in direct damage to the brain. This is referred to as an *open head injury*. Injuries to the brain that do not involve a penetrating injury are referred to as *closed head injuries*.

## Non-Traumatic Brain Injury

A *non-traumatic* brain injury is an acquired insult to the brain not related to an external force. This type of insult may result in diffuse or localized injury to the brain, depending on the nature of the insult. Non-traumatic brain injuries are often overlooked or not specifically addressed in literature on acquired brain injuries.

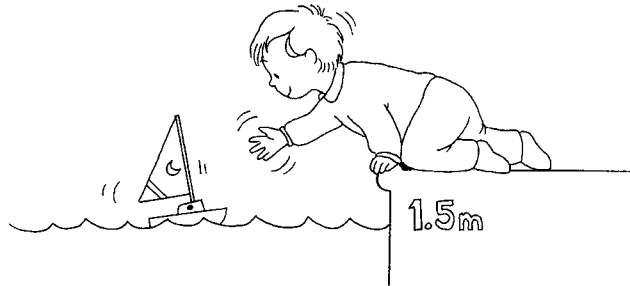
Causes of non-traumatic brain injuries in children and adolescents include the following:

- reduced oxygen to the brain
- brain infections
- strokes
- brain tumours
- toxic exposure
- metabolic disorders

The most common causes are highlighted below.

## Anoxic or Hypoxic-Ischemic Injuries

Anoxic or hypoxic-ischemic injuries result from reduced oxygen to the brain. The supply of oxygen to the brain depends on two factors: the level of cerebral blood flow and the oxygen content of the blood. A drop in either of these may lead to *cerebral anoxia* or *hypoxia* (reduced oxygen to the brain). Some non-traumatic causes of anoxia include near-drowning, suffocation, cardiac arrest, and *status epilepticus* (continuous or repetitive seizure activity). Anoxic damage can also occur as a complication of other types of acquired brain injuries, including stroke, infection, and traumatic injury.



## Strokes

Non-traumatic *cerebral vascular accidents* (CVAs), or strokes, occur less often in children than in adults. However, strokes can occur in children of all ages, from infants to adolescents. There are two types of strokes: *hemorrhagic*, involving a ruptured blood vessel and bleeding into or around the brain, and *ischemic*, resulting from blockage of a cerebral artery or vein. The damage caused by strokes is typically more localized to the specific area of the brain where the blood vessel ruptured or was blocked.

## Central Nervous System Infections

Two of the most common types of central nervous system (CNS) infections seen in children are meningitis and encephalitis. Sometimes children contract meningoencephalitis, a combination of the two.

*Meningitis* is an inflammation of the membranes (*meninges*) covering the spinal cord and brain. Meningitis, particularly bacterial meningitis, is the most common CNS infection of childhood. Anyone can contract meningitis, but most cases are in children, with a peak incidence between 6 and 12 months of age.

*Encephalitis* is an inflammation or swelling of the brain. It occurs less frequently than meningitis, but is more often associated with significant injury to the brain. Encephalitis is most often caused by a viral infection. The infection may also cause bleeding within the brain, resulting in further damage to the nerve cells.

## Brain Tumours

The signs and symptoms of brain tumours vary depending on the location of the tumour. Increased intracranial pressure may result from the growth of the tumour and/or from obstruction of cerebral spinal fluid flow. Long-term problems are related to lesion size and location, age at onset, age during treatment, and the type of treatments required. The general treatment of intracranial tumours is surgical removal of as much of the tumour as possible, followed by radiation therapy and/or chemotherapy. In addition to the injury to the brain caused by the tumour, radiation treatment can cause further delayed injury to the brain.

## Severity of Injury

Traumatic brain injuries are typically categorized as *mild*, *moderate*, or *severe* using medical criteria of severity obtained at the time of injury. The literature is inconsistent in terms of the criteria used to determine these categories. The medical categories of injury severity used to describe traumatic injuries are less typically used in discussions of non-traumatic forms of acquired brain injuries, particularly when the injuries are more focal (for example, stroke).

For traumatic brain injuries, the three main measurements used to define severity are:

- depth of unconsciousness as defined (during the first hours following trauma) by the Glasgow Coma Scale (GCS) score
- duration of unconsciousness
- duration of post-traumatic amnesia

*The Glasgow Coma Scale (Teasdale & Jennett, 1974) is the most common scale used for assessing depth of unconsciousness. It is typically used by emergency health care workers or in the hospital.*

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	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>
<b>Glasgow Coma Scale Score</b>	13–15	9–12	3–8
<b>Duration of Unconsciousness</b>	30 minutes or less	30 minutes to 6 hours	More than 6 hours
<b>Duration of Post-Traumatic Amnesia</b> (see page 1-15)	5 to 60 minutes	1 to 24 hours	1 to 7 days

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Adapted from Iverson, 1998.

Some definitions of the severity of a traumatic brain injury also include the presence or absence of neurological deficits (such as weakness or trouble speaking) or abnormalities on CT (computerized tomography) scans (such as bleeding or swelling). It is important to note that a child can sustain a significant brain injury without actually losing consciousness. Further, CT scan and MRI (magnetic resonance imaging) studies can miss significant microscopic injuries to the brain.



## Early Stages of Improvement (Return to Consciousness)

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Popular culture provides us with much misleading information about the effects of brain injury. Movies, television, comics, and cartoons provide daily examples of characters getting a bang to the head, losing consciousness, and waking up even after prolonged unconsciousness with no lasting consequences. Occasionally, if characters are unlucky, they will completely lose their past memory, while retaining all other skills, then recover abruptly and completely from their amnesia!

Fortunately, the effects of brain injuries are beginning to be discussed more realistically in other realms, such as sporting activities. For example, when sports broadcasters discuss the most recent players to have suffered a concussion, they show a growing awareness that these players can't just jump right back into the game after getting their "bell rung." Assessment protocols are now used to determine whether players are alert and oriented, or whether they need to sit out for a time. Professionals now recognize that some of these players need a gradual and monitored re-entry into the game over a period of days and weeks.

It only makes sense that children who have recently suffered a moderate to severe brain injury, not just a concussion, also need to have their level of cognition and awareness evaluated and to have a gradual and carefully monitored return to school and play.

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Immediately following an acquired brain injury there is typically a period of *reduced level of consciousness*, which is a reduced or absent awareness of oneself and one's surroundings. This can range from complete loss of consciousness to a period of reduced alertness with decreased cognitive and physical functioning. The duration may be brief, as in the case of a mild brain injury, or may last for weeks or months for severe injuries. In a small number of cases involving a very severe or catastrophic injury, the child may never regain full consciousness.

The concept of *levels of consciousness* is central to understanding the child's post-injury phases. Knowing the child's level of cognitive functioning is also a key factor in guiding further assessments, planning interventions, and making decisions about the return to school and leisure activities.

## Level of Consciousness at Discharge from Hospital

Most children who have sustained moderate to severe brain injuries regain consciousness. These children also tend to make a relatively good physical recovery following a brain injury. At the time of discharge from the hospital, most are able to walk, talk, eat orally, and carry out basic self-care activities. However, the onset of “alert” behaviour, and even walking and talking, generally does not signal a full return to normal level of consciousness. Often children are discharged from the hospital before this process is complete. In many cases these children appear to be doing well, but have important changes in their functioning that are overlooked. The changes may also be attributed to something other than the injury to the brain. Regardless of how the child appears to be doing, the child’s level of consciousness must be determined to make good decisions about the next steps to take.

## Determining Level of Consciousness

The return to consciousness is a continuous process. There are, however, identifiable levels that children typically move through and skills that emerge at each level. Pediatric scales for assessing level of consciousness for infants, preschoolers, and school-age children were developed at Rancho Los Amigos Hospital in Downey, California. A modified summary of the levels included in the Rancho pediatric scales is provided on page 1-17. A discussion of children’s function at each of the levels in the scale is included below.

## Early Levels of Reduced Consciousness

(Levels 5, 4, and 3 on the Rancho Los Amigos Pediatric Scale)

Children at the most severe end of the scale are *comatose*. Their eyes are closed and they are completely unaware of and unresponsive to any external stimuli. These children may require life support in the intensive care unit.

Over a period of hours, days, or weeks, children typically emerge to a state where their eyes are open, sleep/wake cycles are present, and they have some generalized, non-specific, reflexive responses to stimuli. At this stage, children remain unaware of their environment and are still considered unconscious. The term *vegetative* may be used to describe children at this level. (This term refers to a return of the vegetative functions of the body such as breathing, digestion, and temperature regulation.)

*For a discussion of assessment of level of consciousness, see Chapter 5.*



As children continue to improve, an inconsistent awareness of their surroundings emerges. This in-between stage is referred to as the *minimally conscious* or *minimally responsive* state.

At these early stages of return of consciousness, children are not walking or talking, are not able to safely take food or liquid by mouth, and are dependent for all care. They are in hospital, and planning for discharge from acute care typically involves transfer to another medical or rehabilitation centre rather than to home.

### Return to Full Consciousness

(Levels 2 and 1 on the Rancho Los Amigos Pediatric Scale)

Behaviours that indicate that children have regained consciousness include following directions, initiating purposeful behaviour, and *actively* participating in activities. Children appear increasingly alert and responsive to their environment. Infants often recognize their mother, smile and giggle when played with, and enjoy imitative play. Pre-injury personality starts to emerge, and a child's chronological age becomes more important. Most children at these levels are medically stable and begin speaking, walking, and safely eating orally. Although children may superficially look good, significant problems in cognitive functioning may be present.

**Level 2** – Children at Level 2, while aware of and responsive to their environment, are not fully oriented to themselves or their surroundings. At this stage most children have some loss of pre-injury information (*retrograde amnesia*) and are not able to retain new information (*post-traumatic amnesia*). These children are often able to answer questions about basic personal facts (name, age, birthdate, home community, school, grade). However, they are not yet able to consistently store and recall new information (for example, a visitor or conversation they had a few minutes ago or what they did the previous evening). During the stage of post-traumatic amnesia, some children tend to unintentionally fabricate information (*confabulation*) to fill in the missing gaps in their recent memory.

Impaired orientation and post-traumatic amnesia are deceptively difficult to evaluate at first glance. Children at Level 2 have difficulty with attention, and become overloaded and fatigued more easily. Safety is a key concern due to their reduced insight into their abilities, poor reasoning, and inconsistent recall of directions.

*Rather than thinking of the return to consciousness in terms of flipping a light switch from the “off” to “on” position, think of returning to consciousness as a process like the gradual turning of a dimmer light switch: the child's level of consciousness gradually lightens, just as the room gradually becomes brighter.*

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Amnesic disturbances in the acute stage after traumatic brain injury:

**Retrograde Amnesia** – This refers to loss of memory for the actual moment of injury and immediately preceding (days, weeks, or longer). Retrograde amnesia usually clears up, but there may be gaps in recall of old information. In most cases, children never remember the moment in time when they lost consciousness.

**Post-Traumatic Amnesia (Anterograde Amnesia)** – This refers to a period that begins immediately following the injury during which children are unable to store continuous memory for ongoing (recent) events.

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**Level 1** – As children emerge into Level 1, they appear oriented within familiar settings and within their daily routine. Initially, *affect* (expression of emotion through facial expressions or voice) may be flat, and children are often overly compliant. Over time they become more animated, more interactive with their environment, and more independent, requiring less structure. Infants begin playing with toys, wanting their bottle, and initiating social contact.

Children at Level 1 are oriented to personal information and time, as appropriate to their age, and are generally able to store continuous memories of recent events and to carry over new learning. They are no longer experiencing post-traumatic amnesia; however, they may demonstrate deficits for specific aspects of memory functions (see *Cognition* later in this chapter).

**Levels 2 and 1** – The children at Levels 2 and 1 described above are the focus of the following chapters in this manual. These children typically return directly home from the hospital. As noted in the description of the *Pediatric Levels of Consciousness* on the next page, Level 1 is not the same as return to pre-injury status. Despite being fully conscious and oriented, children who have sustained a significant brain injury will likely continue to demonstrate changes in function, particularly cognitive and social-behavioural function. Some of the common problems (*sequelae*) are described in the next section.

# Pediatric Levels of Consciousness

This summary is adapted from the Levels of Consciousness, Pediatric Brain Injury Service, Rancho Los Amigos Hospital, Downey, California.

## **Level 5: No Response to Stimuli**

- eyes closed, no sleep/wake cycles, often on life support

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*End of Coma*

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## **Level 4: Generalized Response to Stimuli**

- eyes open, sleep/wake cycles present, typically off life support
- responses are often the same regardless of the stimulus presented (gross body movements to pain or to loud sounds, vocalizing)
- responses are limited and often delayed

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*End of Unconsciousness*

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## **Level 3: Localized Response to Stimuli**

- responses are specific and localized to the stimulus presented (withdrawal of extremity to pain, blink to threat, visual tracking, localizing to sound)
- may show vague awareness of body/self
- may demonstrate slow automatic behaviours (pushing arm through sleeve)
- may respond more consistently to familiar people

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*Fully Conscious*

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## **Level 2: Aware and Responsive to Environment but Disoriented**

- *disoriented*
- *not able to consistently recall recent events, even though can often remember personal information and events from before the injury; these past memories may be confused or have “gaps”*
- most begin speaking, walking, and safely eating orally
- inconsistent bowel/bladder continence
- may be agitated early in Level 2
- understands simple communication (that is, follows verbal or gestured requests, refuses to follow requests by shaking head or saying “no”)
- initiates purposeful activity
- may behave in an impulsive, unsafe manner

## **Level 1\*: Oriented to Person, Place, and Time: Recording Ongoing Events**

- *consistently oriented to person, place, and time*
- *able to store continuous memories for recent events and new information (but may still have ongoing difficulties with memory)*
- is more animated, has more pre-injury personality traits (but may refuse to participate in tasks more often and behaviour may be socially inappropriate)
- may still behave in an impulsive, unsafe manner at times
- walking, eating, and self-care skills improve
- consistent bowel/bladder continence

\* Level 1 is not the same as return to pre-injury status. (Children may continue to have difficulties in cognitive, social-behavioural, and physical functioning.)

## Common Problems at the Time of Discharge

Virtually any ability or combination of abilities can be impaired following a brain injury. Each brain injury is different, and can be expected to produce a unique pattern of damage and functional difficulties. However, there are important common difficulties.

Changes in the child's abilities can be profound. However, changes can also be relatively subtle, and the impact of the injury on the child is often underestimated. Overly optimistic reports of outcome are not uncommon because of good physical recovery. Things often go relatively well immediately following discharge from hospital, as the family experiences the welcome relief of life beginning to return to normal. However, problems tend to become apparent as difficulties emerge with, for example, safety, peer relationships, behaviour, and new learning.

This can be a stressful and confusing time for the family and for school staff, especially if they have been told that the child has essentially recovered from the injury. They will need time to learn the ways in which the child has changed. The whole family will need time, and often professional support, to adjust and learn how to respond to this new situation.

Following is a brief discussion of some of the more common difficulties that can be evident around the time of discharge. As discussed, some residual difficulty with reduced level of consciousness is common at this time, and can easily be overlooked.

### Health

**Fatigue, Headache, and Disturbed Sleep** – Fatigue is extremely common in the early stages of recovery and can be a long-term concern. Fatigue can limit endurance for both mental and physical activities and generally exacerbates the impact of other deficits. Other health problems can include headaches and disturbed sleep patterns.

**Seizures** – Some children who had seizures around the time of the injury may be taking anti-seizure medication at the time of discharge to minimize the potential for further seizure activity. Most children with an acquired brain injury do not have seizures, either in the early phase or as a late-occurring complication. However, if the physician has identified an increased risk for late-occurring seizures, this always needs to be addressed with the family and school staff.

*For a discussion of assessment and intervention provided to children with acquired brain injuries, see Chapter 5, Rehabilitation.*

In general, the risk of late-occurring seizures is related to both the nature of the injury and the age of the child. For children who have sustained a traumatic brain injury, the risk is significantly increased for more severe injuries (approximately seven percent, Annegers, 1980), but is generally not greater than normal for mild to moderate injuries. Children under age two at the time of injury are more likely to develop late seizures than older children.

## Cognition

Cognitive deficits can affect all areas of a child's function and development, including physical activities, play, communication, social relationships, and academic learning.

Inconsistency of cognitive function over time is common. Children may do better under ideal conditions, and their function may deteriorate due to factors such as the following:

- fatigue
- stress
- overstimulation
- participation in novel or relatively unstructured activities

Some of the more critical areas of cognitive impairment are highlighted here due to their pervasive impact on learning and general function. These areas include attention, memory, and executive function. Problems in these areas are extremely common with traumatic brain injury as a result of the typical pattern of injury. These problems are commonly found with other types of non-traumatic brain injuries depending on the location of the injury.

**Attention and Concentration** – Attention is a foundation for the cognitive processes needed for everyday function, academic learning, and social interaction. Attention deficits can include the following:

- slowed rate of information processing
- short attention span
- difficulty with focused attention
- distractibility
- difficulty shifting attention

**Memory and Learning** – Memory skills are highly complex. In most cases, at the time of discharge children demonstrate relatively good recovery of pre-injury information related to personal experience, and to overlearned knowledge and procedural skills (such as number facts and daily routines). However, specific gaps in recall are common, particularly for more recently learned knowledge and skills.



Specific memory deficits can include difficulties with the following:

- forgetfulness
- immediate and short-term memory
- rate of new learning
- retention of new information in long-term memory
- recall of information from memory storage

Memory deficits can be specific to the manner in which information is presented. For example, children can have severe auditory-verbal memory deficits and normal visual-nonverbal memory function.

**Executive Functions** – Executive functions are the skills needed to formulate goals, to plan how to achieve them, and to initiate and carry out the plans effectively. Specific executive function deficits can include problems with the following:

- self-awareness, judgment, and insight
- initiation, planning, organization
- ability to self-monitor and evaluate performance
- mental flexibility
- ability to generalize newly learned skills to different situations
- abstract and inferential reasoning
- ability to take another person’s perspective
- ability to inhibit impulsive behaviours
- ability to regulate emotional expression

These executive skills are critical in social, academic, and vocational success and independent living. Significant executive system impairment can seriously interfere with rehabilitation and educational intervention. Children and adolescents with poor awareness of their deficits can be difficult to engage in therapy or learning. Those with initiation problems or impulsive behaviours may fail to use the skills and strategies learned in treatment.

## Communication

Communication impairments can involve any aspect of motor speech, language skills (understanding and expression), or the ability to use language in everyday social situations. In addition to specific speech and language deficits, communicative deficits may be present due to general underlying cognitive impairments, such as reduced attention, slow information processing, poor organizational skills, memory, and perceptual impairments.

When level of consciousness is reduced (Level 2, early Level 1), children’s articulation may be imprecise, and their voice may be flat and quiet. Language may be “confused” due to problems such as poor short-term memory, confusion/disorientation, and slow rate of processing. Many of these initial problems tend to resolve as the child’s level of consciousness and orientation improves.



Recovery of basic speech and language skills tends to be relatively good. Most children at Level 1 speak clearly. They regain the ability to follow basic directions, use grammatical sentences, and carry on simple conversation. However, many experience persisting communication problems that often significantly affect social and academic functioning.

Common residual problems with language comprehension include difficulty understanding lengthy, complex, or rapidly spoken language, particularly in stressful or distracting listening environments. Expressive language problems, including deficits in word finding and verbal formulation and organization beyond the sentence level, are common in both verbal and written language.

Many children with acquired brain injuries have difficulty with higher-level language skills, including inferential reasoning and understanding of abstract uses of language such as figurative language or humour. The ability to participate in the “give and take” of social interactions may be limited due to the following:

- difficulty following rapid verbal exchanges
- difficulty understanding the more abstract uses of language, including jokes, irony, and sarcasm
- limited understanding and use of non-verbal communication cues

A small number of children have more severe speech impairments (*dysarthria*, *apraxia*) and language impairments (*aphasia*) that significantly affect functional communication. Aphasic language disturbances typically occur with focal injury to the left side of the brain, due to trauma or strokes, and affect all modes of symbolic communication, including speaking, understanding, reading, writing, and gesturing.

## Sensory/Perceptual

**Sensory Impairments** – A brain injury can disrupt input from any sensory system, such as vision, hearing, somatosensory, and smell. Sensory impairments can result from damage to the sensory organ itself, to nerve pathways transmitting sensory input to the brain, or to the part of the brain primarily responsible for receiving and interpreting that type of sensory input. Some children may have a reduced ability to sense touch, temperature, or where their body parts are in space. Other children may be hypersensitive to sensory input, such as touch, bright lights, or noise.

Sensory impairments can be challenging to identify due to other impairments such as physical limitations, fatigue, distractibility, and reduced self-awareness. Visual acuity is rarely impaired, but there can be a partial loss of vision—for example, in one eye or in part of the visual field. Right hemisphere injury can be associated with impaired awareness of sensory information on the left side of the body or space.



Vision can be affected by impairment of the eye muscles. Common problems can include double vision and difficulty with depth perception, the ability to shift gaze, and the ability to track smoothly when reading.

**Perceptual Impairments** – These include difficulties recognizing and understanding sensory input. For example, children may not be able to understand speech sounds, despite normal hearing. They may not recognize what they are looking at, despite normal eye function.

## Motor Skills

The pattern and severity of residual motor deficits caused by a brain injury can cover a wide spectrum. Some children have significant long-term motor deficits—for example, some degree of *hemiparesis* (weakness or paralysis on one side of the body). At the time of discharge, most children with acquired brain injuries have recovered gross motor function relatively well, and most are walking independently. However, residual problems—for example, with fatigue, balance, coordination, tone, and strength—often affect a child’s return to previous activities. Common fine-motor problems include reduced dexterity, speed, and motor-planning skills (apraxia). Children with a hemiparesis involving the hand dominant for complex fine-motor skills (such as writing) may have to switch hand dominance.

Even when children do not have obvious motor difficulties at the time of discharge, other effects of the brain injury can significantly affect physical function. For example, children may be physically ready to return to their basketball team, but may have problems coping with the demands of the game due to deficits in speed of information processing, distractibility, disorganization, and impulsive behaviour. Physical safety is often a significant concern due to impaired executive function and to any residual motor deficits.



## Academic

These children commonly have marked difficulty working independently on their school work and need a high level of learning assistance. Any academic skill can be impaired on a temporary or long-term basis. In the early stages of recovery, many children recover pre-injury knowledge and skills relatively well, but the rate at which they catch up may be different for different skills, and they may have long-term residual gaps in accessing previous learning. Problems with higher-level, more complex academic skills, such as reading comprehension, written language, and math, are common.

New learning problems often emerge over time. In some cases, the rate of new learning slows down significantly despite initially good recovery of pre-injury skills. Children can have increasing difficulty coping with school work as the demands for abstract learning, complex organizational skills, and quantity of new learning and output increase. The transition from elementary to high school is particularly challenging for students, as they are faced with complex schedules, multiple teachers with differing styles, more complex assignments, and expectations for increased independence.

*For more information on school issues, see Chapter 4, Returning to School.*

## Behavioural/Social

Changes in personality and behaviour are very common and are often the most disabling effect of the brain injury. Some parents report that their child is not the same person. Parents may find that they no longer know how their child will react, and that their old parenting strategies no longer work.

Behavioural changes can be influenced by the characteristics of the child prior to the injury and the characteristics of the environment following the injury. For example, old problems with anger and social skills can be exacerbated. Stress can decrease a child's ability to compensate for neurologically-based changes in behaviour and personality.

At Level 2 and early Level 1, emotional expression tends to be relatively flat. At the same time, problems with *emotional lability* (quick, relatively intense emotional reactions, including anger and crying) are common.

Impulsive, disinhibited behaviours (sometimes associated with marked hyperactivity) may emerge as level of consciousness improves. At this stage of recovery, most children and adolescents still have a very limited ability to understand the implications of their brain injury. Most can recognize obvious changes in their physical abilities, but as these improve, they tend to deny that anything else is wrong with them. Their frustration often increases and it can become difficult to engage them in therapy activities, or to convince them of the need to comply with restrictions placed on activities for safety reasons.

*For suggestions on providing support and assistance to parents and siblings, see Chapter 2, Family Issues.*

Emerging problems with behaviour and social relationships are common following discharge from the hospital. Children and adolescents often appear less mature. They can be somewhat egocentric. Inflexible, perseverative thinking may result in difficulty shifting gears, and demanding or noncompliant behaviours. They may exhibit new problems with irritability, aggressive behaviours, and temper outbursts.

These children often have difficulty fully appreciating the impact of their behaviour on other people. They may engage in inappropriate behaviour in social interactions—for example, rude, insensitive, or sexually inappropriate behaviour.

Children and adolescents often have difficulty fitting back into their peer group due to impaired executive function and changes in communication, perception, attention, and motor skills. Increasing problems with social isolation and withdrawal are common. Without information and support, peers can be put off or confused by changes in their old friend's behaviour.

Children's ability to initiate or engage in activities independently may be impaired. Interests often change, usually to simpler activities that might appeal to a younger child. They may form friendships with children three or four years younger than their age peers. Their play and recreational skills may be less complex and creative. They may not be able to return to former athletic activities.

Safety is often a critical concern due to cognitive deficits such as reduced judgment, poor self-monitoring, and impulsive, disinhibited behaviours, as well as to physical deficits. Close supervision is often required. Common concerns include traffic safety, contact sports, and unsafe familiarity around strangers. Driving, sexuality, and alcohol and drug use are major issues for adolescents. Peers often do not understand their friend's limitations, leading to unsafe situations. Adolescents need to be referred for a specialized driving assessment that includes assessment of cognitive and psychosocial function.

As self-awareness increases and children begin to experience the impact of their injury, many experience profound anxiety, sadness, or anger. A common problem for adolescents is their desire to return to their normal activities and their parents' unwillingness to reduce their vigilance. Loss of independence and failure to achieve important goals and milestones, such as getting a driver's licence or going to university, are major issues.

Many children and adolescents need counselling at different times in their recovery and at different stages of their development to address emotional distress, to help them understand the impact of their brain injury, and to develop effective skills and coping strategies. Some individuals demonstrate signs of a *post-traumatic stress disorder* (PTSD) and need specialized clinical support.

## Outcome and Developmental Considerations

The ability to predict long-term outcome following a pediatric brain injury is limited and must be considered within a developmental perspective. Whether children are toddlers or adolescents when injured, they are still in the process of developing and learning. The injury disrupts this process and affects both current abilities and ongoing development. The process of improvement is complex and is affected by a large number of interactive factors (Lehr & Savage, 1990, Ylvisaker, 1998).

### Factors Related to Improvement from Injury

Factors that contribute to the course of improvement and long-term outcome include the nature of the injury, any potential for physical recovery of the brain, the individual characteristics of the child, and the child's environment.

#### Characteristics of the Injury

Different causes of an acquired brain injury tend to be associated with different patterns of problems and outcomes. Characteristics of the injury that contribute to the child's recovery or outcome include the severity of the injury, specific areas of the brain that are damaged, extent of the damage, and diffuse or local nature of the tissue damage.

#### Physical "Recovery" of the Brain

Nerve cells that are killed will not be replaced. However, some degree of spontaneous physical recovery can be expected to occur following an acquired brain injury. For example, some nerve cells that were injured may recover. Blood from bruised areas is reabsorbed. Swelling is gradually reduced over time. As pressure in the brain decreases, normal blood flow can be restored.

Some degree of compensation and reorganization of the brain structure can occur. In some cases, it appears that a different neural network may become responsible for the impaired brain function. However, there are important limitations to the potential for "takeover" by other areas of the brain. Certain areas of the brain appear to be committed to specific functions, even in infancy, and not all areas of the brain can assume all functions. Also, the transfer of responsibility can result in some loss of the function originally assigned to the undamaged area and/or to some loss of the function that is taken over by that area. Finally, the potential for reorganization generally appears to be decreased when the injury is more diffuse.

## The Individual Child

Characteristics of the child that contribute to outcome include age at the time of injury, previous skills, knowledge, and personality, any history of pre-existing developmental or learning difficulties, and individual differences in brain organization.

## The Child's Environment

Outcome is also affected by the availability and quality of medical care and rehabilitation, and by individual family characteristics. Rehabilitation provided by health care professionals and school staff, together with support provided by family and friends, can have a powerful impact on the recovery process and long-term outcome. Intervention tailored to the needs of individual children can improve their general function during early recovery, decrease the development of secondary functional complications, and help them reach their potential in terms of long-term outcome. Ultimately, the family is the most critical component of the recovery process and provides the primary support for the child (Ylvisaker, 1998).



## Prognosis

The term *prognosis* refers to the probable eventual outcome or degree of functional recovery that may be expected after an injury or illness. Knowing the probable limits on a child's recovery helps suggest a realistic rehabilitation plan, and helps the injured child and family anticipate and adjust to new circumstances they encounter.

In most cases of injury or illness—for example, a broken arm or acute appendicitis—professionals know what to expect in terms of the course of recovery and eventual outcome, and often expect to see a full recovery. After a moderate to severe brain injury, on the other hand, a full recovery is typically not expected. No one can perfectly predict the final outcome for an individual child, and this uncertainty is very difficult for families. However, prediction about long-term outcome becomes more accurate with the length of time elapsed since the injury, and as more information becomes available about the child's abilities. Each child requires comprehensive initial and periodic follow-up assessments. The information provided by these assessments will contribute to ongoing planning and help the child and family understand the impact of the brain injury.

The severity and nature of a child's deficits can be expected to change over time. Change tends to be relatively rapid in the first few months, then slows down. Different functions improve at different rates. New deficits may emerge over time as the child goes through new developmental stages.

Most spontaneous physical healing from moderate to severe brain injuries is thought to occur in the first year after the injury. Most of the functional improvement is widely believed to occur during the first six months, and virtually all within the first one to two years following the injury. For most children, any residual deficits apparent at this stage are likely to remain as permanent sequelae of the brain injury (adapted from Spreen, Risser, & Edgell, 1995). However, the following are some critical considerations to bear in mind about long-term prognosis in children.

### The Potential for Improvement Never Ends

Families often hear from medical or rehabilitation professionals that their child will continue to recover for up to one to two years. This can be encouraging during the acute stages. However, for some families this information can have a devastating effect when the predicted period of “recovery” has ended (Lezak, 1996).

While the rough parameters of long-term sequelae and outcome are generally known at approximately the one-year mark, the possibility of further improvement never ends for these children, as they continue to learn and develop. Children with brain injuries whose level of function appears to have levelled off may later make significant gains, years after their injury. The amount of time that has elapsed since the injury does not preclude effective intervention.

### Delayed Onset of Deficits

Some childhood injuries may initially appear mild, but evidence of substantial deficits may surface later in life. Children may suffer damage to a part of the brain that does not become functionally mature until a later stage of development. The consequences of this damage may be evident only when developmental expectations are not met. For example, a young child with an injury that involves the frontal lobes may appear normal, or have only minimal difficulties at the time of discharge, but demonstrate substantial impairment during adolescence because the brain injury disrupts normal development of the executive functions.

Further, some deficits that appear to have minimal impact on a child’s ability to function at the time of discharge can in fact have more profound consequences over time. Subtle cognitive deficits that affect new learning can result in a steadily widening gap between children with brain injuries and their peers. Poor self-awareness, limited ability to read social cues, or disinhibited behaviours may pose minor problems during the first few months at home, but can later develop into significant, long-lasting social difficulties.



## Children Do Not Recover Better Than Adults

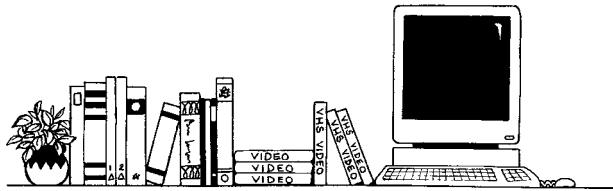
A common misconception is that outcome following brain injury is better if an individual is injured earlier rather than later in life. Recovery is better in children than in adults only when outcome is judged in very global terms—for example, independent walking, self-care, and talking. Recovery of motor skills tends to be more rapid and complete. However, children and adolescents are more vulnerable in terms of their cognitive and psychosocial outcome. As a group, they are at high risk for long-term educational, vocational, and interpersonal problems.

For children and adolescents with brain injuries, the process of recovery and improvement is complicated by a reduced capacity for future learning and development. Injury to the immature nervous system affects a brain still in the process of maturing and acquiring new information and skills. A disruption in the development of one function can have a cumulative effect on subsequently developing functions. In general, the younger the child is at the time of the injury, the greater the impact on new learning and development and long-term outcome.



## Additional Reference Materials

### For Professionals



#### Books

- Begali, V. (1992). *Head injury in children and adolescents: A resource and review for school and allied professionals*. (2nd ed.). Brandon, VT: Clinical Psychology Publishing.
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- Savage, R.C., & Wolcott, G.F. (Eds.). (1995). *An educator's manual: What educators need to know about students with brain injury*. Washington, DC: Brain Injury Association.
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- Spreen, O., Risser, A.H., & Edgell, D. (1995). *Developmental Neuropsychology*. New York, NY: Oxford University Press.
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#### Web Sites

[www.tbi.org](http://www.tbi.org)  
[glaxocentre.merseyside.org](http://glaxocentre.merseyside.org)



## Chapter

# 2

## Family Issues

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### Chapter Overview

**Who is this chapter for?** Rehabilitation and school professionals.

**Who is this chapter about?** Families of children who have recently sustained a moderate to severe acquired brain injury and who are beginning to regain previous skills such as walking and talking.

**What is this chapter about?** The experiences these families have in hospital and over the next few months at home. Ideas for providing support and assistance to families are also discussed.

Few types of injuries or diseases present a set of problems and emotions as complex as those experienced by the families of a child with an acquired brain injury. In this chapter we look at some of the common experiences and needs families have on their journey from hospital to home, and provide some ideas about how professionals can help. We also discuss some future considerations for families and professionals.

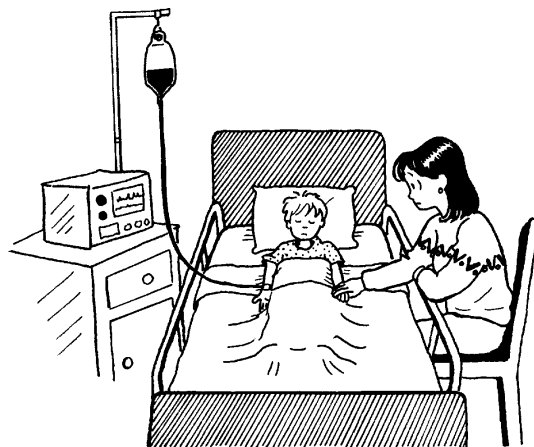
## Family Experiences from Hospital to Community

Each family's experience is unique when their child sustains a moderate to severe acquired brain injury. Professionals need to listen and learn from each family's experience to determine how to help the family work together in the healing process.

### In the Hospital

Families are unprepared for the rapid series of events that immediately follow the child's injury. Family members may travel in the ambulance with the child, or may frantically race to the hospital after learning of the injury. The child may have been taken to a larger hospital many miles away, and parents may need to arrange for a stay away from home, time off work, and care for other siblings. The accident may have caused serious injuries or fatalities to other family members or friends. Injured family members may be in different hospitals or be recovering at home.

Once at the hospital, parents often fear the worst when they see their child attached to medical equipment, surrounded by professionals speaking in terms that are new and confusing. The family may be told that their child may die in the intensive care unit. Many families feel overwhelmed and numbed by the crisis. The child's siblings may feel frightened by medical equipment, seeing their parents in distress, and not knowing whether their brother or sister will live or die. Some parents remember, in graphic detail, the moment of the child's injury and their stay at the hospital. Other parents have no memory of what happened at the hospital and tend to lose track of the days.



*“We were home that evening when we heard a knock at the door. My daughter answered, and a policeman stood there in the doorway, with my son’s running shoe. I broke down right there. When the police took us to the hospital, I learned he was in critical condition and had been hit by a car. Life seemed so unreal to us when we were at the hospital. My son looked really bad in the intensive care unit and my wife and I just prayed all the time. You really feel helpless in a situation like this.”*

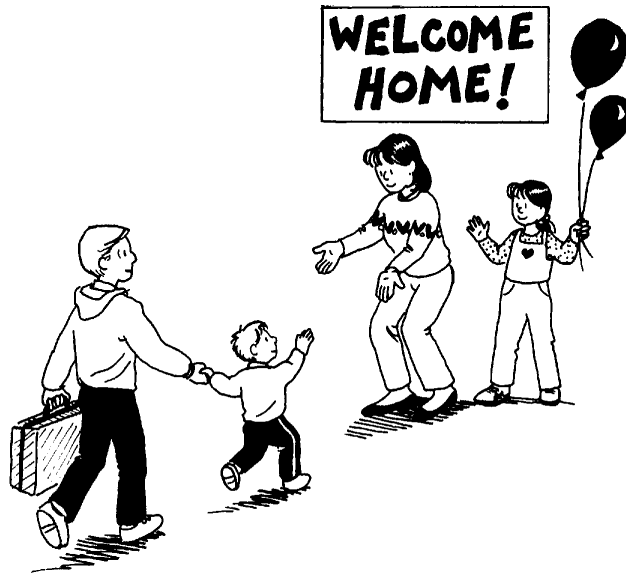
With the family’s focus on the injured child, siblings may feel neglected, and younger siblings may have fears of abandonment. Families may be separated, with one or both parents staying with the injured child in another city or at the local hospital much of the time. Older siblings may have to take care of themselves for the first time, or may be given too many responsibilities at home. Siblings of all ages may experience guilt, especially if they were with the child at the time of the injury. They may be relieved that the child survived but also feel anger or resentment toward the injured child or their parents for creating so many changes and disruptions in their own lives. These feelings may result in delinquencies or social problems at school. Siblings may have difficulty expressing their thoughts to their parents or teachers, and by their silence may appear to be coping well.

Grandparents, other relatives, and friends may offer invaluable help, or may cause additional family stress during the child’s hospitalization due to their own emotional responses to the child’s injury. Parents may feel inundated with the demands of too many relatives, or may feel hurt if no one visits. Some families become newly aware of how close and supportive their family can be in a crisis. This experience redefines family relationships and brings out strengths and weaknesses in the family.

When the child survives, often defying medical predictions, families often regain hope that the child will make a full recovery. When the child regains consciousness, begins to walk and talk, and displays old personality traits, some families begin to think that family life will soon return to normal. They may have been told about the brain injury in such a way that they did not hear the diagnosis. Families may hope for a full recovery whether they heard the diagnosis or not. Some families may need additional information or a different approach to help them absorb the meaning of the child’s injury. Professionals need to respect the family’s viewpoint and not take hope away.

## Early Stages at Home

In the first few days and weeks at home, family members often believe that the hardest part is over. The child may now be able to walk, talk, and interact with others, and may no longer be agitated. However, many families soon discover that the return home can be incredibly stressful. They may begin to notice new areas of difficulty in the child that were not apparent in the structured routine of the hospital or at early stages of recovery.



Upon returning home, some children can be more willful, noncompliant, irritable, or emotionally unstable. Others are extremely passive or unable to initiate activities. They may be confused, seem dazed at times, and fatigue easily, causing their abilities to vary considerably throughout the day. In the early stages, many children also have poor safety awareness and judgment and behave impulsively, requiring families to provide constant supervision.

Medical and physical problems are more easily explained than emotional, cognitive, or behavioural difficulties. These changes remain the most prominent sequelae of acquired brain injury and cause the most stress to families (Lezak, 1986). Parents may not know how to handle their child's behaviour. They may be embarrassed or concerned about how to explain these changes to grandparents, neighbours, friends, or the school. Some families feel lost not knowing where to turn or who to ask for help. The family's reaction to sudden changes in the child, combined with the stress of daily living, may create great sadness for them.

*“When we first got home, I guess we didn’t expect she would be so active or so moody. She didn’t sleep at all and would roam around the house at 2 a.m. In the morning she would have a dark cloud over her head. She would turn the whole house upside down by throwing things and picking on her siblings. After a few weeks, when she threatened to run away, we had to put locks on all the doors. We weren’t sure who to call for help. My other kids and I couldn’t take much more of this, and we wondered how long it would last.”*

During the next few months, families may experience a “roller-coaster ride” of challenges, successes, and disappointments.

Plans initially made in the hospital or during the first few weeks at home may eventually fall apart in the community. Families may feel unsure about who is setting up community rehabilitation for their child, or may be overwhelmed with having to arrange these services themselves. Families may need to keep the home quiet and supervised for many weeks before the child returns to school. After returning to school, the child may have significant learning and behaviour difficulties. Social isolation, role changes, and financial worries may also take their toll. If family members see a certain disability as permanent, they may worry about the child’s future.

Sisters or brothers of an injured child often expect everything to return to normal as soon as their family is together at home. However, their relief and anticipation may be short-lived as they realize that their injured sibling continues to be the focus of their parents’ attention. Some want to help their sibling at school and home, while others feel burdened by this. They may feel embarrassed about their injured sibling’s unusual behaviour and then feel guilty about these feelings. They may fight with their sibling more often and have trouble understanding that their injured sibling’s behaviour is not always deliberate. They may feel saddened that their sibling does not play or act the same way. Changed relationships and roles can add to a sibling’s sadness.

Although some brothers and sisters of an injured child hold themselves together initially, they may start to fall apart as time passes. Some have unique issues requiring specialized attention—for example, if they were injured themselves or if they witnessed the injury.

## Grief and Family Adjustment

Families of children with brain injuries may experience any combination of emotions at any one time, throughout the day and for years into the future. Adjusting to new circumstances is a continual process of adapting to and accommodating the changing needs of the injured child. A successful adjustment process may last a lifetime and will involve unique changes in the perceptions, attitudes, and actions of family members.



This process of adjustment is not the same as the final process of “acceptance” discussed in Kubler Ross’s often-cited description of the stages of grief. Kubler Ross’s linear model implies that people reach an end point or a final stage of acceptance after passing step by step through a series of emotions (1969). This type of model does not fit well with families of children with brain injuries. Rather than reaching a final stage of acceptance, these families continually adjust and adapt throughout their lives.

### Grieving the Losses

Some parents grieve over lost hopes and dreams they had for their child. They may continue to hope for ongoing improvement throughout the child’s life. Other families do not see any permanent losses or changes in the child and, expecting the child to fully recover, do not grieve. A family traumatized together does not always respond or grieve in the same way. Some of the strong emotions that families may experience are discussed below.

#### Shock or Disbelief

*“When I first received the phone call from the hospital, I thought this cannot be happening—it’s a dream and I will wake up soon.”*

When families first hear that their child is severely injured or may die, they may not believe it and later may not have any memory of what was said to them. They often feel numb. This shock may have long-lasting effects on later coping strategies and on family functioning.



## Guilt/Blame

*“The fact that we were both in the car together really means, I guess, that we are both to blame. We will never forgive ourselves and sometimes it’s hard to look at each other.”*

Parents search for meaning about why their child was injured. They may look for someone to blame. Most parents feel somewhat responsible even if they were not directly involved. Parents who were responsible in some way for the child’s brain injury may carry guilt that torments them at times throughout the recovery process. Some families feel that their God is teaching them a lesson, or that an evil spirit was involved in hurting their child. If families with strong religious beliefs feel anger towards their God for abandonment, they may experience additional feelings of guilt.

## Hope and Over-Optimism

*“She has always been a determined girl. I know everything will come back to her, we just have to keep working on it.”*

Hope gives families the courage to carry on with new roles and responsibilities. It enables them to encourage the injured child to keep trying in rehabilitation. Professionals will recognize a parent’s hopeful encouragement as a help to the child in active treatment.

However, hope can sometimes result in strong beliefs that the child will reach goals that may not be attainable. Overly high expectations may place undue pressure on the child, which can result in subsequent behaviour problems. Unrealistic hope may eventually lead parents to depression as they realize that some of their dreams for their child are lost.

## Anger and Frustration

*“Before my son was injured, I could keep everything pretty cool, but now I’m angry all the time—I just feel like going out on the street and punching the first guy I see.”*

Families experience anger when they begin to recover from shock and gain some awareness of the tragedy of the situation. Exhaustion from prolonged caretaking, frustrations with poor communication with professionals, lack of information, financial burdens, and feelings of powerlessness can cause angry feelings. A family member may feel frustrated or angry with the behaviour of other family members or the injured child, but be unable to express this frustration directly for fear of hurting the family. Anger may override all other expressions of feelings and interfere with productive problem solving.

## Despair

*“Our whole family is turned upside down. He says that he hates all of us and that he is going to run away. He’s only 8 years old. All our hopes were on him. We just want our little boy back.”*

Families may go through periods of despair during difficult times in the child’s healing process. These periods can be momentary or can last for days or weeks, making it difficult for the family to feel positive about rehabilitation.

## Denial

*“I know this will sound funny to you, but we all thought Mary’s problems would be gone when we got back from Disneyland.”*

Denial may work alongside hope as a coping strategy. Denial helps to preserve hope and gives families the energy to continue to support the recovering child. Families of children who recover many of their previous skills may hold on to the belief that underneath their unusual behaviour, they remain unchanged and will eventually show themselves to be fine. Some families take several years to gain an accurate picture of who the child really is or will become (Lezak, 1996). Most families go through a natural process of adjustment. Professionals must trust in the family’s ability to make these transitions and not rush the process by taking a family’s hope away in an effort to be realistic.

## Factors Influencing Family Adjustment

Many factors influence a family’s ability to adjust to the new needs of a child with a brain injury. The following factors may help professionals predict future difficulties and needs for family support.

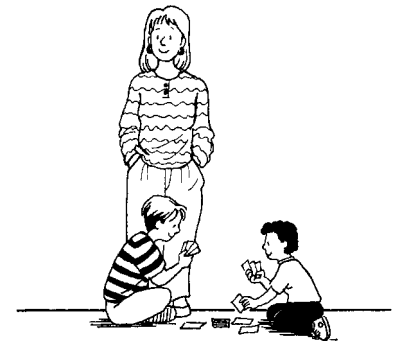
### Pre-Injury Family Environment

Information about the family environment prior to the injury can be helpful in understanding the complexity of the issues that influence family adjustment. The family environment can be described in part as the shared values, communication styles, and relationships of family members that shape how they will cope with the child’s brain injury. It includes family finances, education, lifestyle, literacy, religion, and culture, as well as the unique characteristics of individual family members. The pre-existing community support services and the family’s relationship with the community are also part of the family environment.

Difficulties that the family experienced prior to the injury may affect their reaction to the child's brain injury and their subsequent needs. The child's injury may trigger or exacerbate family difficulties such as marital stress, poor parenting skills, sibling conflict, family violence, and child abuse or neglect. The injury may also aggravate family members' personal problems, such as alcohol or drug abuse, depression, other forms of mental illness, or physical health concerns. Past personal traumas may be retriggered by the child's injury. Even in the strongest families, the child's brain injury may cause new problems for individual family members.

### Single-Parent Families

Single-parent families may have different stresses, responsibilities, supports, financial resources, and roles and responsibilities than many two-parent families. Siblings often take on greater responsibilities and have larger roles to play in the family. Some single-parent families need more time to change and adapt to the needs of the child because they have fewer family resources than two-parent families. An estranged parent may become re-involved in the family at the time of the injury, causing unique stresses to the single-parent family.



### Culture and Language

A family's culture influences their perception of the injury, the brain and its functional role, the healing process, and treatment. Professionals need to be aware of the family's cultural values and religious beliefs that influence their acceptance of certain interventions and approaches. Providing culturally sensitive rehabilitation interventions may help parents and the child develop trust in their professional helpers.

Families who speak English as a second language may need an interpreter to communicate clearly with health professionals. However, families may not be able to easily express feelings to the interpreter, or their words may be lost in the translation to English. Written information in the family's language may not be accessible to them.

### Family Life Cycle

Parents of infants or preschoolers may have different perspectives and expectations of family life than parents of teenagers. Each family's lifestyle and perspective on life may need careful consideration before support services are offered.

## **Families at Risk**

Families coping with a family member who has a problem with violence, criminal activity, mental illness, emotional abuse, or substance abuse need special consideration. They may need additional services to address these issues before they can focus on the child's rehabilitation.

Since these families may be in crisis from the time of injury and throughout the child's rehabilitation, the child's progress must be closely monitored by a skilled counsellor who understands the family situation. Children of families in crisis may be at greater risk for a second injury. Child protection services need to be contacted immediately if the child's safety is at risk.

## **Circumstances Surrounding the Injury**

The circumstances surrounding the injury may influence how the family copes and may indicate future difficulties with adjustment. For instance, often a family member was driving the motor vehicle involved in the accident that caused the child's brain injury. Other family members, including parents, may have been seriously injured or may have died in the accident. The child's brain injury may be the result of abuse by a family member or a caregiver entrusted by the family. Friends or family members may be investigated by police. Guardianship and custody disputes may begin. The media may be involved, adding stress to the situation. These variables may direct the type of support services that are needed to help the family.

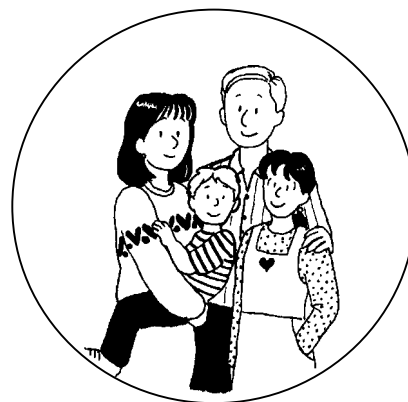
## **Nature of the Injury**

The child's brain injury is sudden and acquired. The family has little time to prepare for the possibility of their child having new difficulties or a permanent disability. They have certain expectations for their child's future, and will not want these expectations to change. Some children may also be aware that the brain injury is causing them new difficulties and ask for parental reassurance that their future will be the same. For these reasons, a family may be under tremendous pressure to minimize the effects of the brain injury.

## Family Support and Assistance

*“...the family [is] becoming the centre of the rehabilitation process” (Turnbull & Turnbull III, 1991).*

Family-centred care is now considered to be the optimal form of practice in pediatric health care (Johnson, Jeppson, & Redburn, 1992). The basic philosophy of family-centred care is to involve families in all aspects of care and to treat both the child and the family rather than the child alone. The value of parental involvement in community rehabilitation and school teams is sometimes underestimated. Families are the constant in the child's life, while professionals come and go.



Children need the support of their families if they are going to reach their full potential in life as well as in rehabilitation. Families provide practical support, emotional support, and social links to the community. Parents play a vital role in planning the child's rehabilitation and return to school. They are often the only ones who can tell therapists and teachers what the child was like before the injury. They may be more closely attuned to their child's subtle signs of fatigue or emotional stress.

Families who are emotionally traumatized themselves (often because of their own injuries or involvement in the accident) may need the support of rehabilitation professionals before they can play a role in the child's rehabilitation. Professionals treating the child listen to the family's concerns and help them absorb the changes that have occurred. Professionals have a responsibility to attend to the emotional needs of the family and to include them every step of the way to ensure a successful approach.

Professionals need to help families identify and access a range of support services during their journey from hospital to home. The success of a child's progress in the hospital and community depends in part on the family's strength to meet the child's needs. Family support and education are the keys to guiding the family on a strong path towards emotional adjustment and successful care of the child.

*“The role of parents as service coordinators over the long-term course of children's recovery from ABI needs to be acknowledged and respected by professionals...” (Lash, 1996).*

## The Needs of Families in the Hospital and Community

Several studies have assessed the priority of needs of families of children with serious brain injuries. Using a family needs questionnaire, researchers found that families frequently rated the following needs as most important (Mauss-Clum & Ryan, 1981; Kreutzer, Camplair, & Waaland, 1988; Marks, Sliwinski, & Gordon, 1993; Kreutzer, Serio, & Berquist, 1994):

- the need for honest, understandable answers to their questions
- the need to understand completely the child's difficulties with cognitive and physical skills
- the need for assurance that the child is receiving the best medical care and resources
- the need to have a professional they can turn to when the child is in need

## Suggestions for Providing Support and Assistance

Although the needs listed above can act as a guide for selecting appropriate family support services and approaches, each family has unique needs that require individualized attention and customized support. The family needs listed above are addressed in some of the following approaches.

### Offer Information and Education

*“...the family suddenly finds themselves immersed in a medical system they may never have needed before and interacting with professionals who seem to speak a different language”*  
(Williams, 1991).

Families rated highly the need for honest, understandable answers to their questions. Parents need to hear medical information delivered in a frank, honest, and open way. At the early stages in the hospital, families need professionals to refrain from making medical predictions. Families in hospital need to be educated about medical concerns that may affect the child, such as seizures or difficulties with vision, hearing, or physical skills.

A family's need to access accurate information may be best met if one person in the hospital is designated as a spokesperson who provides information and education to reduce the risk of misinterpretation. Answering the family's questions and providing careful explanations about medical procedures and treatment will help assure them that their child is receiving the best medical care. A professional also needs to impart to the family that an injury to the brain may cause future impairments, without predicting specific deficits which may or may not emerge.

*For an information package to give to families, see Appendix 3-C in Chapter 3, Linking to Services.*

Parents may need to hear this information several times to reinforce their learning, because they may easily misunderstand or absorb only a fraction of the information due to their fatigue, shock, and feelings of uncertainty.

*“This initial delivery of information by professionals, and how the family then translates that information into their own reality, has a lasting effect on families” (Williams, 1991).*

In the surveys of family needs, parents expressed a strong desire to know more about the child’s cognitive and physical difficulties caused by the brain injury. At each stage, beginning in the hospital and then in the community, rehabilitation professionals need to take time to review assessment findings with the family and answer their questions. Explanations about the need for future appointments for assessment or treatment may also be needed. Most parents want to be informed so that they can make wise decisions when planning.



Family educational topics that focus on the family rather than on the child were not identified by families as a high priority on the needs questionnaires. However, this education may provide support for families wanting to learn new coping strategies or problem-solving skills. In the hospital or in the community, parents may ask for information about their child’s brain injury but do not know to request family education on other topics. The social worker, family support worker, psychologist, or family counsellor may need to review a list of topics with the family to identify possible areas of interest and to offer available resources. The following are possible topics for ongoing family education:

- financial and employment issues
- how to create a network of community supports (informal and formal)
- advocacy skills
- how to work successfully with service coordinators
- how to link the child with appropriate rehabilitation services over time
- how to tailor existing support services to meet the child’s unique needs
- how to identify the appropriate professional to call when help is needed
- how to navigate the school system
- stress management skills
- changing roles and responsibilities for family members
- sibling support
- behaviour management
- how to juggle the needs of the family and injured child so that both family and rehabilitation goals are met

Families may need support to find a balance between work, rest, and play for all family members, including the injured child. Professionals can support this process, but families ultimately make their own choices to keep a balance in their family life.

### **Offer Rehabilitation Services**

On the needs surveys, families indicated that they also wanted assurance that their child was receiving quality services. The family's focus is primarily on the injured child, and the need to obtain services quickly. Hospital and community professionals can best support families by ensuring that the child's needs will be met by the appropriate rehabilitation services.

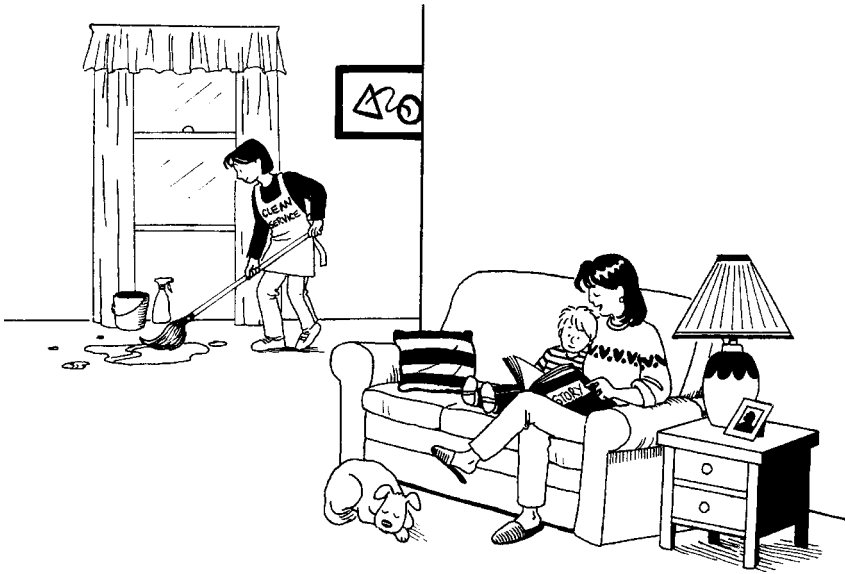
*“Poor relationships with professionals and the absence of important social services can have devastating effects within the family....Families feel unsupported and overburdened, which in turn creates tension and stress...”* (Seligman & Darling, 1989).

Also highly rated by families was the need to have an identified professional to call when they need help for the child. Initially, the child's service coordinator or the primary therapist working closely with the child may be the most appropriate professional to call. The service coordinator may provide valuable support to the family by coordinating treatment services, ensuring the team and family communicate regularly, and establishing a structure for monitoring the child's progress over time, particularly when direct treatment is no longer recommended. In time, some families may want to take on a coordinating and advocacy role themselves. In cases involving litigation, the child's lawyer may request the involvement of a private case manager to gather information and advocate for the child's needs. This professional is funded through the child's settlement and can provide additional support to the family.

### **Offer Practical Assistance**

On the needs surveys, practical family assistance, such as homemakers or transportation, was rated as a low priority for families in hospital (Kreutzer, Serio, & Berquist, 1994). However, the opportunity for the family to participate actively in the 24-hour care for the child in hospital was rated as a high priority. In order for families to provide 24-hour care, practical support may be necessary. Homemakers, medical transportation, financial services, and medical interpreters for families who speak English as a second language can all help meet the short-term emergency needs of families who spend many hours at the hospital.





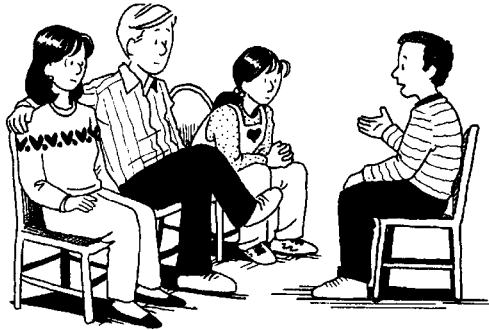
Such practical support may also help parents after they leave the hospital by freeing up time they can then spend with their injured child, other children, spouse, or friends. For instance, a youth worker may reduce the risk of exhaustion and sibling neglect by accompanying the injured child on recreational swims. The family and the child need to be considered as a unit in the healing process. Practical support can help families achieve their goal of fitting the injured child into normal family life.

### **Offer Emotional Support**

Although most families want to focus all of their energy on their child, they may also want emotional support to help them with the new tasks of family adjustment and problem solving. Some families need to tell their story over and over to an empathetic listener. Telling the story helps families absorb what has happened and decide what to do. Listening may be the most helpful approach to providing emotional support.

During the first few weeks or months at home, some families become aware that the brain injury is different than a physical injury to any other part of the body. The child may appear fine, but unusual changes in personality or behaviour may be alarming and may disrupt family life.

Counselling may be helpful at any transition or difficult period in the recovery and adjustment process. Families may need to learn about the different types of counsellors and approaches before deciding on the one best suited for them. The support of a family doctor, neuropsychologist, psychiatrist, family therapist, play therapist, social worker, counselling psychologist, or behaviour therapist may address difficulties experienced by both the injured child and the family. Sometimes two separate counsellors, such as a play therapist for the child and a family therapist for other family members, are beneficial. These counsellors need to coordinate their services to ensure that individual issues are addressed without conflicts of interest.



Professionals may need to offer support to families to better assist siblings. For instance, they may need to recognize the parents' wish to turn their attention away from the injured child toward a struggling sibling from time to time. A parent's one-on-one time with a sibling away from the hospital or home may reassure the sibling that the family also cares about his or her welfare. Families under stress may need gentle reminders to avoid overburdening siblings with too many household chores or responsibilities. Some siblings need to be reassured that the increased responsibilities will only last for a certain amount of time and that their sibling relationship will not involve frequent babysitting.

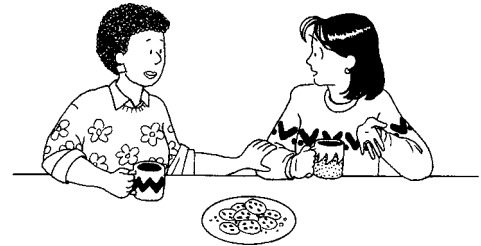
Professionals may need to welcome parents to include siblings in treatment activities or peer inservices. Younger siblings may be able to participate in therapy sessions, or have their fears about certain pieces of medical equipment eased. Older siblings may be invited to family and team conferences or may play a small role in the injured child's care.

Some siblings have difficulty talking about their feelings to anyone at home or school. A special effort may need to be given to a sibling in crisis. If proper care and attention are not provided, the troubled sibling may turn the family upside down.

Some families want to focus only on the injured child until the child has significantly recovered before they address their own needs. Rehabilitation professionals need to respect the family's decision to wait before seeking family support.

## Sources of Informal Family Support

Many families gain strength from informal support systems such as other family members, friends, neighbours, religious groups, or recreational centres or clubs. Some families enjoy talking to other families in similar situations who they met at the hospital or on the Internet. A family support group can be a strong resource for informal peer and parent support. Informal emotional support for siblings may come from parents, other siblings, close friends, religious youth groups, and teachers at school. Siblings may enjoy talking to other siblings they have met through Internet sibling chat lines.



Some families who rely solely on family and friends may not receive enough support to cope well with all the challenges facing them. In the early stages, these families may need help from a combination of informal and formal support sources. Personal networks may be more valuable to families than professional support over the long term (Jacobs, 1988). However, families should be encouraged to ask professionals for help if they are not receiving emotional support from informal sources (Dunst, Trivette, Gordon, & Pletcher, 1989).

## Sources of Formal Family Support

In the hospital, a social worker, psychologist, nurse clinician, and pastoral counsellor are often available to help. In the community, the child's service coordinator, family counsellor, religious counsellor, case manager hired by the lawyer, family support worker, social worker, psychologist, and family doctor may be available for support. Multicultural community workers and immigrant services may provide family counselling and emotional support to ethnic minority families. Specific formal support for siblings may be available through school counsellors, mental health centres, child and youth teams, and *sibshops* (workshops for siblings of children with special needs). Sibshops are available at times, depending on interest, through child development centres and provincial rehabilitation centres.

**The Case Manager** – Following an acquired brain injury, a child receives rehabilitation services and care from a number of professionals or caregivers in a variety of settings, at different times, throughout the developing years. A case manager is needed to coordinate and evaluate these services. This could be either the parent or a designated professional.

Families have different strengths and abilities to assume the responsibility of case manager. Early in the transition from hospital to home, families need to discuss with the rehabilitation team how much responsibility they wish to hold and what assistance they might need from a professional for case management and advocacy.

Funding for a case manager is often available to children with insurance funds through their lawyer. For children without funds or with limited funds, the family and rehabilitation team may need to identify a professional who is already involved with the child to take a coordinating role. This role is invaluable to the clinical team and the family in ensuring the child's rehabilitation needs continue to be monitored as the child grows.

The following are some additional sources of formal support for families in the community:

**The Child's Service Coordinator** – One of the following service coordinators may locate support for families and may have funding available for counselling and group programs:

- when the child's brain injury is a result of a motor vehicle accident and meets the eligibility criteria for insurance coverage from the Insurance Corporation of BC (ICBC):

ICBC Rehabilitation Coordinator

Phone: (604) 647-6120 or  
1-888-388-9882 (outside the lower mainland)  
Fax: (604) 647-6129

- when the child is not receiving funding from ICBC, private insurance, or Workers' Compensation Board:

Community Brain Injury Program for Children and Youth  
CBIPCY Coordinator  
Phone: (604) 451-5511 or  
1-877-451-5511 (outside the lower mainland)  
Fax: (604) 451-5651

**Local First Nations Band Offices** – Medical or social development officers may provide support.

**Local Child Development Centre** – Family support workers may provide support and information about community resources.

**Local Government Offices** – Information about community and family services may be available from these local offices:

- Ministry for Children and Families
- Community Health Unit
- Mental Health Centre
- Ministry of Education School Board Offices

**BC Brain Injury Association** – BC BIA has contact with the various family support groups in BC and provides information about brain injury and community support.

Phone: (604) 520-3221 or 1-800-510-3221 (outside the lower mainland)  
Fax: (604) 520-3206  
Web site: [www.bcbia.org](http://www.bcbia.org)

**BC College of Family Physicians**

Phone: (604) 878-8772

**BC Association for Marriage and Family Therapy**

Phone: (604) 687-6131

**College of Psychologists of BC**

Phone: (604) 736-6164

## Future Considerations

In the months and years following the injury, many families feel they will be able to return to a normal and happy family life. Many families show great resiliency and strength in their adjustment to the child's changing needs. Families are often able to use formal and informal support to form a strong community network.

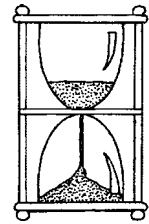
Family members often remember the anniversary of the child's injury as a tribute to the child's courage and strength to survive. This date may trigger sudden grief if a certain milestone is not reached or the child is developing new difficulties. This response is known as the *anniversary reaction syndrome*. Parents may become depressed on this date, and may visit the hospital or former therapists to regain a hopeful perspective. Families may need extra support at this time.

*"I knew I'd be sad on this anniversary day so I took Mary back to the hospital for a visit. They were so happy to see how far she's come along. I know we've got a lot to be thankful for."*

Some family members may also experience feelings of deep sorrow as they realize that their child or sibling will never be the same person, or that family life may be forever more complicated. One long-term issue that often creates a conflict between family members is the struggle concerning the overprotection or underprotection of the injured child. The brain injury may produce unwelcome role changes in the family. Family relationships may become more strained. Marital or sibling conflicts may occur. For instance, parents' jobs may need to be permanently altered, and siblings may face hours of after-school care. Some families have great difficulty shifting the central focus away from the injured child and looking at the family as a whole.

As time passes, families who are unable to adjust to the changes related to the injured child may experience the following:

- chronic fatigue
- increased psychosomatic illnesses
- depression
- marital separation or divorce
- social isolation and loneliness
- new feelings of hostility
- rejection of the injured child



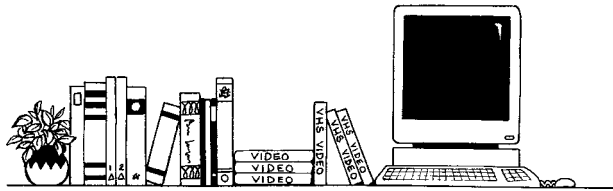
By recognizing the risk of long-term family difficulties, professionals can support families by linking them with appropriate services in the community and helping them navigate the system of services.

As the child's rehabilitation services in the community or at school gradually decrease, the family may lose much of the indirect support they were receiving. Families often begin to see their own need for more support at this time. This may leave them feeling somewhat abandoned, isolated from help, and uncertain about where to seek assistance. They may be suddenly thrown into the unfamiliar role of case management to advocate for their child in an overwhelming health care system. At this time of transition, families may benefit from education about how to assume these roles and who to contact about future child and family support concerns.

With professional guidance and support, families may experience a greater sense of confidence to successfully manage and advocate for appropriate services in the future.

## Additional Reference Materials

### For Professionals



#### Books

Dell Orto, A.E., & Power, P.W. (1994).

*Head injury and the family: A life and living perspective.* Winter Park, FL: PMD Publishers Group.

Sellars, C.W., & Vegter, C.H. (1993). *Pediatric brain injury: A practical resource.* Tuscon, AZ: Communication Skill Builders.

Sellars, C.W., & Vegter, C.H. (1997). *Pediatric brain injury: The special case of the very young child.* Houston, TX: HDI Publishers.

Singer, G.H.S., Glang, A., & Williams, J.M. (Eds.). (1996). *Children with acquired brain injury: Educating and supporting families.* Baltimore, MD: Paul H. Brookes Publishing.

Williams, J.M., & Kay, T. (Eds.). (1991). *Head injury: A family matter.* Baltimore, MD: Paul H. Brookes Publishing.

#### Videos

University Hospital School. *Families living with brain injury.* Iowa City, IA: University of Iowa.

#### Web Sites

[www.tbi.org](http://www.tbi.org)

[www.tbiguide.com](http://www.tbiguide.com)

[www.waiting.com](http://www.waiting.com)

*For materials to give to families, see Appendix 3-C in Chapter 3, Linking to Services.*

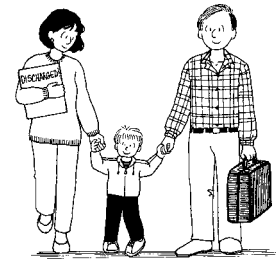




# Linking to Services: Hospital Discharge and Community Re-Entry

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## Chapter Overview

**Who is this chapter for?** Hospital and community professionals such as therapists, nurses, social workers, and teachers.

**Who is this chapter about?** Children who have recently sustained a moderate to severe acquired brain injury, who are still in the hospital or have recently returned home. These children are beginning to regain previous skills such as walking and talking.

**What is this chapter about?** How to link these children to appropriate community rehabilitation services in BC.

**C**hildren with moderate to severe brain injuries are sometimes discharged directly home from the hospital without being connected to rehabilitation services in the community. As a result, these children may not receive the therapy services or school assistance they need. This chapter is intended to assist hospital and community professionals with making referrals to the appropriate services.

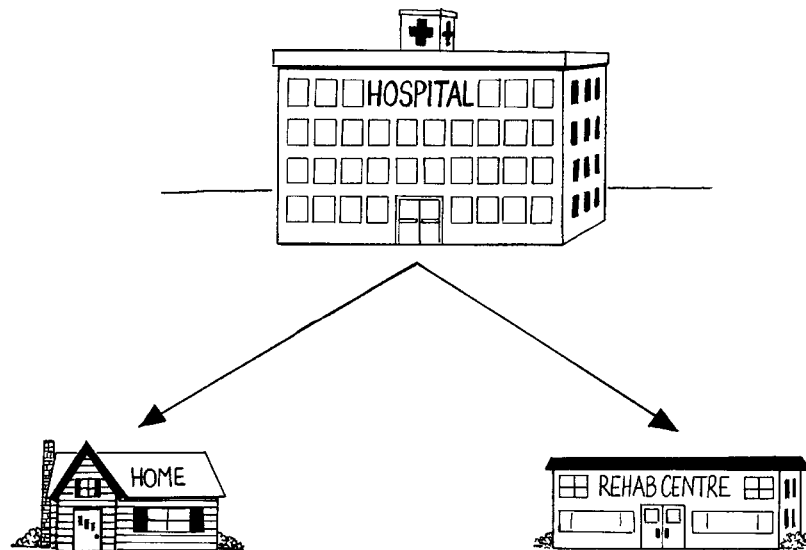
In this chapter we review some of the issues to consider when deciding whether to discharge a child to home or to a rehabilitation centre. We then focus on the plan for discharge to home and outline five key steps for linking children with community services.

## Discharge to Home or to a Rehabilitation Centre?

Before a child with a brain injury is discharged from the hospital, the hospital physicians and team discuss the possible options for discharge with the child's family. They consider whether the child should be discharged directly to their home or to a rehabilitation centre such as:

- Sunny Hill Health Centre for Children in Vancouver, BC
- G.F. Strong Rehabilitation Centre in Vancouver, BC
- Queen Alexandra Centre for Children's Health in Victoria, BC
- Gorge Road Hospital in Victoria, BC

*For more information about these rehabilitation centres and their admission criteria, see Appendix 3-A.*



A period of acute rehabilitation and intensive support at a rehabilitation centre is often required when children or their families need a level of service beyond that which the community can provide. The rehabilitation centres listed above have expertise in pediatric brain injury, and provide interdisciplinary assessment and rehabilitation and assistance with the transition to home, school, and community.

The decision of when and where to discharge a child is made by considering each child's unique situation. It depends in part on:

- the child's specific difficulties and the level of support required
- the family's wishes and their needs for support and assistance
- the availability of services in the rehabilitation centre compared to the community
- the child's level of consciousness

## The Child

When deciding whether to discharge a child to home or to a rehabilitation centre, it is important to consider the child's needs:

- the child may have significant medical, physical, feeding, cognitive, or behavioural difficulties that are challenging, slow to improve, or that require a high level of support and rehabilitation
- the child's tolerance for therapy is limited so that short, frequent sessions throughout the day are needed
- the child may be changing quickly, so that recommendations about how to appropriately support and interact with the child need to be updated frequently

## The Family

It is important to consider the family's needs:

- other family members may have died or been seriously injured in the accident
- custody, protection, or criminal issues may be associated with the circumstances surrounding the child's brain injury
- the family's readiness, emotional preparedness, and comfort level for discharge
- the family may require daily assistance and emotional support to care for and manage the child's special needs and behaviours
- family members may need to return to work or home to care for other family members
- the family home or community may not be physically accessible

*For information on rehabilitation centres in BC, see Appendix 3-A.*

*For a more detailed description of level of consciousness, see Chapter 1, Acquired Brain Injury, and Chapter 5, Rehabilitation.*

## Availability of Services

It is important to consider the availability of services in the rehabilitation centre compared to the community:

- each rehabilitation centre has its own admission criteria—some see children of all ages and levels of functioning, while others see defined ages and require a particular level of ability
- some rehabilitation centres may have a waiting list
- access to services in the community may be limited, or the level of support the child or family requires may be beyond that which the community can provide

## Level of Consciousness

It is important to consider the child's *level of consciousness* and the potential impact of this level on the child's family. The following describes some of the main issues to consider at each of the five levels of consciousness on the Rancho Los Amigos Pediatric Scale.

### Levels 5, 4, and 3

Children at Levels 5, 4, and 3 on the Rancho Los Amigos Pediatric Scale are either unresponsive or minimally responsive to their surroundings and are fully dependent. Children who remain in these low-level states, even when medically stable, are often best referred to a rehabilitation centre for the acute rehabilitation phase due to the complexity of care and long-term planning they require. Families of these children also benefit from the intense level of support and education offered by rehabilitation centres.

### Levels 2 and 1

Although children who are functioning at Level 2 have often regained mobility and talking skills, they are still disoriented and are not able to recall new information and recent events. Their ability to learn new skills is significantly impaired, they are dependent on structured support from others, and they require constant supervision to ensure their safety due to difficulties with impulsivity, attention, and behaviour. Children at Level 1 are oriented and can remember new information more consistently; however, they may also require a high level of support due to difficulties with cognition and behaviour.

Many families with children at Level 2 or 1 believe that their child's improvements in walking or talking mean that the same level of recovery has occurred with thinking and behaviour. However, once these families return home, they are often unprepared for the changes they see in their child and are unsure of how to provide the needed support.

With knowledge about the child, family, available community services, and child's level of consciousness, hospitals may be better able to decide, together with the family, where the needs of the child and family would be best met—at a rehabilitation centre or in the community.

## Linking to Community Services

When the decision has been made to discharge the child directly home, hospital professionals can complete a few key tasks to help link the child with the appropriate community services.

Sometimes a child returns home or to school without all steps being completed, and still needs to be connected to community services. In this case, community professionals may complete the process of linking the child to services. The tasks for community professionals are not identical to those of hospital professionals, but are very similar.

The steps for hospital and community professionals are summarized below and described in more detail in the following pages.

---

### Summary: Tasks for Hospital Professionals

#### Step 1: Identify a Hospital Discharge Planner

The hospital team identifies a discharge planner to coordinate the discharge and make the initial links to community services.

#### Step 2: Identify the Service Coordinator

The hospital discharge planner determines which service coordinator—the Insurance Corporation of BC (ICBC) or Community Brain Injury Program for Children and Youth (CBIPCY)—can assist with funding and organizing rehabilitation services in the community.

#### Step 3: Develop Recommendations for Ongoing Rehabilitation

The hospital team develops recommendations that will address the child's rehabilitation needs in the community.

#### Step 4: Meet With the Family

The hospital discharge planner meets with the family to:

- discuss rehabilitation recommendations and the role of the service coordinator
- provide the family information package (see Appendix 3-C)
- request permission to send referral letters

#### Step 5: Make Referrals

The hospital discharge planner sends a referral letter to the child's ICBC or CBIPCY service coordinator and school principal.

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## Summary: Tasks for Community Professionals

### Identify the Service Coordinator (same as Step 2 above)

The community professional determines which service coordinator—ICBC or CBIPCY—can assist with funding and organizing rehabilitation services in the community.

### Meet With the Family (similar to Step 4 above)

The community professional meets with the family to:

- provide the family information package (see Appendix 3-C)
- request permission to send referral letters

### Make Referrals (same as Step 5 above)

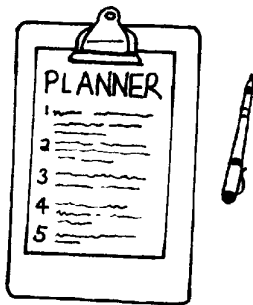
The community professional sends a referral letter to the child's ICBC or CBIPCY service coordinator and school principal.

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## Step 1: Identify a Hospital Discharge Planner

By identifying a single person to be the hospital discharge planner, the hospital team can simplify the discharge process and ensure that critical links are made with community services.

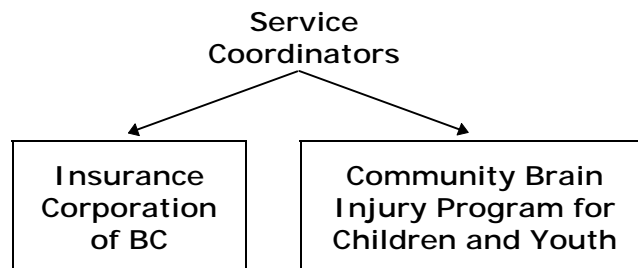
The person in charge of discharge planning varies from hospital to hospital. However, this role is often assumed by the occupational therapist, physiotherapist, social worker, or nurse. The discharge planner may have limited time, but the following steps can be completed relatively quickly. Of course, additional time may be needed to more thoroughly discuss issues with the family or other team members.



## Step 2: Identify the Service Coordinator

The hospital discharge planner identifies the child's service coordinator. The service coordinator helps the family locate and coordinate rehabilitation services if the child is being discharged directly to home from the hospital. Currently, all children who sustain moderate to severe brain injuries in BC can receive some funding and service coordination from one of two main sources: ICBC or CBIPCY.

*For more information about service coordinators and their contact numbers, see Appendix 3-A.*



Children who have been in motor vehicle-related accidents and who meet the eligibility criteria for ICBC insurance coverage may be assisted by the ICBC rehabilitation coordinator. Children who are not eligible for ICBC and are not receiving funding from private insurance or WCB may be assisted by the CBIPCY coordinator.

If the family has not yet filed an ICBC claim (or other insurance claim), they may need assistance with this process. Some discharge planners request that the hospital social worker assist the family if too many complexities arise.

If the child was injured as a result of a crime or while on the job, the Workers' Compensation Board may be the service coordinator (see Appendix 3-A).

### Step 3: Develop Recommendations for Rehabilitation

The recommendations made by hospital professionals are important. The family and service coordinators use the hospital team's input to guide their decisions about which community rehabilitation services to arrange for the child.

Ideally, the hospital team should recommend the following:

- specific therapies or approaches to use with the child
- that the child be assessed by an interdisciplinary team in the community consisting of a neuropsychologist, speech-language pathologist, occupational therapist, and physiotherapist
- that the child not return to school immediately



Although children may appear to be doing well in hospital, the significance of their difficulties often does not become apparent until they return home or to school. For this reason, an interdisciplinary team assessment is critical to understanding how the brain injury has affected the child's ability to think, learn, and behave in real-life situations.

Although the child may not require treatment from every discipline, a team assessment can help others recognize the child's problems and how to best help. This assessment also guides the development of appropriate rehabilitation goals and plans for the child in the community.

Delaying the child's return to school enables the family, school, and community rehabilitation team to carefully plan a successful re-integration. Time is needed to determine if the child is ready to attend school, and to plan the types of curriculum and school support services that are appropriate for the child.



## Step 4: Meet With the Family

The hospital discharge planner meets briefly with the family to:

- review the recommendations for rehabilitation and the role of the service coordinator
- give the family the information package
- request permission to send referral letters

During this meeting, it may become apparent that the family is having difficulty coping, and a referral to the hospital social worker or community counsellor may be necessary. If the discharge planner is the hospital social worker, the discharge planner may wish to schedule additional time with the family to provide counselling support.

### Recommendations for Rehabilitation

The discharge planner and family discuss the hospital team's recommendations for rehabilitation in the community, including the need for:

- specific therapies or approaches to use with the child
- an interdisciplinary team assessment in the community
- delaying the child's return to school

In addition, the child's service coordinator is identified to the family so that they know who will be funding and organizing rehabilitation services for the child upon the return home.



*For more information about family experiences and support, see Chapter 2, Family Issues.*

### Family Information Package

Most children only stay in the hospital for a short time, and few appropriate educational materials are available for families of children with acquired brain injuries. The family information package in Appendix 3-C provides answers to some of the questions families often have. If there is time, the discharge planner may want to review some of the main ideas in these handouts with the family.

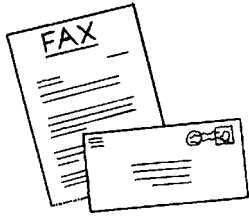
The five handouts in the family information package include:

- *Frequently Asked Questions About Brain Injury*
- *Rehabilitation Services for Children With Brain Injuries*
- *Returning to School*
- *Finding Information About Brain Injury*
- *Support Services for Families*

*See the Family Information Package in Appendix 3-C.*

### Referral Letters

The hospital discharge planner requests permission from the family to send two referral letters, one to the service coordinator and one to the school principal. The letters alert these professionals about the child's need for immediate assistance upon returning home. The discharge planner may need to obtain the appropriate names, phone and fax numbers, or addresses from the family.



*See the sample referral letters in Appendix 3-B.*

*For more information, see Chapter 4, Returning to School.*

## Step 5: Make Referrals

With the consent of the family, the hospital discharge planner faxes or mails the referral letters to the child's service coordinator and school principal.

### Service Coordinator

When a child is injured in a vehicle accident, an ICBC claim needs to be filed. An ICBC adjuster is initially in charge of this file. However, if the child sustained a brain injury in the accident, this file needs to be forwarded to the ICBC Rehabilitation Department. A referral letter should be directed to the ICBC rehabilitation coordinator if one has been assigned. Otherwise, the hospital should send the referral letter to the ICBC adjuster so that the file will be quickly sent to the ICBC Rehabilitation Department.

The service coordinators at ICBC and CBIPCY are quick to respond and will contact the family to begin planning soon after receiving a referral, sometimes while the child is still in hospital.

Some hospitals already follow a procedure for referring children to local services such as a child development centre, health unit, school, infant development program, or private services. However, the hospital should also contact the child's ICBC or CBIPCY service coordinator so that the child may receive additional assistance and funding for rehabilitation, if needed.

### School Principal/Preschool or Daycare Supervisors

Some children with moderate to severe brain injuries return to school, preschool, or daycare too early or without adequate planning. In addition, these services may not be informed of the brain injury or its significance for learning and behaviour. The hospital can provide some of this information by sending the school principal or preschool/daycare supervisors a referral letter. This informs these services of the child's brain injury and the need for a carefully planned return to school and the possible need for school, preschool, or daycare support services.

## Provincial Resources

### Rehabilitation Centres

#### Sunny Hill Health Centre for Children (Children's and Women's Health Centre of BC)

- This centre provides inpatient and outpatient acute rehabilitation services to children and adolescents (aged 0 to 19 years) with acquired brain injuries. Outreach services are provided as appropriate.
- Assessment, treatment, and community re-integration services are provided by an interdisciplinary team of professionals with expertise in pediatric brain injury.
- To access inpatient services, children and adolescents must be medically stable and require nursing care. Some children and adolescents are admitted while still unconscious. Other inpatients and outpatients may be at a higher level of cognitive and physical functioning.
- Referrals need to be made by a physician. There is usually no waitlist for services.
- This centre is a provincial resource for anyone in BC and the Yukon who would like more information about pediatric brain injury.
- For information, contact:

Brain Injury Team Leader  
Sunny Hill Health Centre for Children  
3644 Slocan Street, Vancouver, BC, V5M 3E8  
Phone: (604) 453-8300 Fax: (604) 453-8301  
Web site: [www.sunnyhill.bc.ca](http://www.sunnyhill.bc.ca)



### G.F. Strong Rehabilitation Centre (Vancouver Hospital and Health Sciences Centre)

- The Adolescent/Young Adult Program provides inpatient and outpatient acute rehabilitation services to adolescents and young adults (aged 12 years and older) with neuromusculoskeletal disabilities, including acquired brain injuries. Outreach services are provided as appropriate.
- Assessment, treatment, and community re-integration services are provided by an interdisciplinary team of professionals with expertise in brain injury.
- To access inpatient services, adolescents and young adults must be at a level of functioning where they can physically take part, demonstrate readiness to participate, begin to identify goals, and learn within the program.
- Referrals need to be made by a physician. There may be a waitlist for services.
- This centre is a provincial resource for anyone in BC and the Yukon who would like more information about adolescents and young adults with acquired brain injuries.

- For information, contact:

Program Coordinator  
Adolescent/Young Adult Program  
G.F. Strong Rehabilitation Centre  
4255 Laurel Street, Vancouver, BC, V5Z 2G9  
Phone: (604) 734-1313 Fax: (604) 737-6359  
Web site: [www.vanhosp.bc.ca](http://www.vanhosp.bc.ca)

### Queen Alexandra Centre for Children's Health (Capital Health Region)

- This centre provides inpatient or outpatient acute rehabilitation services for children and adolescents (aged 0 to 18 years) with acquired brain injuries. Outreach services are provided as appropriate.
- Assessment, treatment, and community re-integration services are provided by an interdisciplinary team of professionals with expertise in pediatric brain injury.
- To access inpatient services, children and adolescents must be medically stable and require nursing care. Some children and adolescents are admitted while still unconscious. Other inpatients and outpatients may be at a higher level of cognitive and physical functioning.
- Referrals can be made by physicians, community professionals, and families. To make a referral, contact the Coordinated Intake Service at (250) 721-6706. There is usually no waitlist for services.

- This centre is a regional resource for anyone on Vancouver Island who would like more information about pediatric brain injury.
- For information, contact:  
Coordinator, Rehab/Respite Program  
Queen Alexandra Centre for Children's Health  
2400 Arbutus Road, Victoria, BC, V8N 1V7  
Phone: (250) 477-1826 Fax: (250) 721-6828  
Web site: [www.caphealth.org](http://www.caphealth.org)

### Gorge Road Hospital (Capital Health Region)

- This hospital provides inpatient and outpatient acute rehabilitation services for adolescents and adults (aged 14 years and older) with acquired brain injuries. Outreach services are provided as appropriate.
- Assessment, treatment, and community re-integration services are provided by an interdisciplinary team of professionals with expertise in brain injury.
- To access inpatient services, adolescents and adults must be medically stable and require nursing care. Inpatients and outpatients may be at a higher level of cognition and physical functioning.
- Referrals need to be made by a physician. There may be a waitlist for services.
- The hospital is a regional resource for anyone on Vancouver Island who would like more information about adolescents and adults with acquired brain injuries.
- For information, contact:  
Traumatic Brain Injury Program Assistant  
Gorge Road Hospital  
63 Gorge Road East, Victoria, BC, V9A 1L2  
Phone: (250) 995-4740 Fax: (250) 995-4759  
Web site: [www.caphealth.org](http://www.caphealth.org)





## Support Organizations

### BC Brain Injury Association

- The association is a provincial support and advocacy group for people who have experienced a brain injury and their families. It acts as an umbrella for family and peer support groups around BC.
- The association can advocate to government, insurance companies, and other funding sources to provide needed services.
- The association can refer to medical, legal, and community resources recommended by others with brain injuries and by their families.
- The association has a library and information packages. It also has a quarterly newsletter and an annual international conference.

- For information, contact:

BC Brain Injury Association  
218 Sixth Street, New Westminster, BC, V3L 3A2  
Phone: (604) 520-3221 or  
1-800-510-3221 (outside the lower mainland)  
Fax: (604) 520-3206  
Web site: [www.bcbia.org](http://www.bcbia.org)



### The Brain Tumor Foundation of Canada

- The foundation assists in meeting the information needs of individuals with brain tumours and their families. They provide resource booklets about pediatric brain tumours.
- The foundation can put people in contact with family support groups in BC.

- For information, contact:

Suite 100, 650 Waterloo Street  
London, Ontario, N6B 2R4  
Phone: 1-800-265-5106 or (519) 642-7755 Fax: (519) 642-7192  
Web site: [www.btfc.org](http://www.btfc.org)

# Service Coordinators



## Insurance Corporation of BC

- The Rehabilitation Department provides long-term medical and financial management for eligible claimants with serious injuries resulting from motor vehicle accidents.
- Part 7 (no fault insurance) provides coverage of up to \$150,000 for medical and rehabilitation services.
- Rehabilitation coordinators are assigned to children or adolescents with moderate to severe acquired brain injuries. If the child is recently injured, the claims adjuster may still need to forward the file to the rehabilitation department.
- Rehabilitation coordinators help to identify required rehabilitation services and may contact, monitor, evaluate, and terminate these services. They are involved in developing and implementing an individualized rehabilitation plan for the child along with the rehabilitation team they establish. They do not perform any diagnostic assessment and do not recommend treatment.

- For information, contact:

Rehabilitation Department  
Insurance Corporation of BC  
#108 – 808 Nelson Street, Vancouver, BC, V6Z 2H2  
Phone: (604) 647-6120 or  
1-888-388-9882 (outside the lower mainland)  
Fax: (604) 647-6129

If the family has not yet made an ICBC claim, they should contact the provincial ICBC Telephone Claims Department at (604) 520-8222 or 1-800-910-4222 (outside the lower mainland).

## Community Brain Injury Program for Children and Youth

- The Community Brain Injury Program for Children and Youth (CBIPCY) is administered for all children and adolescents in BC through the Centre for Ability.
- This program coordinates and provides funding for community-based, short-term, intensive rehabilitation and support services for children and adolescents (aged 0 to 18 years) as they leave the hospital or rehabilitation centre and settle in their home community. Follow-up services may be provided at key transition times.
- To access this program, children and adolescents must not be receiving ICBC insurance funds, other private insurance funds, or funds from the Workers' Compensation Board.



- Bridge funding may be available during lengthy waiting periods for other available funding.
- Children and adolescents must be referred within one year of being injured.
- Children and adolescents may be referred to the program by hospital staff, the community, or parents.

- For information, contact:

Community Brain Injury Program for Children and Youth  
Coordinator

Centre for Ability

2805 Kingsway, Vancouver, BC, V5R 5H9

Phone: (604) 451-5511 or

1-877-451-5511 (outside the lower mainland)

Fax: (604) 451-5651

Web site: [www.cbip.bc.ca](http://www.cbip.bc.ca)



### Workers' Compensation Board of BC

- If an adolescent sustains a brain injury while on the job and has WCB coverage, the local WCB claims office should be contacted to look into benefits that may be available.

- For information, contact:

Workers' Compensation Board of BC

Box 5350, Vancouver, BC, V6B 5L5

Phone: (604) 273-2266 or

1-800-661-2112 (outside the lower mainland)

### Criminal Injury Compensation Program (WCB)

- If a child or adolescent sustains a brain injury as a result of a crime, compensation may be available. This includes funding for medical and rehabilitation costs.
- A claim should be made early by the child's parent, guardian, or other representative by contacting the number below.
- A decision on whether the claim is acceptable will generally take up to six months because of the need to gather information for the claim file. (The Community Brain Injury Program for Children and Youth can provide bridge funding until these funds are available).

- For information, contact:

Criminal Injury Compensation Program

Workers' Compensation Board of BC

Box 5350, Vancouver, BC, V6B 5L5

Phone: (604) 244-6400 or

1-800-661-2112, local 6400 (outside the lower mainland)

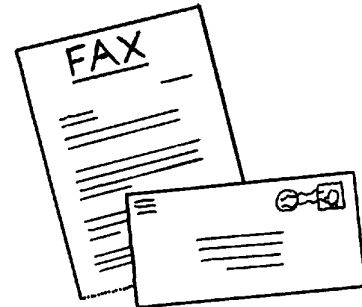




## Sample Referral Letters

Please feel free to photocopy and use or modify these sample referral letters as needed:

- *Letter of Referral to ICBC*
- *Letter of Referral to the Community Brain Injury Program for Children and Youth*
- *Letter of Referral to the School Principal*





## Letter of Referral to ICBC

Date: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Dear \_\_\_\_\_:

### **RE: Coordination of Rehabilitation Services**

As you may know, (*name of child*) \_\_\_\_\_ sustained a moderate to severe brain injury as a result of a motor vehicle accident. This child will soon be discharged home to (*name of city*) \_\_\_\_\_ from (*name of hospital*) \_\_\_\_\_ and is in immediate need of community rehabilitation services. To assist with this process, we request that the claims adjuster pass this child's file to the rehabilitation department as soon as possible.

Our hospital team recommends that the child be assessed by an interdisciplinary team in the community to determine how the brain injury has affected the child's knowledge and abilities, and which rehabilitation services are required for treatment. We anticipate that the following services may help this child:

- Neuropsychology \_\_\_\_\_
- Speech-Language Pathology \_\_\_\_\_
- Occupational Therapy \_\_\_\_\_
- Physiotherapy \_\_\_\_\_
- Audiology \_\_\_\_\_
- Ophthalmology \_\_\_\_\_
- Dietitian \_\_\_\_\_
- Family Counselling \_\_\_\_\_
- Other: \_\_\_\_\_

These services may be available from the local child development centre, health unit, infant development program, school, or private practices. The parents/legal guardians (*name*) \_\_\_\_\_ (*phone*) \_\_\_\_\_ are looking forward to hearing from you at your earliest convenience. Thank you for your attention to this urgent request.

Sincerely,

\_\_\_\_\_

## Letter of Referral to the Community Brain Injury Program for Children and Youth

Date: \_\_\_\_\_

CBIPCY Coordinator  
2805 Kingsway, Vancouver, BC, V5R 5H9  
Phone: (604) 451-5511 Fax: (604) 451-5651

Dear \_\_\_\_\_:

**RE: Coordination of Rehabilitation Services**

---

We are writing to inform you that (*child's name*) \_\_\_\_\_ sustained a moderate to severe brain injury. This child will soon be discharged home to (*name of city*) \_\_\_\_\_ from (*name of hospital*) \_\_\_\_\_ and is in immediate need of community rehabilitation services.

Our hospital team recommends that the child be assessed by an interdisciplinary team in the community to determine how the brain injury has affected the child's knowledge and abilities, and which rehabilitation services are required for treatment. We anticipate that the following services may help this child:

- Neuropsychology \_\_\_\_\_
- Speech-Language Pathology \_\_\_\_\_
- Occupational Therapy \_\_\_\_\_
- Physiotherapy \_\_\_\_\_
- Audiology \_\_\_\_\_
- Ophthalmology \_\_\_\_\_
- Dietitian \_\_\_\_\_
- Family Counselling \_\_\_\_\_
- Other: \_\_\_\_\_

These services may be available from the local child development centre, health unit, infant development program, school, or private practices. The parents/legal guardians (*name*) \_\_\_\_\_ (*phone*) \_\_\_\_\_ are looking forward to hearing from you at your earliest convenience. Thank you for your attention to this urgent request.

Sincerely,

\_\_\_\_\_

## Letter of Referral to the School Principal/ Preschool or Daycare Supervisors

Date: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Dear \_\_\_\_\_:

**RE: School, Preschool, or Daycare Re-Integration Planning**

---

We are writing to inform you that (*child's name*) \_\_\_\_\_, a student at your school/preschool/daycare, sustained a moderate to severe brain injury that may affect the child's physical, behavioural, or academic abilities. This child will soon be discharged home from (*name of hospital*) \_\_\_\_\_.

This child has been referred for rehabilitation services in the community. The established rehabilitation team may include professionals from a private practice, child development centre, health unit, infant development program, or school.

Due to the serious nature of this brain injury, the child should not return to school/preschool/daycare immediately. The child will require a carefully planned return to school, and may require school support services.

The parents/legal guardians (*name*) \_\_\_\_\_ (*phone*) \_\_\_\_\_ have given consent to send this letter and look forward to being contacted by yourself or the identified school/preschool/daycare case manager in the near future.

Thank you for your assistance in planning the child's return to school with the family, appropriate school/preschool/daycare personnel, and the established community rehabilitation team.

Sincerely,

\_\_\_\_\_



## Family Information Package

Please feel free to photocopy and use the handouts in this family information package as needed:

- *Frequently Asked Questions About Brain Injury*
- *Rehabilitation Services for Children With Brain Injuries*
- *Returning to School*
- *Support Services for Families*
- *Finding Information About Brain Injury*







# Family Information Package



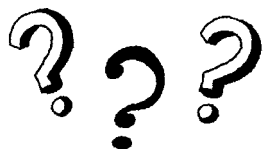
**For Families of  
Children and Adolescents with  
Acquired Brain Injuries**

**Source:** *Children With Acquired Brain Injuries: The Transition from Hospital to Community.* (1999).  
Vancouver, BC: Sunny Hill Health Centre for Children.



# Frequently Asked Questions About Brain Injury

**K**nowing more about your child's brain injury will help you understand what has happened to your child, how to best help your child, and what to expect in the future. The following are questions families frequently ask about brain injuries. Although the answers may give you some general information, you will need to talk to your doctors and therapists to learn more about your child's particular brain injury.



## What are some of the difficulties children may experience after a brain injury?

Children may have some of the following difficulties:

- ◆ tire easily
- ◆ take longer to get things done
- ◆ have trouble starting, finishing, or organizing an activity
- ◆ have difficulty paying attention
- ◆ forget things
- ◆ get mixed up about time and places
- ◆ have difficulty expressing thoughts
- ◆ have a harder time learning
- ◆ act without thinking, be unsafe
- ◆ be restless, fussy, or easily upset more often
- ◆ act differently or more immaturely
- ◆ have difficulty with physical skills such as balance, coordination, and handwriting

Not every child with a moderate to severe acquired brain injury will experience these problems, but many do. Some of the problems may be obvious, while others may be difficult to notice. The therapists in the community who work with your child will be able to identify, with you, your child's specific areas of strength and difficulty and provide suggestions on how to help.



## How much do children improve following a brain injury?

The improvement seen following a child's brain injury tends to be relatively rapid in the first few weeks and months. Children generally regain many of their previous abilities, such as walking and talking. However, they often demonstrate changes in their thinking, learning, and behaviour. These changes may not be apparent until they return home or to school, or until they face new challenges. Some of the effects from brain injury are temporary, while others may last a lifetime.

Improvement may continue for years, though at a slowed rate. As children continue to grow and develop, new difficulties related to the brain injury may become apparent. Because of these ongoing changes, it is important that children with acquired brain injuries be closely monitored and periodically reassessed. This helps to ensure that everyone understands how to best meet their unique needs at home, at school, and in the community.



## How can I best help my child when we first get home?

The following are some general suggestions that may help your family provide the kind of care your child needs when you first return home from the hospital. Your doctor or therapist may be able to give you more suggestions that are specific to your child's individual needs.

## Provide Safety

Children with brain injuries often have poor safety awareness, judgment, or insight. They may act without thinking, have difficulty paying attention, or forget safety rules. They may not understand why they cannot do something they used to be able to do or were previously allowed to do. They may also have specific physical or feeding problems that cause a safety risk.

To create a safer environment when you first get home, consider providing the following:

- ♦ constant supervision, especially in high-risk situations (for example, outdoors, on stairs, in the bathtub or kitchen)
- ♦ a safe, clean, well-lit passage from bedroom to bathroom at night
- ♦ clear guidelines to avoid contact sports and driving
- ♦ supervised play or visits with peers outside of the home
- ♦ supervised meal times to ensure safety and good nutrition

## Provide Structure

Most children with brain injuries are able to function best when you slow down the family routine and keep it structured and predictable. The following suggestions may be helpful:

- ♦ ensure that meals are at a consistent time and that sleep routines are followed
- ♦ offer regular rest breaks (a nap or a quiet activity)
- ♦ try to reduce noise and distractions in the home
- ♦ keep the child's bedroom visually organized and free from clutter
- ♦ reduce the number of activities planned for a day and avoid spontaneous changes in plans
- ♦ help the child start, finish, and organize tasks
- ♦ avoid giving the child complex directions or too many choices, present one idea at a time using short, simple sentences, and allow plenty of time for the child to respond
- ♦ limit the number of visitors to one or two at a time

- ♦ avoid busy public places
- ♦ keep family outings short
- ♦ provide clear expectations and enforce rules in a consistent way
- ♦ several times a day, review with the child what he or she did during the day, what will be happening next, and what time of day it is (avoid testing the child about this information)
- ♦ respond immediately to mood swings or angry outbursts by calmly redirecting the child and providing reassurance and rest

## Encourage Success

Children with brain injuries may or may not be aware of what their new difficulties are, but they will definitely benefit from feeling good about themselves and having success.



Consider these suggestions:

- ♦ focus on what the child can do rather than what the child cannot do
- ♦ build self-esteem with praise—remind or show pictures or videos of how far the child has come in recovery
- ♦ delay participation in activities that the child was previously very good at, that involve a lot of skill, or that the child may not be ready for (for example, a team sport)
- ♦ simplify or change tasks the child was previously able to do to ensure success
- ♦ help find new, less difficult activities that the child enjoys
- ♦ help siblings play with the child by playing cooperative instead of competitive games and activities
- ♦ have one friend visit at a time, for a short period; help structure an activity your child can do
- ♦ encourage the child to do basic self-care and household duties on his or her own as much as possible

# Rehabilitation Services for Children With Brain Injuries

## What rehabilitation services will my child need?

The hospital team may refer your child to local therapy and medical services in your community, or they may refer your child to a rehabilitation centre such as:

- ◆ Sunny Hill Health Centre for Children or G.F. Strong Rehabilitation Centre in Vancouver, BC
- ◆ Queen Alexandra Centre for Children's Health or Gorge Road Hospital in Victoria, BC

No matter where your child is discharged to, he or she should be assessed, ideally by the following:

- ◆ neuropsychologist
- ◆ speech-language pathologist
- ◆ occupational therapist
- ◆ physiotherapist

This team assessment will identify how the brain injury has affected your child's thinking, perception, communication, behaviour, physical skills, and everyday functioning. It will help guide the goals and plans that are made for the child's rehabilitation and return to former activities. This assessment will also help you, your family physician, the rehabilitation team, and the school determine when the child should return to school and the type of assistance that may be needed.



If you want your child to receive treatment or therapy for specific concerns, discuss this request with your service coordinator and family physician.

Some of the following rehabilitation professionals may become part of your child's rehabilitation team:

- ◆ physician
- ◆ neuropsychologist
- ◆ speech-language pathologist
- ◆ occupational therapist
- ◆ physiotherapist
- ◆ recreation therapist
- ◆ play, art, or music therapist
- ◆ ophthalmologist
- ◆ audiologist
- ◆ dietitian
- ◆ social worker
- ◆ family counsellor
- ◆ rehabilitation assistant
- ◆ community health nurse
- ◆ case manager



## How do I find rehabilitation services for my child?

Before discharging your child to home, the hospital staff may recommend rehabilitation services in your community and refer you to a service coordinator at the Insurance Corporation of BC (ICBC) or with the Community Brain Injury Program for Children and Youth (CBIPCY).

If your child's brain injury is the result of a motor vehicle-related accident and meets the eligibility criteria for ICBC insurance, you may be referred to the ICBC Rehabilitation Coordinator in the ICBC Rehabilitation Department at (604) 647-6120 or 1-888-388-9882 (outside the lower mainland).

If your child is not receiving funding from ICBC insurance, private insurance, or Workers' Compensation Board, you may be referred to the CBIPCY Coordinator at (604) 451-5511 or 1-877-451-5511 (outside the lower mainland).

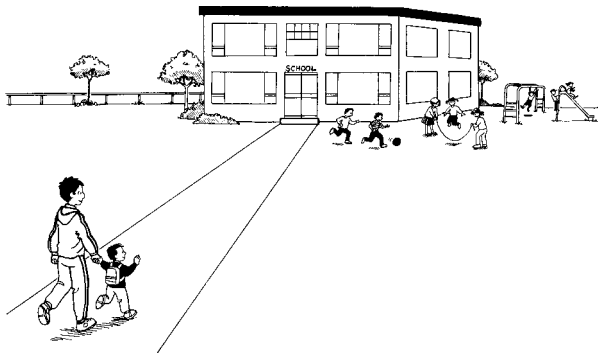
These service coordinators will help locate, fund, and organize some of the rehabilitation services that your child needs. If you are uncertain about who your service coordinator is, contact ICBC or CBIPCY at the numbers listed above.

Although your child may have been connected to therapy services at your local hospital, child development centre, health unit, infant development program, school, or other private service provider, one of the service coordinators listed above should still be contacted, as they can work with the community team and help organize additional services as needed.

# Returning to School

## When is it appropriate for students with brain injuries to return to school?

Students with moderate to severe brain injuries should **not** return to school immediately after returning home from the hospital. Even if students ask to return, this does not mean that they are ready.



Brain injuries cause some changes in how students think, learn, and behave, and it is critical that their return to school be planned very carefully. Although each situation is unique, students with brain injuries need to have certain skills before returning. For example, these students must:

- ◆ always know where they are, what time of day it is, and personal information about themselves
- ◆ be able to remember **new** information and recent events on an ongoing basis—for example, they should be able to remember what they did previously today and yesterday, and what will be happening in the near future (as appropriate for their age)
- ◆ not be overly fatigued
- ◆ be able to cope in a busy environment for an extended period of time



## What is the initial focus of school?

Families may be concerned about how much school work their children have missed while in hospital. However, students with brain injuries should not be expected to catch up.

The initial focus of school is to help students get used to the school routine, experience success, and adjust socially and emotionally. At this stage, it is important for teachers to understand how the student best functions and learns.

To ensure success, a limited number of subjects should be chosen for students based on their abilities, and a plan for gradually attending school should be made. As students improve, school attendance can increase, and more academic content and subjects may be slowly added.



## What needs to be done to prepare for the return to school?

Every student's return to school is different and depends, in part, on the student's needs and the support available. However, the following steps may help ensure that the student's return to school is carefully planned:

- ◆ The school principal/high school counsellor should be contacted about the student's brain injury as early as possible.
- ◆ The school principal/high school counsellor may identify a school case manager who can pull together an appropriate school team. For example, the team might include the classroom teacher, learning assistance teacher, special education assistant, school counsellor, and school therapists such as an occupational therapist, physiotherapist, or speech-language pathologist.

- ◆ Before the student returns to school, a community rehabilitation team can give the school and family helpful information about when to return to school and how the brain injury has affected the student's functioning, thinking, learning, and behaviour. An assessment by a neuropsychologist is particularly important because they have specialized skills in this area.
- ◆ The school team, community rehabilitation team, and family should plan the student's return to school together. They should discuss:
  - the student's brain injury and current functioning
  - what type of curriculum and support is needed and available
  - a plan for gradually returning to school
  - the possible need for a peer inservice and sibling or peer support at school

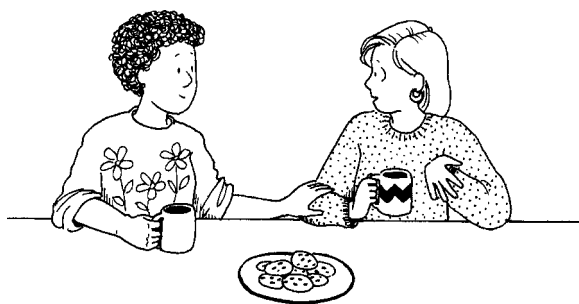
After the student has returned to school and the school team has had time to better understand the effects of the injury, an Individual Education Plan (IEP) may be developed that includes strategies for helping the student learn in the classroom.

The school team, community rehabilitation team, and family should meet regularly to discuss the student's progress and ensure that education plans and strategies are carried out and updated as the student changes.



# Support Services for Families

Most families rely on support from friends and family members. But at some point, you or other members of your family may want to consider seeking formal support to deal with the changes your child's brain injury has created in your lives. Here are a few suggestions for where to find assistance.



## Your Child's Service Coordinator

One of the following service coordinators may locate supports for families with funding available for counselling and group programs:

- ◆ when your child's brain injury is a result of a motor vehicle accident and meets the eligibility criteria for insurance coverage from the Insurance Corporation of BC (ICBC):  
ICBC Rehabilitation Coordinator  
Phone: (604) 647-6120 or 1-888-388-9882 (outside the lower mainland)  
Fax: (604) 647-6129
- ◆ when your child is not receiving funding from ICBC insurance, private insurance, or Workers' Compensation Board:  
Community Brain Injury Program for Children and Youth (CBIPCY)  
Coordinator  
Phone: (604) 451-5511 or 1-877-451-5511 (outside the lower mainland)  
Fax: (604) 451-5651

## Your Local Child Development Centre

Family support workers may provide support and information about community resources.

## Local Government Offices

Information about community and family services may be available from these local offices:

- ◆ Ministry for Children and Families
- ◆ Mental Health Centre
- ◆ Community Health Unit
- ◆ Ministry of Education School Board Offices

## Local First Nations Band Offices

Medical or social development officers may be able to provide assistance to families.

## BC Brain Injury Association

The BC Brain Injury Association has contact with the various community support groups in BC and provides information about brain injury and community support.

Phone: (604) 520-3221 or 1-800-510-3221 (outside the lower mainland)  
Fax: (604) 520-3206  
Web site: [www.bcbia.org](http://www.bcbia.org)

## BC College of Family Physicians

Phone: (604) 878-8772

## College of Psychologists of BC

Phone: (604) 736-6164

## BC Association for Marriage and Family Therapy

Phone: (604) 687-6131



# Finding Information About Brain Injury

**Y**ou may have difficulty finding information that applies to your child's brain injury or your family's situation. For this reason, your best source of information is the rehabilitation professionals who work with your child and have experience in brain injury. Your family doctor, local hospital, child development centre, or health unit may also have helpful information.

In addition, the following BC resources have expertise in brain injury, and a few have lending libraries that may help.

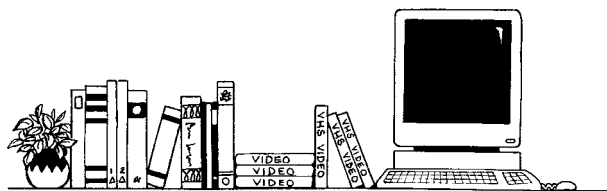
BC Brain Injury Association  
218 Sixth Street  
New Westminster, BC, V3L 3A2  
Phone: (604) 520-3221 or 1-800-510-3221  
Fax: (604) 520-3206  
Web site: [www.bcbia.org](http://www.bcbia.org)  
(has contact with local associations and regional community support groups throughout BC)

Brain Injury Team Leader  
Sunny Hill Health Centre for Children  
3644 Slocan Street  
Vancouver, BC, V5M 3E8  
Phone: (604) 453-8300 Fax: (604) 453-8301  
Web site: [www.sunnyhill.bc.ca](http://www.sunnyhill.bc.ca)

Program Director  
Adolescent/Young Adult Program  
G.F. Strong Rehabilitation Centre  
4255 Laurel Street  
Vancouver, BC, V5Z 2G9  
Phone: (604) 734-1313 Fax: (604) 737-6359  
Web site: [www.vanhosp.bc.ca](http://www.vanhosp.bc.ca)

Queen Alexandra Centre for Children's Health  
2400 Arbutus Road  
Victoria, BC, V8N 1V7  
Phone: (250) 477-1826 Fax: (250) 721-6828  
Web site: [www.caphealth.org](http://www.caphealth.org)

Gorge Road Hospital  
Traumatic Brain Injury Program Assistant  
63 Gorge Road East  
Victoria, BC, V9A 1L2  
Phone: (250) 995-4700 Fax: (250) 995-4759  
Web site: [www.caphealth.org](http://www.caphealth.org)



## Books, Videos, and Web Sites

The following are a few of the books, videos, and web sites where you may find more information about brain injuries in children and adolescents. To find these references, contact your local public library or the Family Support Institute in Vancouver, BC:  
Phone: (604) 875-1119  
Fax: (604) 875-6744  
Web site: [www.familysupportbc.ca](http://www.familysupportbc.ca)

### Books

BC Rehabilitation Society. (1989). *Brain injury rehabilitation manual*. Vancouver, BC: Author.

Burke, W.H., Wesolowski, M., & Blackerby, W.F. III. (Eds.). *The HDI professional series on traumatic brain injury*. Houston, TX: HDI Publishers.

- ♦ *Brain Injury Rehabilitation: An Overview*
- ♦ *Community Living Skill Development: Teaching Methods*
- ♦ *Adaptive Driving After TBI*
- ♦ *Managing Anger and Aggression*
- ♦ *Managing Attention Deficits*
- ♦ *Management of Memory Disorders*
- ♦ *Developing Social Skills*
- ♦ *Sexuality After TBI*
- ♦ *Developing Motivation*
- ♦ *Brain Injury Rehab with Children and Adolescents*
- ♦ *Developing Self Control*
- ♦ *Increasing Self Awareness*
- ♦ *The Role of the Family in TBI Rehab*
- ♦ *Management of Communication and Language Deficits*

Brain Tumor Foundation of Canada. (1994). *Brain tumor patient resource handbook: Pediatric version*. London, ON: Author.

Castiglione, M., & Johnston, C. (1994). *Waiting to clear. Brain injury: Early stages of recovery*. Atlanta, GA: Pritchett & Hull Associates.

DePompei, R. (1998). *All about me*. Wolfeboro, NH: L & A Publishing/Training.

DePompei, R., & Blosser, J.L. (1998). *Communication: How communication changes over time*. Wolfeboro, NH: L & A Publishing/Training.

DePompei, R., Savage, R., & Lash, M. (1998). *Helping brothers and sisters: When a child has a brain injury*. Wolfeboro, NH: L & A Publishing/Training.

Dikengil, A. (Ed.). (1994). *Family articles about traumatic brain injury*. Tuscon, AZ: Communication Skill Builders.

Lash, M. (1990). *When your child is seriously injured: The emotional impact on families*. Boston, MA: Tufts University/New England Medical Center.

Lash, M. (1998). *Myths & facts: When your child has a brain injury*. Wolfeboro, NH: L & A Publishing/Training.

Marchese, N., Potoczny-Gray, A., & Savage, R. (1998). *Behavior after brain injury: Changes and challenges*. Wolfeboro, NH: L & A Publishing/Training.

Raines, S.R., & Waaland, P.K. *For kids only: A guide to brain injury*. Richmond, VA: Medical College of Virginia.

Rocchio, C., & Lash, M. *Helping families cope: When a child has a brain injury*. Wolfeboro, NH: L & A Publishing/Training.

Sellars, C.W., & Vegter, C.H. (1993). *Pediatric brain injury: A practical resource*. Tuscon, AZ: Communication Skill Builders.

Sellars, C.W., & Vegter, C.H. (1997). *Pediatric brain injury: The special case of the very young child*. Houston, TX: HDI Publishers.

Snyder, H., & Beebe, S. (1998). *Elvin the elephant who forgets*. Wolfeboro, NH: L & A Publishing/Training.

Sunny Hill Hospital for Children. (1987). *A family guide to the rehabilitation of the severely head injured child*. Vancouver, BC: Insurance Corporation of BC.

## Videos

University Hospital School. *Families living with brain injury*. Iowa City, IA: University of Iowa.

## Web Sites

[www.tbi.org](http://www.tbi.org)

[www.waiting.com](http://www.waiting.com)

[www.tbiguide.com](http://www.tbiguide.com)

[www.bcbia.org](http://www.bcbia.org)

[www.bc1.com/vihis/](http://www.bc1.com/vihis/)

[tbichat.org](http://tbichat.org)

[www.biausa.org](http://www.biausa.org)

[www.braininjuryresources.org](http://www.braininjuryresources.org)

[www.neuro.pmr.vcu.edu](http://www.neuro.pmr.vcu.edu)

## Additional Reference Materials

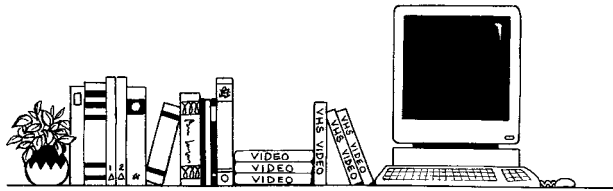
### For Professionals

#### Books

- Castiglione, M., & Johnston, C. (1994). *Waiting to clear. Brain injury: Early stages of recovery*. Atlanta, GA: Pritchett & Hull Associates.
- DePompei, R., Savage, R., & Lash, M. (1998). *Helping brothers and sisters: When a child has a brain injury*. Wolfeboro, NH: L & A Publishing/Training.
- Rocchio, C., & Lash, M. *Helping families cope: When a child has a brain injury*. Wolfeboro, NH: L & A Publishing/Training.
- Sellars, C.W., & Vegter, C.H. (1993). *Pediatric brain injury: A practical resource*. Tuscon, AZ: Communication Skill Builders.
- Sellars, C.W., & Vegter, C.H. (1997). *Pediatric brain injury: The special case of the very young child*. Houston, TX: HDI Publishers.

#### Videos

- BC Children's Hospital to Sunny Hill Health Centre for Children. *The next step*.



*For materials to give to families, see Finding Information About Brain Injury in Appendix 3-C.*



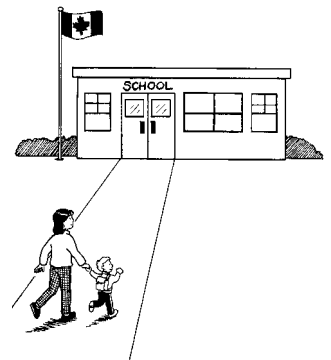
## Chapter

# 4

# Returning to School

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## Chapter Overview

**Who is this chapter for?** School and rehabilitation professionals.

**Who is this chapter about?** Students who have recently sustained a moderate to severe acquired brain injury and who are beginning to regain previous skills such as walking and talking. They may still be in the hospital or may have been discharged home.

**What is this chapter about?** How to help these students make a smooth transition to school life.

**S**chool is often said to be the “work” of childhood. But to most children, it is much more. School is a place to work, a place to play, a place to stretch their bodies and their minds. It is a place to have friends and to be a friend.

For children who have recently sustained an acquired brain injury, returning to school can represent both a goal and a challenge. Returning to school after a stay in the hospital or at home may seem like a welcome return to normalcy: finally the day has a focus, and life may return to a familiar routine.

Unfortunately, for children with acquired brain injuries (ABI), returning to school is not as simple as picking up where they left off. The cognitive and behavioural changes these children experience will affect their education now and possibly for years into the future. This reality may be very difficult for children, families, and educators to understand and accept.

Brain injuries are complex, and the effects may take years to unfold. The job of educators and rehabilitation professionals is to equip children with strategies to cope with these changes, and to modify the educational environment. With the appropriate support, planning, and coordination, the return to school can be a positive and settling experience.

In this chapter we discuss some issues facing students with ABI as they return to school. We also provide some suggestions for facilitating a smooth return to school.

## A Look at Students With Acquired Brain Injuries

Children with moderate to severe acquired brain injuries often regain many of their functional skills, such as walking and talking, within a few weeks of being injured. However, cognitive and behavioural changes may be striking. Other deficits may not be immediately obvious, but may emerge as children develop or face new challenges.

While each child’s brain injury results in a unique set of difficulties, the following are some of the common problems experienced by children with ABI:

- **Cognitive Problems** – Children with ABI often have problems with memory, information retrieval, reasoning, and new learning. While they may regain much of their previous knowledge quite quickly, they may have gaps in their knowledge or have difficulty applying this knowledge in a meaningful way. They also often have difficulty with planning, organization, fatigue, and inconsistency of ability.



- **Motor/Sensory Problems** – These children may have fine-motor difficulties, which may slow their printing and writing. Occasionally, vision is affected, and they have difficulty viewing the information on one side of a page. The injury may also affect gross motor skills, making it difficult to run efficiently or catch a ball.
- **Speech/Language Problems** – Children with ABI often have difficulty processing language, especially complex language. If their ability to retrieve words is affected, they may have trouble communicating and expressing their thoughts. They may also have difficulty following directions longer than one or two steps and interpreting gestures or facial expressions.
- **Social/Behaviour Problems** – Children may experience marked changes in their behaviour and social skills. They may seem immature and more dependent on their families, and may have difficulty sustaining attention. Their judgment and ability to control impulses may be affected, which may influence behaviour on the playground. They may also have difficulty making and keeping friends.



Not every child with a moderate to severe brain injury will experience all of these problems. However, these children will invariably experience some of these difficulties when they return to school.

Children with ABI may resemble children with other disabilities. For example, a child with attention and executive function deficits may have many problems in common with a child with attention deficit disorder or attention deficit hyperactive disorder. Similarly, a child with residual language deficits may resemble a child with a language-based learning disorder. Many of the same interventions and supports that are used with these children are also helpful with children with ABI.

Despite the similarities, there are also many critical differences between children with ABI and children who are born with developmental disabilities. In general, the learning profiles of students with ABI are unique and do not fit into the usual categories of disabilities. These students often have markedly different profiles of strengths and weaknesses. They often recover knowledge and skills they learned prior to the injury, but have significant problems with new learning, behaviour, and higher-level abstract reasoning. Their recovery process is uneven, with unpredictable and rapid spurts of progress. Significant new learning difficulties may emerge over time, even in students who initially appear normal or minimally involved. Due to the changing course of recovery over time, educational programs need to be reviewed regularly.

*For some suggestions on strategies that may help children with ABI, see Appendix 4-C.*

Children who obtain a summary IQ score in the normal range following an ABI may have important cognitive and learning difficulties that are not captured well on a standard IQ battery. Conversely, children with ABI who obtain a summary IQ score in the mentally handicapped range generally retain some pre-injury knowledge and skills that are not typical of globally developmentally delayed children. These children may also improve to a higher level of function over time.

Children with ABI differ from children with developmental and learning disabilities in terms of the recency of their trauma and loss. Their self-concept and social-emotional needs will be based on their pre-injury function. They may have little or no awareness of the changes caused by the brain injury, or they may be aware of feeling different and be distressed by this. Prior to their brain injury, they may have been typical students whose development and learning style were essentially normal. Even if they had learning disabilities before the brain injury, the cognitive, behavioural, and social problems brought on by the injury are new to them.

## When Should Students Return to School?

Children with brain injuries often have a strong desire to return to school, and their families may be anxious to resume their normal lives as well. However, children should not return to school until the school can accommodate the changes the brain injury has caused. The following are some of the issues that need to be resolved before these children return to school.

**Children should be oriented to their environment and able to store new memories (that is, they should not be at a reduced level of consciousness).** Their level of orientation, which can be assessed by therapists, should be used as the first indicator that they are ready to begin the process of returning to school. Children who are not fully oriented may be very disturbed by the school environment. If they are agitated, they may upset their friends and classmates, which may lead to ongoing social problems.

**Children should be able to cope in a busy environment for an extended period of time.** This time period may be half an hour or several hours, depending on the age of the child and the demands placed on the child. For example, a six-year-old may be expected to concentrate for about 20 minutes at a time before taking a break, while a high school student may be expected to concentrate for up to 60 minutes with only 5- or 10-minute breaks between classes. The length of time for which children can concentrate in their normal environment is variable and needs to be monitored.

*For more information about levels of consciousness, see Chapter 1, Acquired Brain Injury.*

**Children should no longer be significantly affected by fatigue, or their fatigue should be accommodated at school.** Fatigue, which includes both sleepiness and mental fatigue, may be an ongoing problem for children returning to school after a brain injury, and may take a long time to improve. These children may benefit from attending for half days or less for the first few weeks as they build up their stamina for a full day. Children attending school for a full day may need a place to rest during the school day. For high school students, this may mean dropping some courses for a time and having a place to unwind or recharge during the day.



**All necessary assessments by the community rehabilitation team should be complete before children return to school** so that a clear picture of the cognitive, behavioural, and physical changes caused by the brain injury can be acknowledged and understood. Assessments by members of an interdisciplinary team in the community can help the school make decisions about the kinds of programs children need and how the current curriculum should be adapted or modified.

These assessments are also very important in determining the level of support that children need. Observation of a child in natural settings and diagnostic teaching and therapy can provide valuable insight into the child's level of functioning.

A formal **neuropsychological assessment** is essential to accurately document the cognitive changes in a child and contribute to educational planning. Children with ABI need to be seen by a pediatric neuropsychologist trained in assessing brain injuries. This assessment is helpful to identify their profile of strengths and weaknesses in cognitive and behavioural function. The tests commonly used to identify special needs children are not adequately sensitive to all of the new learning and functional deficits commonly associated with brain injuries. The neuropsychologist may be available for ongoing consultation to help the school understand the changes experienced as the child moves through the developmental levels of childhood and beyond.

A child who does not have a community rehabilitation team may need to be directed to the Community Brain Injury Program for Children and Youth (CBIPCY) if the child is not receiving funding through the Insurance Corporation of BC (ICBC) or Workers' Compensation Board (WCB).

*For information on contacting the CBIPCY or ICBC service coordinator, see Appendix 3-A.*

# Returning to School: Tasks for School and Rehabilitation Professionals

The following steps may help school and community rehabilitation professionals effectively integrate children with recent acquired brain injuries into school life. With careful planning, the complex needs of these children may be identified and the appropriate programs developed. These steps apply to all students with ABI, whether they attend a public, independent, or First Nations school.

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## Summary of Tasks

### Step 1: Seek Notification

If necessary, the school may need to seek official notification of the student's brain injury.

### Step 2: Identify the School Case Manager

The school principal or counsellor identifies a school case manager who is responsible for coordinating the student's return to school and monitoring the student's progress over time.

### Step 3: Identify the School Team

The school case manager helps to form an appropriate school team to meet the student's needs. The school team may include the principal, classroom teacher, resource teacher, school counsellor, special education assistant, school therapists, and district resource staff.

### Step 4: Meet to Plan the Return to School

Before the student returns to school, the school team, community rehabilitation team, and family meet to exchange information and plan the student's return. The following are some of the main areas that need to be addressed at the school planning meeting:

- review the student's brain injury and current functioning
- identify initial educational programming and support
- establish a plan for a gradual return
- consider the need for a peer inservice

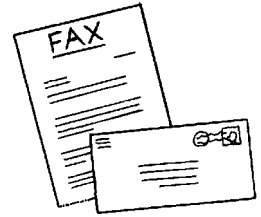
### Step 5: Develop an Individual Education Plan

If the student needs special educational support, an Individual Education Plan is developed.

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## Step 1: Seek Notification

Most school districts require some kind of official notification when a student's status changes. Although schools often become aware that one of their students has had an accident or illness, they are often not aware of the nature of the injury or illness. The hospital, community rehabilitation team, or teacher at the provincial rehabilitation centre may send a letter to provide official notification. Sometimes the school is only informed once the student's ICBC or CBIPCY service coordinator makes contact to plan the student's return to school. If the school is not notified by the hospital or other agencies, it should seek official notification.



## Step 2: Identify the School Case Manager

Upon receiving notification of a student's brain injury, the school principal should identify a **school case manager**. A resource teacher or school counsellor who will work directly or indirectly with the student usually assumes this role. The school case manager is responsible for:

- liaising with the community rehabilitation team, provincial resource teacher (if one is involved), school district special education staff, and student's family
- obtaining and distributing information about acquired brain injury and the return to school
- staying informed about how the student is progressing with community rehabilitation services
- making referrals to school-based therapists as appropriate
- arranging the school planning meeting
- supervising the writing of the Individual Education Plan
- monitoring the student's program and progress

Students with ABI need to be assessed and monitored throughout their school years. The school case manager should remain involved while the child is attending the school and should facilitate the transition to high school or post-secondary education. If the school case manager leaves the school, someone else should assume this role.

## Step 3: Identify the School Team

Students with ABI often need extensive support services, which can be challenging for school districts. However, without the appropriate support, these students may have problems for years into the future.

The support services required vary from student to student, but some generalizations can be made. The support that students need at school generally mirrors the support they have been receiving from the community rehabilitation team. The level of school support depends on their assessed needs at the time of their return to school.

## In-School Therapy Professionals

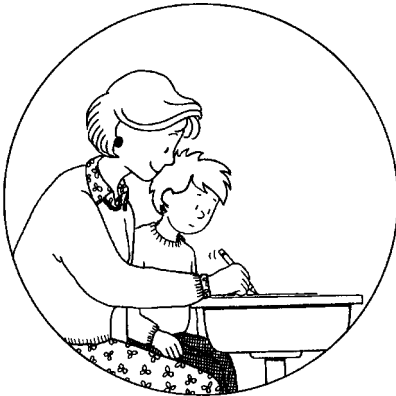
Ideally, students should receive ongoing monitoring from an in-school support team consisting of an **occupational therapist**, **physiotherapist**, and **speech-language pathologist**.

Not all school districts are able to provide direct therapy for children at school. However, these professionals may be available to the classroom or resource teacher for ongoing consultation.

The school's **community health nurse** should also be alerted to monitor any pending medical issues, such as medications administered during school hours or the need for a seizure protocol.

## Special Education Assistants

**Special education assistants (SEAs)**, **teaching assistants**, or **teachers' aides (TAs)** often play the most important role in accomplishing the difficult task of helping children with brain injuries return to the classroom. Many (though not all) of these students need a full-time or part-time classroom assistant.



SEAs are hired by the school district and may be appointed to particular classrooms or individual children. They work under the direction of the classroom teacher, resource teacher, or other professional in charge of the student's programming.

SEAs are responsible for implementing modified programs for students with ABI. They may be asked, for example, to go over vocabulary to be used in a lesson, or they may implement special reading programs for students struggling to relearn how to decode. They may be needed to focus the attention of students who are easily distracted, or to act as a catalyst to help students socialize with peers.

They may also be needed to provide extra supervision on the playground, or to supervise or assist students in the washroom.

Learning new information can be particularly difficult for students with ABI, and their programs often require extensive modification. Busy classroom teachers have little time to spend with individual students, and must consider the needs of all students, some of whom have other special needs. The school team should discuss whether an SEA is needed to support a child's learning at or prior to the planning meeting so that the SEA can be in place before the child's first day back at school.

## Resource Teachers

**Resource teachers** may be appointed to an individual school or to several schools to oversee the special education programming. They are usually responsible for coordinating the writing and implementation of the Individual Education Plan. They also act as consultants to classroom teachers on the appropriate learning environment for special needs students.

Resource teachers are often asked to take on the role of case manager because, while the classroom teacher changes every year, resource teachers are usually able to follow students throughout their years in either elementary or secondary school.

## School Psychologists or Counsellors

**School psychologists or counsellors** play an ongoing role in helping students adjust to an acquired brain injury. Often the whole school is affected by a serious injury to one of its students, and the student's siblings, friends, and classmates need support.

Students with ABI also need support and counselling to adapt to the changes they are experiencing. School psychologists play a role in tracking these students' progress over time and in overseeing their adjustment to secondary school. However, the initial and follow-up psychological testing of these students is best administered by a neuropsychologist with expertise in pediatric brain injury.

## Step 4: Meet to Plan the Return to School

Before students return to school, the community rehabilitation team, school team, and family need to meet to exchange information and plan the timeline of the return to school. The school planning meeting is usually held after students have been assessed by the community rehabilitation team and are nearing the point when they can reconnect to school and recreational life.



Some support services may have already been requested, and the process of putting these services into place already begun. However, this meeting is important to ensure the teams discuss how the brain injury has affected the student's current functioning. This is essential for planning the student's educational program and securing special education classification, if needed.

During the school planning meeting, the following areas should be addressed:

- review the student's brain injury and current functioning
- identify initial educational programming and support
- establish a plan for a gradual return to school
- consider the need for a peer inservice

### Review the Student's Brain Injury and Current Functioning

A discussion of the history of the student's brain injury, relevant medical details, and current cognitive, behavioural, and physical functioning forms the basis of the school planning meeting. School personnel may not have dealt directly with brain injury before, so all of the available assessment information, especially the information on cognitive changes, will need to be reviewed.

At this first meeting, it may be difficult for the school team to grasp all of the student's new problems, and further meetings may be required for more intensive preparations. The following issues are sometimes overlooked at the first meeting because of the need to discuss cognitive and behavioural issues. However, the student's first day of school should not be considered until these issues have been discussed.

**Safety** – All schools have a duty to provide a safe environment for students. To ensure students' safety, schools normally implement conduct rules, fire drills, and supervision on the playground. Students with ABI often need stronger measures to ensure their safety and the safety of others at school.



Students with ABI often struggle with impulsive behaviour, poor judgment, and a decreased ability to recall safety rules. They may still be experiencing problems with coordination and balance, which may put them at risk on climbing equipment. Visual field cuts or impaired spatial orientation may affect their ability to participate in vigorous physical education classes. They may also have trouble following verbal instructions, especially in an exciting environment such as a gym. These students are at increased risk of sustaining another injury and should not participate in contact sports for at least the first year following the injury.



All of these factors must be considered when establishing a safety plan. The following extra measures may be necessary:

- provide one-to-one playground supervision
- accompany students in secondary school from class to class and allow them to leave class early to avoid crowded halls
- modify the physical education program

**Personal Care** – Occasionally, students with ABI need help with personal care. For example, students who experience weakness on their left or right side may need additional support in the washrooms, such as railings in the cubicles or help with clothing. They may also need to be supervised because of behavioural or attentional problems. These issues should be discreetly addressed before students return to school to ensure that they receive the assistance they need and to avoid embarrassment.

**Seizure Risk** – Most children with ABI do not have seizures. However, if the physician has identified an increased risk, this should be reviewed with the community health nurse. Most school districts establish a procedure to follow in case the child has a seizure. The school should follow this procedure unless otherwise notified by the student’s doctor. A list of any medications the student is taking should be provided to the school.

### Identify Initial Educational Programming and Support

The goals of the return to school are to understand the student and develop an atmosphere in which the student can achieve success. The initial focus is not to “catch up.” Children who have sustained a moderate to severe brain injury should never be expected to do the work they missed while in the hospital or at home. These children are returning to school with new cognitive and social challenges that require special programming and support.

The initial focus of school should be to:

- re-establish the student in a social context within the school environment
- re-establish academic skills the student learned previously
- modify the student’s previous program to accommodate cognitive and behavioural changes
- provide a safe environment in the school and on the playground



Students with ABI often seem younger than their actual age, especially in the first few months following the injury. They may have difficulties with language and concentration, and may process information at a slower rate. They tend to work at a lower grade level in most subject areas, and may have trouble retaining information, organizing assignments, and following instructions. These students may struggle to relearn how to read and perform simple arithmetic. If they have problems with memory, comprehension, new learning, or word retrieval, their participation in subjects such as social studies and science may need to be delayed. When they first return to school, their program should be restricted to a few subjects that present information in small chunks.

Families of children with ABI often want their children to return to a school environment in which they can interact with their peers and function as similarly as possible to typical classmates. Most children with brain injuries do return to their regular classrooms, where they receive some additional support. Only rarely are they placed in a different environment, although an initial placement in a resource room may be helpful. Children in preschool may benefit from remaining in preschool for an extra year.

When students with ABI first return to school, their curriculum may need to be modified extensively, and they may be working at a level several grades below their previous level. At this early stage, they may need to work for at least part of the day in a quiet environment and receive one-to-one assistance to help them concentrate and avoid distractions. The teacher's assistant or special education aid should be available from the first day to support students academically and socially.

An Individual Education Plan is usually not written until a few weeks after students return to school. However, it is important that schools set up, with advice from the community rehabilitation team, an initial program for students that can be in place from their first day.

### **Establish a Plan for a Gradual Return to School**

The timeline of a student's return to school is crucial to the success of the experience. We cannot emphasize enough that this process should be gradual and planned.

Some children adjust more quickly than others, especially if their energy and concentration are stable. However, others can only handle a shortened day for weeks or, in some cases, months. Most elementary school students seem to benefit from a gradual return where they attend, for example, until recess for the first week, until lunch for the second week, and for the full day in the weeks following if they seem to be coping well.

Half days should be extended indefinitely if needed. If students have tried attending for full days but are clearly not coping well, they should revert to a shorter day.

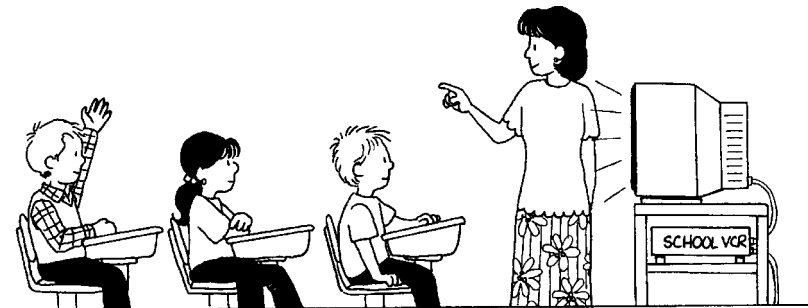
High school schedules present a special challenge to students returning to school after sustaining a brain injury. High school students may need to limit themselves to one or two academic subjects at a time, and may benefit from completing homework and assignments in the learning assistance centre, resource room, or skills centre.

Hospital/homebound teachers can play a role supporting students, especially at the high school level during the transition to full-time school attendance.

### Consider the Need for a Peer Inservice

An inservice or small workshop for the siblings, cousins, friends, and classmates of the injured student can help dispel myths and create a caring and accepting social environment for the student. Peers may be puzzled or troubled by the injured student's behaviour or inability to understand jokes or normal school banter. They may take these changes personally and think that the student's behaviour is deliberate. They may also be curious if, for example, the student has a gait problem or weakness in one hand. Peers invariably have many good questions and often come up with strategies to help the injured student feel good about being back in school.

The effects of the brain injury need to be explained, and the changes that peers have noticed acknowledged and discussed. Sometimes, especially with older children, the injured student or members of the student's family may want to participate in the inservice.



For some suggested peer inservice activities, see *Think Ahead: Learning Activities about the Brain and Brain Injury* (Littleford & Wong, 1994).

The following are some suggestions for the peer inservice:

- provide background information on the structure of the brain and the effects of the injury
- provide simulation activities to illustrate some of the difficulties the student is experiencing
- brainstorm ways to help the injured student fit back into classroom activities
- discuss ways to prevent injuries, especially with high-risk groups such as teenagers

Parental consent must be obtained before a peer inservice can be provided. If the injured individual is an adolescent, the individual's permission should be obtained.

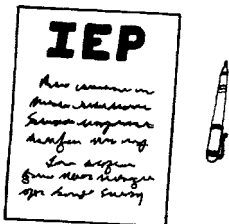
An inservice is appropriate for primary grades if physical changes to the injured student are apparent. Examples of such physical changes include the need for a wheelchair, inarticulate speech, or excessive drooling. Under these circumstances, helping to prepare the social environment for the injured student is especially important. However, if the student has recovered motor and verbal skills, a peer inservice may just draw unwanted attention to the student. Young classmates do not usually notice subtle changes, and are more accepting of behaviour differences.

## Step 5: Develop an Individual Education Plan

An Individual Education Plan (IEP) documents what and how students will learn in the classroom. Every student who is receiving ongoing special education support is required to have a current IEP. A consistent format for preparing an IEP has not been established in BC. Each school district determines the process that will be followed.

The IEP should cover the following:

- the student's current levels of academic performance
- relevant assessments
- learning outcomes set for the student for a specific period
- required adaptations to materials and instruction
- support services to be provided
- a description of where the program will take place
- names of the personnel who will provide the program
- the period of time for which the IEP will be in place
- the process for reviewing the IEP



The following are the key stages in the IEP development process.

**Pre-Planning** – Reports from community therapists and the initial assessment by the neuropsychologist should be complete by the time an IEP needs to be developed. Involving these professionals in the IEP development process is often helpful. Before the IEP is planned or written, as much information as possible should be gathered about the student's injury and its effect on cognition and behaviour. The student's functioning prior to the injury and the natural history of acquired brain injury should also be considered.

**Planning** – During the planning stage, key areas of the curriculum should be isolated and adjusted to reflect the student's new learning style, modifications to the school day should be incorporated, and social and behavioural objectives should be considered. Keeping in mind that the student is likely still changing at this stage, planning short-term goals is more appropriate.

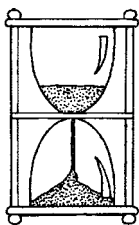
**Implementation** – The IEP should document how the plan will be implemented and who will facilitate implementation. It should list all support services needed by the student and the personnel who will oversee and facilitate the program. All plans and strategies should be flexible, and room should be left to backtrack or re-establish goals if necessary.

**Review** – The first IEP should be reviewed quite frequently since it is prepared at an early stage of a student's recovery. Consultation with the student's community team may be an efficient way to review and coordinate goals and objectives.

## In Summary

Sending a child back to school after a brain injury can be a difficult process. The keys to success are communication and teamwork. Classroom teachers are called upon to use their considerable knowledge and experience to modify programs and teaching styles to accommodate students whose learning abilities may have changed considerably. A modern classroom can be a complex environment; students with ABI may not be the only children in the class with special needs. These students are entitled to our best effort. This effort is rewarded when students feel like valued learners in the classroom community despite their serious disabilities.

Even the best programs need to be revised frequently, especially as students continue to heal and change. It is important for the school team and the community rehabilitation team to stay in close contact and consult frequently so that both teams are working on the same goals.



## Future Considerations

Looking into the future can be frightening for families and educators of children with ABI. Unfortunately, well-developed and valuable school plans and programs may change over time due to budget restrictions. Maintaining the impetus of a program is sometimes difficult as students move through the school system. When they show small improvements in behaviour or cognition, they are sometimes considered “cured” of the brain injury, even though new deficits can emerge at different developmental stages. Sometimes the information that a student sustained a serious brain injury is not passed on to the student’s secondary school. All of this can be frustrating for parents and educators who sincerely want to help these students. In complex cases, families may hire private educational consultants to assist in school planning and transitions.

All relevant information about the brain injury must be passed on to the student’s secondary school. Individual Education Plans should be current and should reflect the changes experienced by the student and the support that is appropriate at the time. Since difficulties may emerge as students develop and face new challenges, neuropsychologists and therapists should continue to monitor the student’s progress.

The following suggestions may help students make the transition to secondary school:

- school psychologists or counsellors may need to discuss the issues surrounding brain injury with subject teachers
- an inservice for teachers may help them understand brain injury
- particular attention may need to be paid to organizational problems and helping students adjust to their timetable
- vocational training and post-secondary education may require careful planning and special focus in later secondary school years

No one can foresee all of the problems that children may experience as they mature. However, with careful planning and ongoing monitoring, professionals can help mediate these problems and provide students with a school environment in which they can participate with their peers in a well-rounded, satisfying program.

## Special Education Funding

### Public Schools

Funding for all of the services needed to support a child with ABI at school comes directly from the BC Ministry of Education to the school district. The school district identifies and designates students with special needs according to the guidelines in the *Manual of Policies, Procedures and Guidelines* (1995).

Funding is based on a student's assessed needs, not on diagnosis alone. Most students with moderate to severe brain injuries fit into the designation *Students with Physical Disabilities or Chronic Health Impairment – nervous system impairment*. The manual states:

*“Medical diagnosis, by itself, does not determine the special education services required by students with physical disabilities or chronic health impairments. Students are eligible for this category if their education is adversely affected by their physical disabilities or chronic health impairments” (Section E, Page 41).*

The manual goes on to state that a current Individual Education Plan must be in place and that ongoing special education services must be provided.

Students under this category are entitled to receive the necessary support to ensure that their health and safety requirements are met and that their academic program is modified to meet their needs. The services of health care professionals, as well as specialized instructional methodologies, may be required for this category. This may include the services of a trained special education assistant and the ongoing technical support of Special Educational Technology of BC (SET-BC). It is important that students with ABI be designated under the category that best describes their support needs.

## Independent Schools



For the family of a student who attended an independent school prior to the accident or illness, the student's return to this school is sometimes very important. This can present a dilemma to parents who are concerned that the independent school will not be able to provide the level of service that their child needs.

Independent schools are increasingly able to accommodate special needs students and willing to put services in place to support these students' learning. Special education grants are made available to **group 1 and 2 independent schools** that provide a special education service to qualifying students as determined by the *Independent School Act*. Students for whom a claim is made must be receiving an additional service that is over and above the regular program, that is clearly identifiable as a special education program or service, and that requires additional expenditure on the part of the school.

The two funding categories are:

- **High Intervention** – This category provides funding for the student who is completely dependent on others for all of the activities of daily living.
- **Moderate Intervention** – This category provides funding for the student who requires some additional personal instruction and/or the support of a part-time program assistant. This category describes physical disabilities of the nervous system and chronic health impairment. These students usually require the intervention of occupational therapists, physiotherapists, and speech-language pathologists.

Clearly, students with ABI fit into the moderate intervention category. If a special education assistant is appropriate to support a student in an independent school, the student's parents or another agency would have to supplement the funding.

## First Nation Schools

At present, 90 elementary schools and 45 high schools in BC are on First Nations reserves and are administered by a local band. These schools are funded by the federal government of Canada. A small grant must cover the costs of assessment and special services for students with special needs.

First Nations students returning to the reserve community from the hospital or a rehabilitation centre who need special education support are usually placed in a public school in the neighbouring community. This poses a problem for many families who want their children to attend the local First Nations school for cultural reasons.



## Appendix

# 4-B

## School Resources in the Community

Provincial Resource Teacher – Brain Injury  
Sunny Hill Health Centre for Children  
3644 Slocan Street, Vancouver, BC, V5M 3E8  
Phone: (604) 453-8300 Fax: (604) 453-8301  
Web site: [www.sunnyhill.bc.ca](http://www.sunnyhill.bc.ca)

Provincial Resource Teacher – Brain Injury  
G.F. Strong Rehabilitation Centre  
4255 Laurel Street, Vancouver, BC  
Phone: (604) 734-1313 Fax: (604) 737-6359  
Web site: [www.axion.net/gfstrongschool/](http://www.axion.net/gfstrongschool/)

Provincial Resource Teacher  
Queen Alexandra Centre for Children's Health  
2400 Arbutus Road, Victoria, BC, V8N 1V7  
Phone: (250) 477-1826 Fax: (250) 721-6828  
Web site: [www.caphealth.org](http://www.caphealth.org)

Special Education Technology of BC (SET-BC)  
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Phone: (604) 261-9450 Fax: (604) 261-2256  
Web site: [www.setbc.org](http://www.setbc.org)

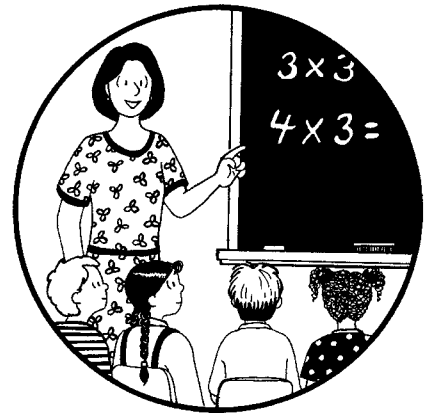
Office of the Inspector of Independent Schools  
Ministry of Education  
PO Box 9153 Station Prov. Gov't., Victoria, BC, V8W 9H1  
Phone: (250) 356-2508 Fax: (250) 953-4908  
Web site: [www.bced.gov.bc.ca/independentschools](http://www.bced.gov.bc.ca/independentschools)

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Phone: (604) 925-6087 Fax: (604) 925-6097  
Web site: [www.fnesc.bc.ca](http://www.fnesc.bc.ca)



## Instructional Strategies

Please feel free to photocopy and use these instructional strategies as needed.



**D**etermining exactly how and what to teach students with ABI is perhaps the most difficult and at times frustrating part of the return to school. Once information is gathered, meetings are over, and therapy is in the background, teachers at school need to plan exactly what these students will learn and how they will participate throughout the long school day.

In addition to providing remedial teaching in these students' areas of weakness, teachers will often need to use compensatory strategies in the classroom. The following strategies may be effective with students with brain injuries. Teachers may already be using some of these strategies with students who have learning disabilities or attention deficit disorders. It is important to remember that not all of these strategies will work all of the time. Many variables, such as fatigue, can hinder even the most effective teaching plans. Students with brain injuries often have very uneven performance profiles.

Teachers are encouraged to develop their own strategies to use with these students, and to share what they learn with other teachers. The behaviour of students with ABI may change early on, so strategies that work one week may not work the next. Teachers can also seek help from the school-based resource team or community rehabilitation team.

*For additional strategies, see Appendix 4-D, Additional Reference Materials, and Appendix 5-B, Specific Intervention Strategies.*

## Auditory Processing

If students with ABI are having trouble with auditory processing and following instructions, and are inconsistently attending to auditory information, the following strategies may be helpful:

- Break instructions down into one or two steps so that students fully understand what they are expected to do. When giving instructions, make sure students have completed step 1 before proceeding to step 2. Asking students to repeat instructions may also be helpful.
- When giving verbal instructions, try to ensure they are accompanied by written instructions, or diagrams if reading is difficult.
- Do not expect these students to listen and take notes at the same time. Write out the salient points of the lesson for them ahead of time.
- Pre-teaching can be a very effective strategy to use with these students. Outline the lesson in point form, highlighting the main ideas so they have a chance to review the ideas. Even though memory may still be a problem, they will have a context for the next day's lesson.
- Talk slowly. Pause occasionally between ideas. Avoid figures of speech and highly descriptive language, and give students adequate time to respond when they are asked a question.
- Use visual illustrations, role-playing, and paraphrasing to help students understand spoken material.

## Reading Comprehension

Students with ABI may have difficulty with reading comprehension. Their understanding of written material may be superficial, and they may struggle with the underlying meaning of written texts. They may have trouble decoding, and their rate of reading may be considerably slower than it was prior to the injury. If students have these difficulties, the following strategies may be helpful:

- Give students short written material with the main ideas highlighted or in bold print.
- Have students read short passages. At least in the first few months after they return to school, use simple language when asking questions, and restrict questions to factual information.
- In the early months, avoid novel studies.
- Summarize textbook material and reiterate facts in simple language and a logical sequence.

## Attention

Students with ABI may have attentional problems that make it difficult for them to follow classwork. These students may need help to stay focused on tasks and complete assignments. The following strategies may be helpful:

- Have students sit in a spot with few distractions, in front of the class or next to the teacher.
- Provide frequent breaks so that students can move about the classroom to relieve tension and restlessness.
- Do not give these students cluttered worksheets, which are confusing for them. If students have trouble starting at the top left of a page, provide a cue such as a red dot to direct their attention.
- Since copying notes off the blackboard requires divided attention and is usually very difficult for these students, have the notes transcribed for them.
- Keep tasks and assignments short and very structured.

## Written Communication

Many students with ABI have difficulty communicating both verbally and in writing. Their ability to communicate may be affected by attentional problems, language retrieval problems, and fatigue. The following strategies may be helpful:

- Ask multiple choice questions that clearly present the correct answer.
- Lower expectations for written communication. These students may have difficulty writing coherent paragraphs or essays. Allow them to use point form when answering essay questions, or to express themselves verbally or visually with a picture or display.
- If students have difficulty with the mechanics of writing, allow a special education assistant to write for them, especially during tests or exams.
- Allow students to use a calculator for math that involves many calculations. After establishing that they understand the processes involved in the math and after they have done a few questions on their own, allow them to use a calculator to finish the page. These students are often overwhelmed by many examples on a page.

# Classroom Management

Sometimes simple adjustments in classroom management make a big difference to how students with ABI are able to cope in the classroom.

The following classroom management strategies may be helpful:

- Call on students if their hand is raised and you are reasonably sure that they can answer the question. Do not call on them if they have made no indication that they know the answer. They may still be processing the question and may be embarrassed.
- Do not overwhelm students with homework. It may be all they can do to get through the day, and they may need time after school for relaxation and continuing therapy.
- Have these students sit with a partner who can model good behaviour and help them follow classroom procedures.
- Praise students (not effusively) for effort.
- Ask leading questions that allow students to tell you what they know. Avoid trick questions that will needlessly confuse them.

## Organization

All students must learn organizational skills to be successful at school. For students with ABI, learning and retaining these skills over time is often very difficult. They may need constant reinforcement. Even a student who was formerly very organized about remembering homework assignments may now need help locating the right books for class and remembering when work is due.

- Make sure students have a daytimer that is kept up to date.
- Consolidate written materials into one binder with section tabs.
- If homework is assigned, make sure students write down exactly what they have to do. Before they leave the classroom, make sure they have all the materials they need.
- If students have difficulty remembering to give messages to parents or remembering events that happened during the school day, create a communication book in which important messages can be relayed to parents and the events of the day can be recorded for review in the evening.
- Make sure intermediate and high school students have a daily schedule on their desk or in their binder so they do not lose track of where they should be.
- Provide students with an area such as a skills centre room or counsellor's office to make sure they are organized for the day and have all the books they need for the next period.

- If the halls are crowded at the period break, avoid confusion by allowing students to leave class early and making sure they have time to get to the next class.
- If necessary, remind elementary students that a transition (such as recess) is coming up, so they can prepare for the disruption.
- Suggest that students have an extra set of textbooks at home.

## Behaviour

The changes in a child's behaviour following a brain injury may affect the child's social relationships and friendships. Students with ABI may have been very popular prior to their injury, but may display impulsive and at times anti-social behaviour following the injury. They may have trouble understanding the rules of friendship, and the changes in their behaviour may confuse other children. School professionals who need explanations of the changes in a student's behaviour or suggestions for managing challenging behaviour should seek help from the student's neuropsychologist.

The following strategies may be helpful in handling daily classroom activities:

- Develop some hand signals to indicate to students that their behaviour is inappropriate, rather than embarrassing them with verbal reprimands.
- Make sure students have a buddy to eat lunch with and are included in playground teams and games.
- Whenever possible, pair students with mature peers who can model appropriate behaviour and exercise patience and understanding.
- Provide frequent breaks and a safe place for students to either blow off steam or relax when they are clearly overwhelmed.
- Avoid situations that may overstimulate or overchallenge these students.
- Don't expect challenging behaviour to disappear overnight. Self-control can take a long time to re-establish.

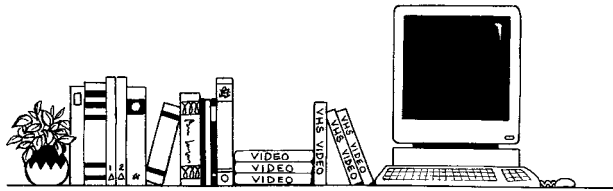




## Additional Reference Materials

### For Professionals

#### Books



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Kansas State Board of Education. (1993). *Perspectives on traumatic brain injuries: Success in dealing with long-term challenges by students, families, teachers and friends*.

Rehabilitation, Research and Training Center (RRTC) on Severe Traumatic Brain Injury, Medical College of Virginia. (1993). *Returning to school following traumatic brain injury: A guide for school personnel*.

University of Kansas Medical Centre. (1988). *Traumatic head injury: Returning to school*.

### Web Sites

[www.tbiguide.com](http://www.tbiguide.com)

[www.tbi.org](http://www.tbi.org)

[www.axion.net/gfstrongschool/](http://www.axion.net/gfstrongschool/)

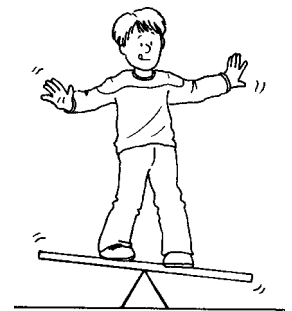
## Chapter

# 5

## Rehabilitation

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### Chapter Overview

**Who is this chapter for?** Rehabilitation or school professionals who are new to working with children with acquired brain injuries.

**Who is this chapter about?** Children who have recently sustained a moderate to severe acquired brain injury and who are beginning to regain previous skills such as walking and talking.

**What is this chapter about?** Interdisciplinary assessment and intervention in the first few months following the injury.

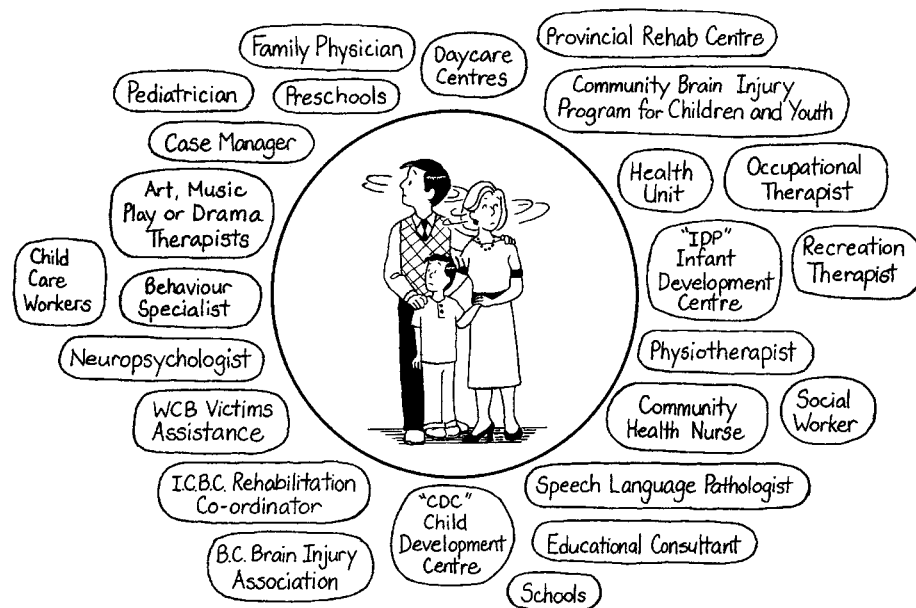
**R**ehabilitation for children with moderate to severe acquired brain injuries (ABI) focuses on understanding how their ability to function has changed as a result of the injury and how to best help them. This chapter aims to give professionals who are new to working with these children a place to begin.

In this chapter we highlight key considerations surrounding the interdisciplinary assessment and intervention provided to children with ABI in the first few months following the injury. Although assessment is discussed separately from intervention, these two processes are very much connected and are often done at the same time.

We begin with a brief review of community rehabilitation services, since the chapter assumes that the child has been linked with the appropriate rehabilitation professionals. We then provide an overview of some of the unique characteristics of pediatric brain injury and the need for an interdisciplinary, team approach to assessment and intervention.

## Community Rehabilitation Services

Some families may feel overwhelmed by the variety of rehabilitation services available, while others may not be aware of their existence. The ever-changing health care system can make it equally difficult for many professionals to know which services to link the child and family with following discharge from the hospital.



Some children with ABI who are discharged from the hospital benefit from the services of a provincial rehabilitation centre such as:

- Sunny Hill Health Centre for Children in Vancouver, BC
- G.F. Strong Rehabilitation Centre in Vancouver, BC
- Queen Alexandra Centre for Children's Health in Victoria, BC
- Gorge Road Hospital in Victoria, BC

Other children who are discharged home benefit from being referred to one of two main service coordinators in BC:

- Insurance Corporation of BC (ICBC)
- Community Brain Injury Program for Children and Youth (CBIPCY)

These service coordinators locate, coordinate, and fund rehabilitation services for these children and their families in their own communities.

## Characteristics of Pediatric Brain Injury

In many ways, a therapist's role in assessing a child is similar to the role of a detective investigating a mystery. The mystery, in this case, is how the brain injury has affected the child's overall ability to function.

Although each child's brain injury results in a unique combination of difficulties, it is helpful to keep in mind some of the characteristics common to pediatric brain injury.

**You Can't Judge a Book by its Cover!** Children with brain injuries tend to quickly recover many of their previous skills (especially physical skills), which can lead people to overestimate their cognitive and social abilities.

**Now You See It...Now You Don't!** Many of these children are inconsistent in their performance throughout the day and from one day to the next.

**Look Closer!** These children may have gaps in their knowledge and skills that are not immediately obvious. Their abilities may be scattered, with difficulties in basic as well as higher-level skill areas.

**Look at the Big Picture!** These children can often perform specific skills in simple, controlled environments, but tend to have difficulty using these skills effectively in new or complex real-world situations.

**Look for Future Clues!** As these children get older, they often demonstrate new areas of difficulty. These "delayed deficits" are related to damage that occurred to parts of the brain that were not yet fully developed at the time of the injury.

*For more information about linking children with ABI to community services, see Chapter 3, Linking to Services.*



## The Value of an “Investigative Team”

The types of difficulties that children experience following a moderate to severe acquired brain injury are extremely diverse and can affect nearly every aspect of their functioning. The typical difficulties they have with attention, memory, level of consciousness, executive function, and behaviour are not specific to one discipline and cross the boundaries of all rehabilitation disciplines. If a team does not work in close collaboration, these global difficulties may either be ignored or not treated in a coordinated manner (Howard, 1988).

An interdisciplinary team approach is required to understand the full impact of the brain injury on the child and to provide coordinated intervention. With this approach, the child is treated as a whole and is not fragmented into skill areas by the disciplines. This interdisciplinary model involves the child, family, and various disciplines, who work together to:

- identify key concerns and goals for assessment and intervention
- gain a clearer understanding of each discipline’s role for individual and cooperative assessment and intervention
- determine the timing and method of assessment
- solve problems as a group to better understand the child’s strengths and difficulties as a whole
- keep up to date about the child’s changing progress through regular communication
- meet with the preschool/school team to plan for the child’s return

Close communication between the child’s team members, including the child’s family, is key. More time, effort, and organizational skills are required to facilitate this cohesive model, but the results are worth it.



Ideally, a core team would involve a physician, neuropsychologist, speech-language pathologist, and occupational therapist. A neuropsychologist’s involvement is particularly critical in gaining a baseline description of the child’s cognitive function and social-emotional well-being. Depending on the age and needs of the child, other team members such as a special education teacher, childcare worker, physiotherapist, or play therapist may become involved.

For the team and family, balancing the involvement of the various professionals with the family’s life is an important consideration. The child’s needs, family’s wishes, and availability of services play a part in determining which rehabilitation disciplines are involved and the timing of their involvement.

# Assessment: Understanding Children With Acquired Brain Injuries

This section discusses some of the key considerations for all disciplines to keep in mind when assessing children with ABI. Suggestions on where to begin the assessment are included and involve:

- gathering information about the child's brain injury and previous abilities
- determining the child's level of consciousness
- determining areas for focused assessment

We then discuss some of the main considerations to keep in mind when providing informal and formal assessments to these children.

## Gathering Information About the Child's Brain Injury and Previous Abilities

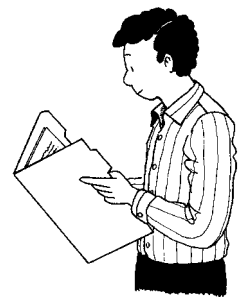
An essential starting point for assessment is to gather information about the child's brain injury and previous abilities.

### The Medical Procedures, Assessment, and Treatment Services Provided

Hospital records can provide information about the medical procedures, assessment, and treatment services provided. This information can be obtained from the discharge summary or reports from the attending physician, neuropsychologist, speech-language pathologist, occupational therapist, and physiotherapist at the hospital, or by talking to these professionals by phone. The child's parent or legal guardian needs to give consent to release hospital records and information about the child.

### The Nature and Extent of the Injury

Information about which parts of the child's brain were injured and whether the brain injury was traumatic or nontraumatic, focal or diffuse can be used as a starting point for where to focus assessment. The child's initial and sometimes transient areas of difficulty can also guide assessment. For example, a child may have experienced right-sided body weakness in hospital that was no longer apparent upon the return home. This would indicate a need to closely attend to possible difficulties associated with the left hemisphere, such as higher-level motor skills, sensation, and speech and language functioning.



## The Circumstances Surrounding the Injury

Information about how the child was injured can give therapists a broader picture of the current situation and of what the family has experienced. For example, the child's injury may have been caused by a motor vehicle accident in which the parent was driving. The child may have been in the care of older siblings or friends, who may have witnessed the injury. The child may have been injured as a result of abuse. Other family members or friends may have also been injured or died in the accident. These factors may affect discharge and rehabilitation planning.

---

## Information About the Child's Brain Injury

*Therapists may want to consider gathering the following information about the child's brain injury from hospital reports.*

- What was the date of the child's brain injury and discharge from the hospital?
  - How did the child sustain the brain injury, and were others injured?
  - What type of acquired brain injury did the child sustain:
    - traumatic brain injury (motor vehicle accident, fall)?
    - non-traumatic brain injury (infection, stroke, near-drowning)?
  - What were the results of relevant tests? (CT, MRI, EEG, angiogram, X-rays)?
  - What areas of the brain were injured? Were the injuries diffuse and/or focal?
  - What other injuries did the child sustain (fractures, cranial nerve injuries)?
  - What medical course and operations did the child have while in hospital (difficulties with extubation, increased intracranial pressure, surgeries)?
  - What medications is the child currently taking?
  - What were the child's main difficulties while in hospital and upon discharge (hemiparesis, agitation, memory difficulties, visual problems)?
  - What areas of functioning were assessed at the acute hospital (level of consciousness, vision, hearing, swallowing/feeding, motor skills, cognition, language)?
-



## The Child's Abilities Prior to the Injury

Taking a detailed history is critical to the comprehensive assessment of the impact of an acquired brain injury on a child. Parents and other family members can provide valuable information about the child's pre-injury development, including interests, abilities, and personality. It is also important to obtain information from the school about the child's pre-injury learning style and accomplishments, through interviews with the teacher and reviews of report cards and samples of the child's school work.

Without this knowledge, it is possible to underestimate or overestimate the effect of a brain injury on specific abilities. Children can sustain a significant drop in function relative to their pre-injury skills and still obtain test scores in the normal range for their age. Some children with ABI may have had developmental difficulties prior to their injury. For example, they may have had a specific learning disability, hyperactivity, or speech and language delays. They may also have a history of emotional or behavioral difficulties. Some children with ABI also speak English as a second language (ESL).

It is important not to overestimate factors such as pre-injury problems or difficulties with English, and fail to recognize the impact of new challenges experienced as a result of the brain injury (Ylvisaker, 1997). A comprehensive assessment that includes a detailed review of the child's history is needed to differentiate between problems that are caused by the brain injury, problems that have been exacerbated by the brain injury, and problems that are unchanged by the injury.

## Determining the Child's Level of Consciousness

Level of consciousness (LOC) should be the **first** area assessed by any therapist, no matter how well the child appears to be functioning. LOC needs to be assessed whether the child is at a hospital, a rehabilitation centre, home, or school. Knowing the child's LOC is the key to understanding the child's cognitive and behavioural skills. It is the precursor to understanding what further assessment, intervention, and education plans are appropriate.

Most children appear alert and physically able upon discharge from the hospital (for example, they are walking and talking). They are able to follow simple instructions and answer personal questions correctly. However, some of these same children have a reduced LOC and cannot consistently remember what happened earlier that day, what time of day it is, or what is planned for tomorrow. They tend to fatigue easily, become overstimulated, and have a great need for structure and repetition throughout their day.

*Determining level of consciousness does NOT simply mean identifying whether the child is conscious or unconscious.*

*For more information about levels of consciousness, see Chapter 1, Acquired Brain Injury.*

*For the Rancho Los Amigos Pediatric Level of Consciousness Scale, see Appendix 5-A.*

If the child's reduced LOC is not recognized, the rehabilitation goals and plans that are developed may place unrealistic expectations on the child. The child may also prematurely return to school or to unsupervised leisure activities, which may compromise the child's safety. Assessing LOC is not discipline-specific and is important for all professionals in both the hospital and community.

### **Assessing Level of Consciousness**

In Chapter 1, *Acquired Brain Injury*, the return to consciousness is described as a process whereby the child gradually becomes more aware of the world. There are predictable steps or levels that these children typically move through and identifiable skills that emerge at each level. The child's responses can be inconsistent throughout the day and from one day to the next, so more than one session is needed to determine LOC.

The two scales most widely used to assess LOC are:

- the Rancho Los Amigos Pediatric Level of Consciousness Scale (for children and adolescents)
- the Rancho Los Amigos Levels of Cognitive Functioning (for adolescents and adults)

These two tools are not standardized assessments. Rather, they are rating scales that provide a framework for describing the cognitive recovery process. On both scales, LOC is determined by informally assessing the child's abilities during daily functional activities. The scales are typically used with children with traumatic brain injuries; however, they can also be useful for assessing children with non-traumatic, diffuse brain injuries. In addition to providing important information for planning assessment, treatment, and programming, these scales help to promote communication between members of the child's rehabilitation team and family.

### **Rancho Los Amigos Pediatric Level of Consciousness Scale**

The Rancho Los Amigos Pediatric Level of Consciousness Scale is specifically designed for use with children and adolescents. This scale takes into consideration how a child's responses may differ depending on developmental level. It contains three age group scales:

- infants (six months to two years)
- preschool age (two to five years)
- school age (five years or older)

Each age group scale ranges from Level 5 (the lowest level of functioning) to Level 1 (the highest level of functioning). Since this manual focuses on children who begin to regain many of their previous abilities, only children at Level 2 and Level 1 are discussed.

Children at Level 2 are **not consistently** oriented to person, place, time and do **not consistently** remember recent events or new information on an ongoing basis.

Children at Level 1 are **consistently** oriented and able to remember recent events and new information. However, these children may continue to have some memory difficulties and gaps in their previous knowledge.

Even though many children progress to Level 1, this does not mean they have returned to pre-injury functioning. They may continue to have various difficulties in areas such as thinking, behaviour, and social relationships (see Chapter 1, *Acquired Brain Injury*).

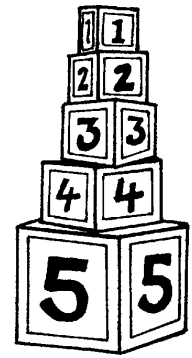
### Rancho Los Amigos Levels of Cognitive Functioning

This scale is designed for use with adults and adolescents. It is less useful for young children because it does not account for differences in developmental levels. For example, young children do not have the language skills necessary to respond to questions about orientation. The Rancho Los Amigos Levels of Cognitive Functioning range from Level I (the lowest level of functioning) to Level VIII (the highest level of functioning). This scale may be more helpful than the pediatric scale for those adolescents who demonstrate more significant agitation, confusion, and behavioural difficulties as part of their impaired LOC. This is sometimes seen, for example, in the recovery of children and adolescents with encephalitis.

### Other Assessments

Two other assessments developed to evaluate orientation and post-traumatic amnesia are the Children's Orientation and Amnesia Test (COAT) (Ewing-Cobbs, Levin, Fletcher, Miner, & Eisenberg, 1990) and the Galveston Orientation and Amnesia Test (GOAT) for older adolescents and adults (Levin, O'Donnell, & Grossman, 1979).

Only the Rancho Los Amigos Pediatric Level of Consciousness Scale is discussed in detail in this chapter.



*For more information about children at Level 2 and Level 1, see Chapter 1, *Acquired Brain Injury*.*

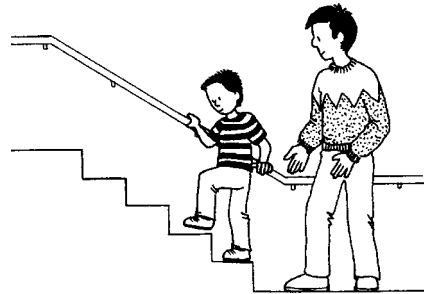
*For the description of the Rancho Los Amigos Levels of Cognitive Functioning, see Appendix 5-A.*

## Determining Areas for Focused Assessment

In addition to assessing level of consciousness, some other key areas of function need to be assessed early on and monitored over time.

### Safety First

Children with ABI are particularly at risk of sustaining secondary injuries. This is due to the specific difficulties they experience as a result of the brain injury. Some of these children have physical difficulties such as reduced higher-level balance skills, weakness on one side of the body, decreased coordination, or poor eating and swallowing skills. In addition, many children have difficulties with impulsivity, visual perception, attention, and executive functioning (for example, judgment and planning).



These problems can affect the child's safety in various activities of daily living, such as eating, bathing, walking, recreational pursuits, and other unsupervised activities outside of the home. Many of these children can look unimpaired, and it can be easy to overestimate their abilities. For these reasons, it is imperative for therapists to thoroughly assess the child's safety in various situations, and help the child, family, and friends understand the need to be overly cautious at first.

### Sensory Function

Children with ABI can sometimes have sensory difficulties, particularly with vision, hearing, or somatosensory functions (smell, taste, touch, temperature, pain, position, and motion sense). They may have cranial nerve damage, structural injuries to their eyes or ears, or injury to the parts of the brain responsible for sensory functioning. These deficits may not be obvious to others because they may be partial sensory losses or they may be camouflaged by other difficulties such as limited attention, organization, or awareness of personal deficits.

Routine testing of hearing, vision, sensation, and vestibular function is important for every child with ABI. These tests help to determine whether these difficulties are peripheral or cortical in nature. Some information about sensory functioning may be available in the hospital reports; however, sometimes these assessments may need to be requested or provided by community rehabilitation professionals. It is important to identify any impairments in the child's sensory functioning before assessing other cognitive, language, or physical difficulties.

## **Priorities for the Child and Family**

The initial focus for professionals is to support the child and family on issues that arise following discharge to home. The child and family initially tend to focus on the child's most obvious problems, such as physical difficulties. At this early stage of recovery, the child and family may have limited awareness of the extent of the child's cognitive or behavioural problems.

The child may also have some areas of difficulty that the family is not ready to consider. This can be challenging when these areas interfere with the child's functioning at school or with social relationships.

## **Specific Skills and the "Big Picture"**

Every child with a moderate to severe acquired brain injury needs to be thoroughly assessed to determine the impact of the injury on the child's thinking, communication, social/behavioural, physical, sensory, self-care, and leisure skills. Each discipline determines which specific skills to assess according to the priorities of the child, family, rehabilitation team, or school. The initial impressions of the child's strengths and difficulties, and the nature and extent of the brain injury, are also important determinants. The skills to be assessed also differ depending on the child's level of consciousness. For instance, a physiotherapist would not assess the ability of a child at Level 2 to remember how to independently use a walker from one session to the next, because new learning is limited at this stage.

In addition, professionals need to consider the "big picture" of how the child's various difficulties interact to affect a particular area of functioning. The interaction between the child and the environment is a key part of this process. It can be challenging to pinpoint which skill or set of skills is breaking down and causing the child difficulty. Therapists can get closer to answering these questions by using an interdisciplinary approach and a combination of informal and formal assessments, as discussed below.

## Informal and Formal Approaches to Assessment

A combination of informal and formal (standardized) assessments is critical to understanding the full impact of the brain injury on the child's abilities. Different professionals may lean more heavily on one form of assessment over the other. The relative usefulness of informal or formal assessment depends on a variety of factors, such as the child's rate of change, level of consciousness, or fatigue and other difficulties.

### Rate of Change

Children with ABI often regain many of their previous skills and knowledge quite quickly, and these changes should be monitored. Continuous assessment or diagnostic therapy is needed to keep planning and recommendations current. It is generally more helpful to delay extensive formal testing until the child's functioning is more stable.

### Level of Consciousness

At Level 2, informal assessment tends to be more useful than formal tests. At this level the child's specific skill deficits are difficult to identify because of confusion, disorientation, and poor memory. It is only possible to gain information about the child's **general** areas of strength and difficulty because of these confounding variables.

At Level 1, the child is generally ready for more extensive formal testing (in addition to informal assessment). At this level the child's **specific** areas of residual strength and difficulty can be more definitively identified. However, it can still be challenging to give formal tests to some children at level 1, particularly if they are experiencing difficulties with excessive fatigue, attention, or behaviour.

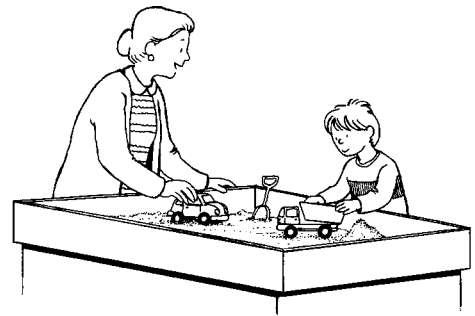
### Fatigue and Other Difficulties

Children with ABI fatigue easily due to the physical effects of the brain injury and the energy required to adapt to new changes in function. They not only experience physical exhaustion, but mental fatigue as well. Other difficulties with attention, memory, behaviour, or speech and language may also interfere with the child's ability to participate. A formal test may need to be delayed or modified accordingly to minimize the effect of these confounding variables on the specific skill area being assessed.

## Using Informal Assessment

Informal assessment is particularly helpful in getting a sense of the “big picture,” and provides valuable information that complements formal test findings. Observing and assessing the child during treatment sessions, games, daily activities, and interactions with others often provides the most worthwhile information about the child’s functioning. Some therapists refer to this process as *diagnostic therapy*, where they try to answer questions and test hypotheses about why the child is experiencing difficulty and how to best help. This form of evaluation is ongoing, and involves gathering information about **how** the child functions and adapts to ever-changing, real-life situations.

Of particular interest for children with brain injuries is how their specific skills and functioning are affected by increasing cognitive demands. For instance, the child may be able to negotiate stairs when alone, but not when distracted by many other students. Knowing whether the child is able to “generalize” skills to new situations is also critically important. For instance, the child may be able to independently shower in the home environment, but not in new, unfamiliar settings such as the community pool.



Informal assessment provides the opportunity to manipulate either the environment, task, or approach to identify which factors help or hinder the child’s functional abilities. The following are a few suggestions on how to alter these variables:

- **Environment** – Compare the child’s ability to function in familiar, quiet, and neat environments where few other people are present to the child’s abilities in unfamiliar, noisy, and cluttered environments where many other people are present.
- **Task** – Compare the child’s ability to perform simple, concrete, familiar, overlearned, motivating tasks that involve one skill area to the child’s ability to perform more complex, abstract, unfamiliar tasks that integrate multiple skills.
- **Approach** – Compare the child’s ability to function with high-level assistance, frequent positive feedback, and consistent interactions with others to their ability to function with less support from others.

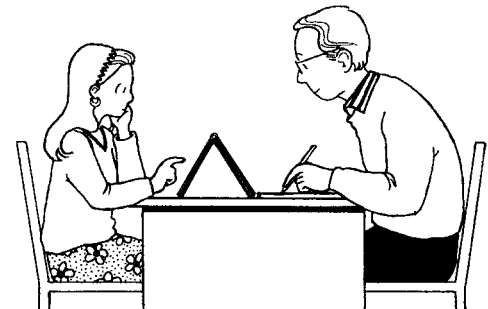
One concern about informal assessments is that specific skill deficits can be more difficult to isolate because most everyday activities require the integration of multiple skills. The child's abilities are also easy to overestimate when only familiar, overlearned tasks instead of new or challenging activities are assessed. The child's difficulties may be further masked by the family's tendency to compensate or do things for the child, which necessitates assessment while the child is not receiving assistance from others.

### Using Formal Tests

Formal (standardized) tests are important tools in the assessment of a child following a brain injury. Test findings can contribute to the identification of specific strengths and weaknesses. The child's performance should be compared to a normative peer group. However, test scores should also be interpreted in the context of the child's pre-injury development and skills. Baseline test findings can be compared to findings from future assessments to monitor changes in the child's function over time.

When a score is low, it is important to consider all of the skills required to succeed at that particular task. For instance, a child's poor performance on a language task may be due to impaired memory, attention, or visual-perceptual skills rather than language deficits. By sharing test findings with other team members, the team can determine where performance is breaking down.

In some cases, formal tests may need to be adapted to compensate for specific difficulties. For instance, verbal directions may need to be simplified, or the child may need to use a different response mode such as saying or pointing to an answer instead of writing it. Depending on the child's individual problems, the print may need to be enlarged, or the amount of printed material per item or per page may need to be limited. Any change in the standardized testing protocol needs to be documented. Changes in the standardized testing protocol may also mean that the normative data no longer apply.



Comparison of performance on timed versus untimed tests may provide useful information about how rate of processing affects performance. Testing below or above the basal and ceiling levels on formal tests can be helpful when there are indicators of unusual scatter or gaps in a child's performance across test items.



## Observations During Testing

During formal testing, it is important to observe **how** a child approaches or performs tasks or test items. These observations can provide information beyond the formal test scores about the quality of a child's responses, the conditions that affected the child's performance, and whether or not the performance was an accurate reflection of the child's abilities.

For instance, the following should be observed:

- the child's level of attention, consistency, endurance, and ability to work under stress (children may be less willing to engage in difficult tasks, particularly if they are aware that their capabilities have changed)
- the need for additional cueing (for example, to stay on task, to visually scan choices, and to stay oriented to task requirements)
- the need for additional time to complete a test or subtest (for example, a child may score within the average range on a test but need an hour rather than the typical 20 minutes)
- differences in performance depending on whether information is presented in an auditory, visual, written, or non-motor format
- the child's spontaneous use of strategies, and whether these strategies are effective
- inflexibility in the child's thinking (for example, difficulty adjusting to changes in content, format, and response modes)
- impulsive responses with little prior thought or planning

## Concerns About the Use of Formal Tests

The results of formal tests provide critical information about the impact of the brain injury and the child's needs for intervention and support. However, an assessment model that relies solely on standardized tests is inadequate for evaluating children with ABI. There is no collection or battery of tests that can be relied on to address the complex range of deficits associated with pediatric ABI. It is important to be aware of the limitations of test results, and of the need to supplement standardized test findings with informal assessment of the functional impact of the brain injury (Ylvisaker and Szekeres, 1986). The following are some concerns about the use of formal tests.

First, children with ABI often score in the normal range on commonly used tests despite having difficulty functioning in daily activities. Many commonly used test measures may not be adequately sensitive to the range of deficits common to children with ABI, such as difficulties with fatigue, attention, complex information processing, new learning, and executive function. For example, tests designed to assess general intellectual function can miss important deficits in higher-level reasoning skills or new learning. Even tests specifically designed to assess executive function or frontal lobe skills in children and adolescents can miss functional deficits that emerge under less structured conditions.

Second, a normal-range score can mask atypical scatter across test items, reflecting significant gaps in knowledge or skill relative to pre-injury function.

Third, test conditions can compensate for, and thereby mask, functional deficits. A child may score in the normal range on a highly structured test under relatively supportive test conditions, but may not be able to function at this level under real-world conditions.

Some of the concerns about test conditions include:

- The low degree of stimulation in the test environment, and short test sessions, can compensate for problems with fatigue and endurance.
- The quiet, orderly test room, and the structure provided by the examiner, can mask problems with attention and concentration.
- Interaction with the examiner can compensate for difficulties with motivation and initiation, or with inhibition.
- Clear explanation of test directions and highly structured task demands can mask deficits in task orientation, flexible adaptation to new tasks, and inferential reasoning.
- Test items that fail to present real-life amounts of information, or to use a real-life rate of delivery, may miss generalized inefficiency in information processing.
- Tests that only tap pre-injury skills and knowledge may generate false optimism about new learning.
- Tests that assess short-term memory or new learning within a test session can miss deficits in the ability to retain or recall new learning from one day to the next.
- One-time testing of a skill area may miss inconsistencies in daily performance.
- Tests of problem solving or new learning may fail to elicit difficulties with generalizing a newly acquired skill to a new situation.

Adapted from Baxter, Cohen, & Ylvisaker, 1985, Ylvisaker & Szekeres, 1986.

Formal test findings must always be supplemented by information about the child's pre-injury function and current abilities under non-test conditions, as well as by clinical observations during testing.

## Specific Formal Tests

Few tests are designed specifically for children with ABI. However, many of the tests that are designed for use with children with developmental difficulties can be useful for assessing children with ABI if the factors discussed above are considered.

The formal tests available to the various rehabilitation disciplines are too diverse and numerous to list in this manual. However, the following are a few references that provide a listing of tests:

- Baxter, R., Cohen, S.B., & Ylvisker, M. (1985). Comprehensive cognitive assessment. In M. Ylvisaker (Ed.), *Head injury rehabilitation: Children and adolescents* (pp. 247-274). San Diego, CA: College-Hill Press.
- Blosser, J.L., & DePompei, R. (1994). *Pediatric traumatic brain injury: Proactive intervention*. San Diego, CA: Singular Publishing Group.
- King-Thomas, L., & Hacker, B.J. (1987). *A therapist's guide to pediatric assessment*. Toronto, ON: Little Brown and Co.
- Rosenthal, M., Griffith, E.R., Bond, M.R., & Miller, J.D. (1990). *Rehabilitation of the adult and child with traumatic brain injury* (2nd ed.). Philadelphia, PA: F.A. Davis.
- Sellars, C.W., & Vegter, C.H. (1993). *Pediatric brain injury: A practical resource*. Tuscon, AZ: Communication Skill Builders.

## Assessment of Preschool Children

Assessment of preschool or very young school-age children with ABI can present special challenges in the early stages of recovery, and these children should be carefully monitored. Even apparently mild difficulties apparent in younger children may be predictive of significant long-term functional deficits.

In the early stages of recovery, these children tend to have poor tolerance for the kinds of test demands typically involved in many formal assessment tools. Play sessions and observations in non-test settings can augment formal test findings and provide valuable information about the impact of the brain injury. Information about pre-injury function is particularly important for assessing preschool children, since the normal range of variability tends to be greater in this age group.

## In Summary

Each brain injury is different and presents a unique set of challenges for the child. However, an appreciation of some of the commonly occurring characteristics of a pediatric brain injury can help guide the assessment process. A combination of formal and informal assessments, together with an interdisciplinary team approach that includes the child, family, and school, provides the most accurate understanding of the child's abilities. Because children with ABI are "moving targets," ongoing monitoring and assessment are required to keep current with their changing status.

The initial assessment provides information about what areas of difficulty the child is experiencing. It also provides information about how the child functions best and which types of assistance promote or interfere with performance. This knowledge is essential to effective intervention and to the development of a rehabilitation plan with the child and family.

# Intervention: Developing a Rehabilitation Plan

Following the initial assessment, the next step is to develop a rehabilitation plan. This includes identifying rehabilitation goals, strategies to achieve those goals, and steps for implementing and supporting the rehabilitation plan. This section discusses general rehabilitation goals and strategies for children with ABI that a variety of professionals may find useful.

## Rehabilitation Goals

The interdisciplinary team works with the family and child to identify and prioritize goals for rehabilitation. These goals should be consistent with what the child and family want and are able to handle. Some children and adolescents are able to assist in setting their rehabilitation goals. However, their reduced insight into their deficits may make this difficult. At this early stage, some families may not be able to articulate their goals, perhaps because of difficulties adjusting to the child's injury or understanding the child's resulting deficits. Nevertheless, the goals the family is able to identify need to be reflected in the rehabilitation plan.

Professionals need to understand that the need of the child and family to maintain hope for a full recovery may prevent them from initially recognizing deficits. Concrete, physical difficulties such as muscle weakness, double vision, or altered vocal quality tend to be identified as areas for early intervention, whereas problems with understanding or reasoning are often not recognized until later. In some cases, the child and family may suggest goals that seem out of reach. Helping the child and family set small, realistic, but meaningful goals can help the family maintain hope and help ensure the success of the child.

Some goals are best addressed by a particular discipline. For example, a physiotherapist may facilitate the child's dynamic balance skills to improve walking on uneven surfaces. If the various therapists are aware of the goals each is addressing, they can incorporate and reinforce some of the treatment strategies used by the primary therapist into their own sessions. The physiotherapist can provide language stimulation to a toddler. The speech-language pathologist can use fine-motor or visual-perceptual strategies suggested by the occupational therapist when working on written language organization. This helps the child generalize skills in a variety of settings.



Some treatment goals cross the boundaries of the rehabilitation disciplines. For example, all team members need to facilitate the child's attention, memory, appropriate behaviour, and self-awareness. A consistent approach is generally helpful when working on these areas of difficulty.

The specific rehabilitation goals that are developed will depend on each child's injury and situation. However, most treatment goals developed in this early stage of recovery fall into these general categories:

- facilitate recovery of previous skills and knowledge
- facilitate self-awareness of difficulties and strengths
- facilitate participation in everyday activities

### **Facilitate the Recovery of Previous Skills and Knowledge**

The child's brain injury may have impaired many of the child's previous abilities. Thus, a key goal of rehabilitation is to facilitate the recovery or improvement of the child's previous skills and knowledge.

The specific skills that improve and their rate of improvement depend in part on the severity and nature of each child's brain injury. There can be spontaneous improvement, especially in physical skills such as walking and talking; however, recovery needs to be guided. While basic motor patterns may show spontaneous improvement relatively quickly, they may need refining. In motor recovery, for example, therapy helps to facilitate the return of normal motor patterns and to prevent bad habits or patterns from developing. Children may regain the ability to walk, but develop hyper-extension of the knee. In therapy, they could practice correct walking movements, hopefully becoming more aware of their walking while receiving specific feedback, and aids such as a foot splint could be provided as needed to assist with this goal.

Higher-level abilities in a particular area may not return spontaneously. Skills that appear to have improved to pre-injury levels can break down when children are fatigued or performance demands (such as speed, endurance, or independence) are increased. Once children appear to be walking well, they may continue to have more subtle problems with balance and coordination that only become apparent when they try to participate in the recreational and competitive sports they were involved in prior to the injury. Therapy can help children regain skills more efficiently and maximize their potential for recovery.

In facilitating the return of previous skills, it is generally best to follow the child's lead and work on recovering skills in the order in which they naturally emerge. Therapists can identify and work on specific areas of difficulty instead of always working from basic to higher-level skills. Skills that were learned earlier in development can generally be facilitated more easily than skills that were recently acquired and are therefore less automatic.

### **Facilitate Self-Awareness of Strengths and Difficulties**

Children with limited self-awareness have a decreased ability to recognize their own deficits. This is a common problem for children with ABI, especially when the injury involves the frontal lobes. Facilitating children's awareness of their impairments can be challenging, but is critical. Limited self-awareness can affect children's ability to understand the purpose of rehabilitation and willingness to participate in therapy.

It is important to help children make the link between their impairment and the need to work on it (Ylvisaker, Szekeres, & Feeney, 1998). Provide immediate, consistent, and direct yet low-key feedback to children about their limitations. It is often easiest to begin addressing more obvious physical problems, such as walking, talking, or eating. For some children, viewing a videotape of themselves can be a useful way to facilitate self-awareness. Videotapes can also provide clear evidence of improvement over time. Group therapy can be an effective medium for children to become more aware of their areas of difficulty and develop compensatory strategies.

Children with ABI should not be expected to fully appreciate their new limitations, especially in the early stages of recovery. They may need to live with their impairments for a long time before they begin to understand the nature of their difficulties. As they begin to register their difficulties, children may feel great distress. They often need support adjusting and coping with their difficulties at different stages throughout their development.

Helping children recognize their relative strengths is extremely valuable. It is an important part of maintaining a positive self-image following a serious injury and keeping them hopeful and willing to stay engaged in therapy. These children may need assistance to recognize their strengths, particularly as they become aware of their new limitations.

## Facilitate Participation in Everyday Activities

While working on the return of previous skills and awareness of difficulties, concurrent treatment goals should focus on increasing the child's participation in important daily activities. Opportunities for the child to participate successfully in increasingly natural settings should be explored. It is important to work with the people in these settings to increase their understanding of the child's difficulties and to provide them with strategies and support. In both therapy and natural settings, children can be taught to use their residual skills well and to use compensatory strategies when needed. Increasing the child's participation in everyday activities will assist in the generalizing of new skills.

Functional adaptations, such as adaptive writing equipment, reduced demands on the child, or increased assistance and supervision, may be used short term and may bridge the gap until skills return in a few weeks or months. However, if the child does not fully regain the specific skills, these modifications and strategies will already be in place and will be familiar to the child, family, and other caregivers.

## Rehabilitation Strategies

The team, family, and child need to work together to develop appropriate strategies to address the established rehabilitation goals. Although strategies need to be tailored to each child, the following are some general kinds of strategies to consider. A combination of these strategies is typically used at the same time to optimize a child's function.

### Work on Specific Skills

Intensive training in specific skills, including aspects of attention, fine motor, perceptual, or language function, can be a valuable part of rehabilitation, especially in the early stages of recovery. This type of training typically involves targeted drill or practice on specific skills—for example, working on grammatical structures with a child who is aphasic. Not all skills will improve significantly with repetitive drill. Improvement depends on the nature of the child's injury and the skills being addressed.

Children with ABI typically have great difficulty generalizing skills learned in therapy to other settings, including real-life situations. Intensive training that is focused on a specific skill in the therapy setting may not translate into a useful functional skill. For instance, children may improve their ability to play a memory game on the computer, but not show improved memory for functional tasks such as learning their multiplication tables.



## Work on Functional Skills in Everyday Activities

Focusing too much on specific skill training may mean that highly important functional skills are not addressed. The child should be engaged in meaningful activities that require multiple skills in realistic and natural situations (Haarbauer-Krupa, Henry, Szekeres, & Ylvisaker, 1985). This form of intervention is different from working on isolated skills (for example, visual-perception or language comprehension) because the skills that are practiced are the actual functional behaviours (for example, following a recipe or conversing with others). This approach is used to help children with ABI generalize and integrate their basic skills into functional daily activities.



This method often involves gradually adapting aspects of the environment, task, and approach (as listed below) to more closely resemble those in real life. A useful place to begin is to consider the team's assessment findings about which factors hinder and which help the child's ability to function.

- **Environment** – Begin with a quiet, neat, familiar environment with few other people present and work towards more stimulating environments as appropriate.
- **Task** – Begin with familiar, overlearned, simple, motivating tasks. Try to design tasks that involve few skills at one time. Gradually work towards more novel, complex activities that integrate multiple skills.
- **Approach** – Begin by providing high-level assistance and frequent positive feedback to the child. Progress to providing assistance or positive feedback only as necessary and have the child interact with others in more varied situations. Remain flexible to continually keep up with the child's fluctuating and changing abilities.

## Compensate for the Child's Limitations

**Adapt the Environment, Task, and Approach** – Compensating for the child's difficulties by adapting the environment, task, and approach can enable the child to function in meaningful activities. Depending on the nature of the child's brain injury and its subsequent effects, independence may not always be an attainable goal. A child may indefinitely require some level of assistance to function effectively.

**Ensure Success** – For children with ABI, experiencing success early in recovery is critical to helping them adjust to their new difficulties. This helps children maintain their interest, motivation, and participation in tasks, and feel hopeful about improvement in their skills and function. The activities chosen and the level of assistance provided should initially be adapted to minimize frustration and failure. As their abilities improve, children should be gradually challenged. This needs to be done carefully to prevent children from feeling negatively about themselves. This balance is particularly important at the time children begin to gain more awareness of their deficits. They will need support to help them adjust to their difficulties and recognize their individual strengths.

**Provide Consistency** – A predictable daily routine and a consistent method of interaction can be essential in promoting the child's ability to function and in limiting behaviour problems. For instance, therapists may facilitate improvement in the orientation of children at Level 2 by providing a consistent routine and by regularly orienting them to where they are and what they are doing. Agitation and other behaviour problems may be reduced by helping children feel more secure about what is happening around them. For children at Level 1, consistent teaching methods may facilitate new learning. Families and therapists may be able to promote more appropriate behaviour by maintaining the same rules over time and interacting with the child in a consistent way.

## Teach Children to Use Compensatory Strategies

Children can be taught compensatory strategies to help them achieve tasks they cannot do on their own. Some examples of external strategies and aids are walkers, pencil grips, homework lists, and memory/orientation books. Examples of internal strategies include using word associations to recall a person's name, or remembering to look to the far left side of a page to compensate for a left visual field cut.

Teaching children to compensate is an important therapy strategy that goes hand in hand with the overall goal of facilitating the recovery of previous skills. In rehabilitation, teaching children to compensate for their difficulties is often felt to be the last resort, something that is only done when they are not able to regain a previous skill. For example, parents may feel apprehensive about the use of a communication board if their child is not speaking because they feel it will prevent the child from trying to talk. However, early provision of the communication board may enable the child to meet daily communication needs and participate more fully in rehabilitation. Teaching the child skills that enable success does not mean that the child will stop trying to improve areas of difficulty. Remediation and compensation can co-exist!

Several factors need to be considered when deciding whether to teach a child a particular strategy. These include the child's level of consciousness, self-awareness, and developmental level. Children are not expected to independently use compensatory strategies until they are at Level 1 on the Rancho Los Amigos Pediatric Level of Consciousness Scale. At this level of consciousness, children are able to store new information in memory. Still, many children at Level 1 tend to be inefficient at learning new information and require specialized assistance. They may not recognize that they are having a problem, or may forget to remember to use the strategy. Children who have some awareness of their difficulties and are of intermediate or high school age tend to be better candidates to use compensatory strategies independently.

Helping children recognize the usefulness of a strategy can increase their motivation to learn it. Selecting tasks that show the value of using the strategy, and showing children that everyone uses strategies, can be helpful in normalizing this process. For instance, showing children that other people use "memory books" (daytimers) and modeling their use may make this strategy more acceptable. Matching children to the appropriate strategy should be based on a thorough understanding of their individual strengths and skill limitations. For instance, a child with visual-perceptual difficulties may not be able to read notes in a memory book if the notes are too visually cluttered. In addition, many children are more successful when they choose their own strategies rather than using the ones the therapist selects. It is important to avoid introducing too many strategies at one time or strategies that are too similar to one another.



Systematic training and consistent support are required to help children with ABI learn to use a compensatory strategy. Children need to learn and practice a compensatory strategy before using it in real life situations. They may need to learn how to differentiate between situations that do and do not require the strategy. Through practice with support and feedback, the child may gradually learn to use the strategy independently. The eventual aim is for the child to generalize use of the strategy in increasingly varied situations, with less support and cueing (see Sohlberg & Mateer, 1989).

Some children may benefit from working on self-awareness skills as a preliminary step to or in conjunction with learning a compensatory strategy. Younger children or those with limited insight into their deficits may be taught some “pre-cursor” compensatory techniques. For instance, a therapist can help a child to understand which tasks are easy and hard, and to ask for help if a task is difficult (Ylvisaker, Sellars, & Edelman, 1998). Even if a child cannot be taught to use a strategy independently, others may be taught to cue the child to use the strategy.

## **Putting the Rehabilitation Plan into Action**

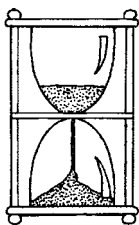
Following the initial assessment and the identification of the individualized goals, a number of decisions need to be made about how to implement the child’s rehabilitation plan. Decisions need to be made about the type of professionals needed to meet the treatment goals. The amount of therapy also needs to be considered. Usually children in the early stages of recovery require frequent, direct therapy to facilitate their skills and keep up with their changing status.

While the assessment and rehabilitation goals and plan need to realistically reflect the needs of the child, they may not reflect what is available in the child’s community. Some children can be appropriately served by local community services. However, other children may need outside community resources, and in some cases, services may need to be developed locally. For example, an occupational therapist (OT) may be available in the child’s community, but have no experience with pediatric acquired brain injury. An outside OT specializing in this area may be identified to support the community OT. In another situation, a local OT may not be available, and the outside OT may come to the community to assess the child and to help develop a therapeutic recreation or handwriting program. If appropriate, the OT could help train and support a local childcare worker to work with the child. The choices made depend in part on the specific needs of the child and the resources in the community.

Incorporating rehabilitation goals into typical daily activities and family life is an important aspect of a successful rehabilitation plan. Leisure activities can often be used to work on therapy goals and can help the child and family regain some normalcy in their lives. For instance, skills such as motor coordination, organization, and dressing can be addressed during a swim session at the neighbourhood pool. This therapeutic approach can also improve the effectiveness of rehabilitation by helping children generalize their skills to new, real-life situations.

Providing indirect support to the family in addition to the direct work done with the child is often one of the most worthwhile aspects of the child's rehabilitation plan. Families benefit from the extra time therapists spend listening, answering questions, and providing suggestions to help the family and friends support the child. In addition, some families want one person on the team to coordinate meetings and rehabilitation planning, while others prefer to take on this role themselves. The rehabilitation team needs to allow time for these important activities, and may need to advocate for time for case coordination, interdisciplinary planning, and indirect family support.

## Future Considerations



Children with moderate to severe ABI can continue to improve for many years. However, these children often have problems with new learning and, over time, may not keep up with developmental expectations in some areas. They can also develop new problems as they mature and are faced with new challenges.

Depending on the needs of the child, a wide variety of rehabilitation professionals may continue to be involved in ongoing assessment and treatment. These professionals can help assess the child's rate and degree of recovery and contribute to ongoing educational and rehabilitation planning. Careful monitoring is particularly important at key transition times in the child's life, such as before beginning the upper elementary grades, high school, post-secondary, or vocational programs, and before engaging in high-risk activities such as driving or team sports.

Close monitoring and evaluation by a neuropsychologist should continue as long as cognitive sequelae interfere with the child's learning, behavioural, or social-emotional adjustment. This is especially important for preschool and very young school-age children. Follow-up neuropsychology assessment is usually recommended at approximately 12 months following the injury, and is often recommended in subsequent years as well.

Professionals can also assist families by advocating for the necessary support services alongside them, by providing follow-up, and by linking them with ongoing support services that can assist them with any future concerns about their child.

## The Juggling Act: A Final Thought



The “juggling act” is a phrase families use to express their experiences in trying to fit rehabilitation plans into normal family life. Meeting the child's special needs on top of regular daily activities can be a challenge for families. Each family is unique and makes different choices and requests in their attempt to adapt to the needs of the child and the family unit. Although professionals can support this process, families make the ultimate decisions on the best course for them.

Above all else, the child and family need to feel like a family. Not every hour of the day needs to be focused on the child's rehabilitation plans or school work. Families need time to be together—to rest, play, and just simply enjoy life!

Appendix

# 5-A

## Level of Consciousness Scales

Please feel free to photocopy these scales for clinical use:

- the Rancho Los Amigos Pediatric Level of Consciousness Scale (for children and adolescents)
- the Rancho Los Amigos Levels of Cognitive Functioning (for adolescents and adults)

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# Rancho Los Amigos

## Pediatric Level of Consciousness Scale

### School Age (5 Years and Older)

**Directions:** Check all behaviors that are consistently present as (+), inconsistently present as (i), or absent as (-) on each date tested.

Name: \_\_\_\_\_ Test Dates: 

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**Level 5: No response to stimuli**

Complete absence of observable change in behavior to visual, auditory, or painful stimuli									
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**Level 4: Gives generalized response to sensory stimuli**

Gives generalized startle to loud sound									
Responds to repeated auditory stimulation with increased or decreased activity									
Gives generalized reflex response to painful stimuli									

**Level 3: Gives localized response to sensory stimuli**

Blinks when strong light crosses field of vision									
Follows moving object passed within visual field									
Turns toward or away from loud sound									
Gives localized response to painful stimuli									

**Level 2: Is responsive to environment**

Follows simple verbal or gestured requests									
Initiates purposeful activity									
Actively participates in therapy program									
Refuses to follow request by shaking head or saying "no"									
Imitates examiner's gestures or facial expressions									

**Level 1: Oriented to time and place; is recording ongoing events**

Can provide accurate, detailed information about self and present situation									
Knows way to and from daily activities									
Knows sequence of daily routine									
Knows way around ward; recognizes own room									
Can find own bed; knows where personal belongings are kept									
Is bowel and bladder trained									

Adapted from Levels of Consciousness Record, Pediatric Brain Injury Service, Rancho Los Amigos Hospital, Downey, California as cited in Sellars, C.W., & Vegter, C.H. (1993).

Source: *Children With Acquired Brain Injuries: The Transition from Hospital to Community* (1999). Vancouver, BC: Sunny Hill Health Centre for Children.

# Rancho Los Amigos

## Pediatric Level of Consciousness Scale

### Preschool Age (2 to 5 Years)

**Directions:** Check all behaviors that are consistently present as (+), inconsistently present as (i), or absent as (-) on each date tested.

Name: \_\_\_\_\_ Test Dates: 

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**Level 5: No response to stimuli**

Complete absence of observable change in behavior to visual, auditory, or painful stimuli

--	--	--	--	--	--	--	--	--	--

**Level 4: Gives generalized response to sensory stimuli**

Gives generalized startle to loud sound

--	--	--	--	--	--	--	--	--	--

Responds to repeated auditory stimulation with increased or decreased activity

--	--	--	--	--	--	--	--	--	--

Gives generalized reflex response to painful stimuli

--	--	--	--	--	--	--	--	--	--

**Level 3: Gives localized response to sensory stimuli**

Blinks when strong light crosses field of vision

--	--	--	--	--	--	--	--	--	--

Follows moving object passed within visual field

--	--	--	--	--	--	--	--	--	--

Turns toward or away from loud sound

--	--	--	--	--	--	--	--	--	--

Gives localized response to painful stimuli

--	--	--	--	--	--	--	--	--	--

**Level 2: Demonstrates awareness of environment**

Follows simple commands

--	--	--	--	--	--	--	--	--	--

Refuses to follow commands by shaking head or saying "no"

--	--	--	--	--	--	--	--	--	--

Imitates examiner's gestures or facial expressions

--	--	--	--	--	--	--	--	--	--

Responds to name

--	--	--	--	--	--	--	--	--	--

Recognizes mother or other family members

--	--	--	--	--	--	--	--	--	--

Enjoys imitative vocal play

--	--	--	--	--	--	--	--	--	--

**Level 1: Oriented to self and surroundings**

Provides accurate information about self

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Is aware of being away from home

--	--	--	--	--	--	--	--	--	--

Knows where toys, clothes, and other objects are kept

--	--	--	--	--	--	--	--	--	--

Actively participates in treatment program

--	--	--	--	--	--	--	--	--	--

Recognizes own room, knows way to bathroom, nursing station, etc.

--	--	--	--	--	--	--	--	--	--

Is potty-trained

--	--	--	--	--	--	--	--	--	--

Shows active interest in toys; will examine or manipulate before mouthing or discarding

--	--	--	--	--	--	--	--	--	--

Watches other children at play; may move toward them purposefully to watch or snatch toy

--	--	--	--	--	--	--	--	--	--

Initiates social contact with adult; enjoys socializing

--	--	--	--	--	--	--	--	--	--

Adapted from Levels of Consciousness Record, Pediatric Brain Injury Service, Rancho Los Amigos Hospital, Downey, California as cited in Sellars, C.W., & Vegter, C.H. (1993).

Source: *Children With Acquired Brain Injuries: The Transition from Hospital to Community* (1999). Vancouver, BC: Sunny Hill Health Centre for Children.

# Rancho Los Amigos

## Pediatric Level of Consciousness Scale

### Infants (6 Months to 2 Years)

**Directions:** Check all behaviors that are consistently present as (+), inconsistently present as (i), or absent as (-) on each date tested.

Name: \_\_\_\_\_ Test Dates: 

--	--	--	--	--	--	--	--

**Level 5: No response to stimuli**

Complete absence of observable change in behavior to visual, auditory, or painful stimuli									
---	--	--	--	--	--	--	--	--	--

**Level 4: Gives generalized response to sensory stimuli**

Gives generalized startle to loud sound									
Responds to repeated auditory stimulation with increased or decreased activity									
Gives generalized reflex response to painful stimuli									

**Level 3: Gives localized response to sensory stimuli**

Blinks when strong light crosses field of vision									
Follows moving object passed within visual field									
Turns toward or away from loud sound									
Gives localized response to painful stimuli									

**Level 2: Demonstrates awareness of environment**

Responds to name									
Recognizes mother or other family members									
Enjoys imitative vocal play									
Giggles or smiles when talked to or played with									
Fussing is quieted by soft voice or touch									

**Level 1: Interacts with environment**

Shows active interest in toys; manipulates or examines before mouthing or discarding									
Watches other children at play; may move toward them purposefully									
Initiates social contact with adults; enjoys socializing									
Shows active interest in bottle									
Reaches or moves toward person or object									

Adapted from Levels of Consciousness Record, Pediatric Brain Injury Service, Rancho Los Amigos Hospital, Downey, California as cited in Sellars, C.W., & Vegter, C.H. (1993).

Source: *Children With Acquired Brain Injuries: The Transition from Hospital to Community* (1999). Vancouver, BC: Sunny Hill Health Centre for Children.

# Rancho Los Amigos Levels of Cognitive Functioning (Adolescents and Adults)

## I. No Response

Patient appears to be in a deep sleep and is completely unresponsive to any stimuli presented to him.

## II. Generalized Response

Patient reacts inconsistently and non-purposefully to stimuli in a nonspecific manner. Responses are limited in nature and are often the same regardless of stimulus presented. Responses may be physiological changes, gross body movements and vocalization. Responses are likely to be delayed. The earliest response is to deep pain.

## III. Localized Response

Patient reacts specifically but inconsistently to stimuli. Responses are directly related to the type of stimulus presented, as in turning head toward a sound or focusing on an object presented. The patient may withdraw an extremity and vocalize when presented with a painful stimulus. He may follow simple commands in an inconsistent, delayed manner, such as closing his eyes, squeezing or extending an extremity. Once external stimuli are removed, he may lie quietly. He may also show a vague awareness of self and body by responding to discomfort by pulling at nasogastric tube or catheter or resisting restraints. He may show a bias toward responding to some persons, especially family and friends, but not to others.

## IV. Confused-Agitated

Patient is in a heightened state of activity with severely decreased ability to process information. He is detached from the present and responds primarily to his own internal confusion. Behaviour is frequently bizarre and non-purposeful relative to his immediate environment. He may cry out or scream out of proportion to stimuli even after removal, may show aggressive behaviour, attempt to remove restraints or tube or crawl out of bed in a purposeful manner. He does not discriminate among persons nor objects and is unable to cooperate directly with treatment efforts. Verbalization is frequently incoherent or inappropriate to the environment. Confabulation may be present; he may be hostile. Gross attention to environment is very brief and selective attention often nonexistent. Being unaware of present events, patient lacks short term recall and may be reacting to past events. He is unable to perform self-care activities without maximum assistance. If not disabled physically, he may perform automatic motor activities such as sitting, reaching, and ambulating as part of his agitated state but not as a purposeful act nor on request, necessarily.

## **V. Confused-Inappropriate**

Patient appears alert and is able to respond to simple commands fairly consistently. However, with increased complexity of commands or lack of any external structure, responses are nonpurposeful, random or, at best, fragmented toward any desired goal. He may show agitated behaviour but not on an internal basis, as in Level IV, but rather as a result of external stimuli and usually out of proportion to the stimulus. He has gross attention to the environment, is highly distractible and lacks ability to focus attention to a specific task without frequent redirection. With structure he may be able to converse on a social-automatic level for short periods of time. Verbalization is often inappropriate; confabulation may be triggered by present events. Memory is severely impaired, with confusion of past and present in reaction to ongoing activity. Patient lacks initiation of functional tasks and often shows inappropriate use of objects without external direction. He may be able to perform previously learned tasks when structured for him but is unable to learn new information. He responds best to self, body, comfort and often family members. The patient usually can perform self-care activities with assistance and may accomplish feeding with supervision. Management on the unit is often a problem if the patient is physically mobile as he may wander off, either randomly or with vague intention of “going home.”

## **VI. Confused-Appropriate**

Patient shows goal-directed behaviour, but is dependent on external input for direction. Response to discomfort is appropriate and he is able to tolerate unpleasant stimuli, e.g., NG tube, when need is explained. He follows simple directions consistently and shows carryover for tasks he has [previously] learned e.g., self-care[, with little or no carryover for new learning]. Responses may be incorrect due to memory problems but are appropriate to the situation. They may be delayed to immediate and he shows decreased ability to process information with little or no anticipation or prediction of events. Past memories show more depth and detail than recent memory. The patient may show beginning awareness of his situation by realizing he doesn't know an answer. He no longer wanders and is inconsistently oriented to time and place. Selective attention to tasks may be improved, especially with difficult tasks and in unstructured settings, but is now functional for common daily activities. He may show vague recognition of some staff and has increased awareness of self, family and basic needs.

## **VII. Automatic-Appropriate**

Patient appears appropriate and oriented within hospital and home settings, goes through daily routine automatically but robot-like, with minimal to absent confusion and has shallow recall for what he has been doing. He shows increased awareness of self, body, family, food, people and interaction in the environment. He has superficial awareness of but lacks insight into his condition, decreased judgment and problem solving and lacks realistic planning for his future. He shows carryover for new learning at a decreased rate. He requires at least minimal supervision for learning and safety purposes. He is independent in self-care activities and supervised in home and community skills for safety. With structure, he is able to initiate tasks or social and recreational activities in which he now has interest. His judgment remains impaired. Prevocational evaluation and counseling may be indicated.

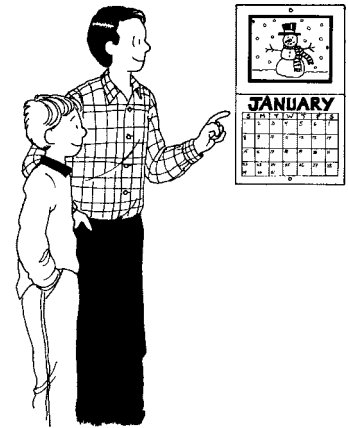
## VIII. Purposeful-Appropriate

Patient is alert and oriented, is able to recall and integrate past and recent events and is aware and responsive to his culture. He shows carryover for new learning if acceptable to him and his life role and needs no supervision once activities are learned. Within his physical capabilities, he is independent in home and community skills. Vocational rehabilitation, to determine ability to return as a contributor to society, perhaps in a new capacity, is indicated. He may continue to show decreases relative to premorbid abilities in quality and rate of processing, abstract reasoning, tolerance for stress and judgment in emergencies or unusual circumstances. His social, emotional and intellectual capacities may continue to be at a decreased level for him but are functional within society.

Malkmus, D., Hagen, C., & Durham, T. (1979). Levels of cognitive functioning. *Rehabilitation of the head injured adult: Comprehensive physical management*. Downey, CA: Los Amigos Research and Education Institute, Inc., of Rancho Los Amigos Medical Center.

## Specific Intervention Strategies

The specific intervention strategies that are useful for each individual child will be different. In addition, different strategies may be needed at various stages in the child's recovery. The following strategies are not intended to be comprehensive, but are meant to provide a helpful starting point. Many of the strategies that are helpful for children and adolescents with acquired brain injuries (ABI) overlap with strategies used with children with developmental difficulties.



### Orientation

These suggestions may be useful for children at a reduced level of consciousness who may not be fully oriented to their surroundings and present situation.

- Provide orienting information throughout the day. Use a conversational style with occasional questions (do not quiz). Keep information simple and concise.
- Begin with familiar, biographical information, then introduce simple information about the child's present situation. Photographs of family, friends, and school can be helpful.
- Initially you may need to re-introduce yourself each time you see the child. Do not expect the child to remember who you are, what you do, or what you previously worked on together.
- Use a calendar to help orient the child to the day, date, and season.
- Review simple schedules of planned activities several times throughout the day.
- For an older child, wearing a digital watch with the time and date can be helpful. Set the alarm to beep at regular intervals as a cue to look at the watch.

*For additional strategies, see Appendix 5-C, Additional Reference Materials, and Appendix 4-C, Instructional Strategies.*

- Create a simplified journal or “memory/orientation book” and document through words or photographs the main daily activities in which the child participates. Keep the language simple and the printing neat so the child can read it. Ensure that others use this journal with the child to help reinforce correct memories for recent events. Try to review it with the child before and after main activities and at key times of the day, such as before bed.
- For a child who confabulates, redirect and provide the correct information in a matter-of-fact way. A memory/orientation book can be helpful.
- Work with family, friends, and team members to ensure that a consistent approach is used. Children at Level 2 are not expected to use any of these strategies on their own; they do not learn new information well at this stage.

## Attention

- Structure the environment to reduce distractions and help the child focus.
- Monitor the need for cues to help redirect the child’s attention and focus on a task.
- If the child is impulsive and/or has poor safety awareness, ensure that one-to-one supervision is provided, especially in potentially dangerous situations such as on a playground or street, or near a hot stove.
- Present materials in a vivid manner so they stand out from the background.
- Mark a clear beginning and a clear end to each activity or topic. Provide cues to signal how much time or work remains in a task.
- Look for signs of frustration and adapt or change the activity so it is within the child’s tolerance level. Ensure the activity is challenging enough to maintain interest.
- Early in recovery, you may need to change the activity often within a session to keep interest high. Over time you can reduce the number of activities, and increase the time spent on each.
- Initially, restructure activities so the child doesn’t have to focus on more than one thing at a time. Gradually increase complex activities that require divided or alternating attention.
- Allow the child to change position regularly by working on the floor or standing at a table. Provide calming types of sensory input (for example, have the child sit in a bean bag chair).



- Help the child slowly wind down from active or stimulating activities. Music is often helpful.
- Provide positive feedback when the child is attending well. Try to avoid negative feedback for distractible, off-task behaviour since this is often not under conscious control.
- Teach the child self-monitoring skills to improve attention (not appropriate for a child at Level 2). For example, use a timer to increase the ability to attend to a task, or have the child rate his or her own ability to attend to tasks. Give the child feedback on a graph of increased time attended to tasks.
- Work with family, friends, and team members to ensure that a consistent approach is used.

## Visual Perception

- Adapt materials to compensate for the child's specific visual-perceptual deficits. For example, try enlarging materials. Present less information at one time. Provide clear contrast between foreground and background.
- For a child with disorganized visual search skills, help the child systematically scan information in his or her visual field (for example, on a page, during a board game, when riding a bike).
- Help the child understand what he or she is seeing and focus on the critical visual information.
- For a child who has difficulty maintaining his or her place on a line of text or has difficulty processing too much text on a page, try to teach the child to use a cardboard reading guide, to move a finger along the line of text while reading, or to cover part of the page.
- For a child with a visual field cut, or who fails to consistently attend to visual information in one side of space, ensure that materials are oriented in the child's preferred visual field. Use verbal and visual cues to direct the child's attention to important visual information (for example, tell the child to turn his or her head, use a red line on the left side of the page to cue where to begin reading or writing).
- Work with family, friends, and team members to ensure that a consistent approach is used.

## Communication

- For a child who has difficulties processing language, ensure you have the child's attention. Limit the amount of information presented at one time. Introduce the topic clearly, including any changes in topic. Do not speak too quickly. Present information in an organized manner, pausing occasionally to allow the child to process what has been said.
- Monitor the child's understanding. For important information, particularly when safety is involved, ask the child to repeat what he or she has heard.
- Be explicit. Do not expect the child to infer information that is not stated. Limit the use of more abstract language such as figurative expressions, sarcasm, and humour.
- Allow the child time to express information, particularly if the child has difficulty with word retrieval. Teach strategies to assist word retrieval.
- For a child who has difficulty formulating ideas or expressing thoughts verbally in an organized manner, provide support through structured questioning.
- Teach appropriate social use of language, including introducing the topic, staying on topic, attending to the listeners' shared knowledge and interest, and taking turns during conversation.
- For reading activities, the child may benefit from some specific instruction in strategies, such as identifying headings, scanning for key information, or using a structured guide to help identify the main idea and supporting details.
- Use structured visual guides for a child who has difficulty writing clearly organized stories or essays. Consider limiting the amount of written work that is expected.
- Work with family, friends, and team members to ensure that a consistent approach is used.

## Planning/Organization

- Monitor the need for organizational cues to help the child plan, initiate, and complete activities.
- Structure the environment to help the child organize materials and possessions (for example, closets, drawers, school bags, pencil cases, toys/leisure equipment, music tapes or disks).
- Role-model neatness, and exaggerate your own organization and planning for everyday tasks.
- Use structured schedules to help the child know what to expect during the day. This can include activities such as meal times, therapy sessions, classes, and rest breaks.
- Provide a standard lists of things to bring when going to school or on an outing such as a swimming lesson (for example, swimsuit, shampoo, and towel).
- Use everyday activities to teach an organized approach. Help the child create a written outline of the steps involved in achieving a task. Then help the child gather the appropriate materials and prepare for the task in a step-by-step manner. Use functional activities to teach simple sequencing and decision making, such as renting a video, cooking, or crafts.
- Work with family, friends, and team members to ensure that a consistent approach is used.

## Memory/Learning

- Monitor how much the child can process at one time. Decrease the amount of information given at one time. Decrease the rate at which it is given. Use repetition.
- Regularly summarize and chunk information together in themes.
- Adapt presentation of information to compensate for the child's specific memory problems. For example, for a child who has difficulty remembering spoken information, emphasize visual supports. For a child who has difficulty relying on visual information to learn new routes, verbally describe key visual landmarks.
- Teach compensatory strategies. For example, to decrease memory load, write down important information in a personal organizer. Use a journal or phone list to record important information. Do not expect the child to use these strategies independently or in new situations without specific practice.

- For a child who has difficulty retrieving information from memory, provide recognition cues to facilitate recall. For example, avoid open-ended questions; instead, ask a question that includes a few possible answers to choose from. On written tests, a multiple-choice format rather than an open-ended question format may help the child retrieve information he or she has learned.
- For a child who has difficulty with prospective memory (remembering to remember), use compensatory strategies (for example, alarms, watches). To-do lists can help to cue everyday routines.
- For a severely amnesic child, try to ensure error-free learning when teaching new procedural skills. Skills can improve with intensive repetition even when the child does not specifically remember the previous therapy sessions.
- Work with family, friends, and team members to ensure that a consistent approach is used.

## Problem Solving, Judgment, and Reasoning

- Help the child recognize situations that require a problem-solving strategy. Engage the child in everyday problem-solving tasks, such as how to reach an item off the top shelf, or what to do if the child doesn't know where to find an item in a store.
- Use structured questions to guide problem solving (for example, what is the problem, what are the possible solutions, what are the pros and cons, and which is the best solution). Help the child use this approach independently.
- The child may need help to create a plan, and then help to initiate using the plan, evaluate how it's working, and change the approach if necessary.
- Promote flexibility in thinking by introducing complications where the child needs to find an alternate solution.
- Engage the child in group activities where real-life problems and possible solutions are discussed.
- For a child who is a literal or concrete thinker, help the child identify and integrate critical information he or she sees, reads, or hears in conversation. Help the child infer missing or implied information. This can be a particularly difficult skill to address and greatly affects learning and social success.
- Work with family, friends, and team members to ensure that a consistent approach is used.

## Behaviour

It is important to evaluate and address the specific factors in children with brain injuries and in their environment that underlie any problem behaviours. The following are general suggestions for supporting appropriate behaviours.

**Set the child up for success** with careful planning of task requirements and environment. Try to prevent behaviour problems before they develop.

- Ensure the child is well rested. Fatigue tends to exacerbate problems the child may have.
- Maintain consistent and reasonable expectations. Ensure task requirements are within the child's abilities. Do not over-challenge the child to a point of frustration or excessive fatigue. Provide assistance as needed for success. Monitor the need for added support when the child's routine changes.
- Limit the number of people interacting with the child at one time. Avoid overstimulating or overloading the child. Limit potential choice of activity with peers.
- Review the "rules of behaviour" before beginning an activity and again as needed during the activity. This is particularly important where safety is a concern. Even though the child may be able to recite the rules, the child may need reminders in the moment.
- For some children, it can be helpful to pair them with peers or siblings who model appropriate behaviour. Helping the peers understand their friend's difficulties is important.
- Teach the child to observe what other people are doing in a particular setting for clues about what is acceptable behaviour.
- Teach the child to use compensatory strategies to reduce inappropriate behaviour. For example, teach them to walk away when angry, until they have calmed down.

*For a discussion of cognitive and behavioural/social problems, see Chapter 1.*

**Provide explicit feedback** to the child to help develop more appropriate behaviour and increased self-awareness.

- Provide positive feedback on appropriate behaviour.
- Provide feedback on negative behaviour in a calm, matter-of-fact manner, using brief, simple explanations with redirection towards desired behaviour.
- Role-playing can be useful to teach appropriate behaviour. For some older children, the use of videotape can give helpful feedback on how to improve social interactions with others.
- If the child uses offensive language or acts in a disinhibited manner, quietly redirect the child and suggest how to express feelings or act in a more acceptable way.
- If the child has an outburst, redirect away from the source of frustration—don't dwell on the outburst or on what the child did. To help the child regain self-control, offer an alternative, such as going for a walk. Tell others about the situation so they are also prepared and can modify their activities as needed. It is important to evaluate the specific factors that led to the outburst.
- If the child perseverates (gets stuck) on a thought or activity, alert the child of the repetition and ask him or her to stop. Be specific about the action you are talking about. If the child continues the behaviour, try redirecting back to the desired topic or task. A sudden distraction may also help interrupt perseverative behaviour.
- Work with family, friends, and team members to ensure that a consistent approach is used.

Depending on the individual child's brain injury, self-regulation may be very difficult to achieve. It can be helpful to work with a behavioural psychologist or neuropsychologist to evaluate the specific factors underlying the child's behaviour and to identify appropriate management strategies. Some children benefit from individual counselling to help them deal with the impact of their injury and to develop effective coping strategies.

## Physical Skills

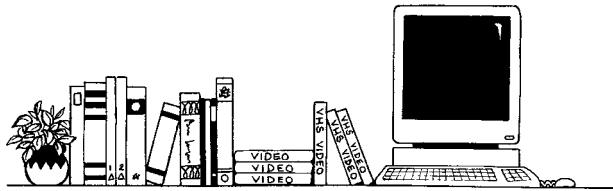
- Provide the appropriate level of supervision and assistance with physical activities, especially in potentially dangerous situations (for example, playground, stairs). Children with a brain injury are often at increased risk for bodily injury because of cognitive impairments such as poor visual-perceptual function, poor judgment of danger, distractibility, and/or slowed response time. This is a concern even if the residual motor impairment is minor.
- The child's readiness to return to contact or competitive sports should be reviewed with the rehabilitation team and physician. Because these children often have impairments in cognitive functioning that affect motor performance, in addition to the motor impairments themselves, it is often recommended that their return to these sports be delayed for one year.
- For many children, it may be helpful to delay the return to activities that involve a lot of skill, that they were previously very good at, or that they are wary of trying (for example, team sports, playing the piano).
- Simplify or change tasks that the child was previously able to do to ensure success. Help find new activities the child can enjoy. Cooperative rather than competitive activities are generally more appropriate. Activities that focus on individual rather than group performance may be less frustrating (for example, swimming, dance, non-contact martial arts).
- Facilitate skill development through functional activities (for example, practice printing while making Christmas cards).
- Demonstrate tasks by standing next to instead of in front of the child. Children with a brain injury often have difficulty transposing movements from left to right, as in a mirror image.
- Hand-over-hand assistance may be needed initially to cue the correct position or movement. Provide hands-on support only when necessary so that the child does not depend on the support to execute the correct movement.
- For simple activities, teach the task as a whole (for example, throwing a ball, standing up from chair). For complex activities, break the task down into a few "natural" steps and teach each step (for example, serving a badminton birdie may be broken down into two steps: drop birdie onto racquet; swing racquet). After all of the individual steps are mastered, teach the whole task (for example, smooth service of badminton birdie).
- Motor learning is enhanced when a child experiences both successful and unsuccessful attempts at movement. As a step to improve skills, ask the child to critique his or her performance after a few attempts (for example, what was good, what could be improved and how).

- For a child with motor planning difficulties who has difficulty using feedback, try to have the child experience successful (error-free) learning and practice.
- Mirrors, photographs, and videotapes may be useful methods of increasing self-awareness about motor abilities. These methods can help show the child how his or her skills have improved and what still needs work.
- Compensate for difficulties by providing the necessary adaptive equipment (for example, the child may need a pencil grip to compensate for poor thumb strength).
- Teach the child new or compensatory strategies when the typical strategy is not effective. For example, teach a child with weakness in one arm to use a non-slip clipboard to stabilize paper during writing tasks. Teach a child with one-sided weakness to dress by putting the weaker limb in the pant leg or sleeve first.
- Work with family, friends, and team members to ensure that a consistent approach is used.



## Additional Reference Materials

### For Professionals



#### Books

Blosser, J.L., & DePompei, R. (1994).

*Pediatric traumatic brain injury: Proactive intervention.* San Diego, CA: Singular Publishing Group.

Burke, W.H., Wesolowski, M., & Blackerby, W.F. III. (Eds.). *The HDI professional series on traumatic brain injury.* Houston, TX: HDI Publishers.

- ◆ *Brain Injury Rehabilitation: An Overview*
- ◆ *Applied Behavior Analysis in Brain Injury Rehab*
- ◆ *Community Living Skill Development: Teaching Methods*
- ◆ *Developing the TBI Rehab Plan*
- ◆ *Adaptive Driving After TBI*
- ◆ *Managing Anger and Aggression*
- ◆ *Managing Attention Deficits*
- ◆ *Management of Memory Disorders*
- ◆ *Developing Social Skills*
- ◆ *Sexuality After TBI*
- ◆ *Developing Motivation*
- ◆ *Brain Injury Rehab with Children and Adolescents*
- ◆ *Accessing Community Resources: Discharge Planning*
- ◆ *Developing Self Control*
- ◆ *Increasing Self Awareness*
- ◆ *Teaching Job Seeking Skills*
- ◆ *Developing Adaptive Work Behaviors*
- ◆ *Supported Employment and TBI*
- ◆ *The Role of the Family in TBI Rehab*
- ◆ *Management of Communication and Language Deficits*

DePompei, R., & Cluett, B. (1998). *All about me.* Wolfeboro, NH: L & A Publishing/Training.

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- Marchese, N., Potoczny-Gray, A., & Savage, R. (1998). *Behavior after brain injury: Changes and challenges*. Wolfeboro, NH: L & A Publishing/Training.
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- Ylvisaker, M. (Ed.). (1998). *Traumatic brain injury rehabilitation: Children and adolescents*. (2nd ed.). Boston, MA: Butterworth-Heinemann.

### Web Sites

[www.waiting.com](http://www.waiting.com)  
[www.tbiguide.com](http://www.tbiguide.com)  
[www.nlm.nih.gov](http://www.nlm.nih.gov)  
[www.neuroskills.com](http://www.neuroskills.com)  
[www.bcbia.org](http://www.bcbia.org)  
[www.biausa.org](http://www.biausa.org)  
[www.neuro.pmr.vcu.edu](http://www.neuro.pmr.vcu.edu)

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