ACQUIRED BRAIN INJURY IRELAND

ON WITH LIFE

PROGRAMME FOR FAMILIES & CARERS

A Guide Book for Carers

A guide for those supporting loved ones with a brain injury.

This project was approved by Government with support from the Dormant Accounts Fund

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Introduction Letter

Dear reader,

Welcome to Acquired Brain Ireland's Carer's Guidebook which you have received as a caregiver to someone living with an Acquired Brain Injury (ABI). We understand that a brain injury doesn't just happen to the individual, it happens to the whole family.

The goal of our Carers Guidebook is to provide families and carers of brain injury survivors with information, guidance and support on your own personal journey. We know that caring for a loved one with a brain injury can be difficult without any help or support. Many family members and friends are thrust into the role of carer without warning.

Living with and caring for someone with a brain injury is a life changing event. We're here to help you understand more about brain injury and the new life you are currently living.

Please know that you are not alone. It is estimated that there are 120,000 people currently living with a brain injury in Ireland today and many are being assisted by someone like you.

Rebuilding lives after a brain injury is a lifelong journey. Part of the rehabilitation process involves learning as much as possible about brain injury. Relationships are essential to an individual's recovery. The involvement and support from family and friends is a key factor in the success of every personalised rehabilitation plan.

Our guidebook is a practical tool to help you understand what you are experiencing and give you practical advice on how to help your loved one as well as looking after yourself.

Yours sincerely,

Barbara O'Connell

About Acquired Brain Injury Ireland

We are expert, we are kind and we rebuild lives. Acquired Brain Injury Ireland is the leading national provider of community-based neuro-rehabilitation services for adults with a brain injury and their families.

A brain injury can affect a person's ability to manage their own life. Through personalised rehabilitation plans, we empower people to regain independence and maximise their potential after their brain injury.

We work in communities across Ireland delivering neuro-rehabilitation through a variety of settings including our residential, transitional living, clubhouse and community rehab services. We support families through our case management and family support services. We also campaign, educate and advocate for the rights and needs of this hidden group in society.

Our Vision

A society where brain injury is understood and all those impacted receive world-class, personalised rehabilitation and support, as and when they need it.

Our Mission

We will passionately serve and relentlessly advocate to empower and support people impacted by brain injury to rebuild their lives.

Thank you to our funders

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Medical Information

You might find it helpful to keep important health-related information readily available.

This book belongs to:

Date of Injury:

Diagnosis:

Health Care Providers:

Name of GP:

Phone/Email:

Name of Hospital:

Name of Consultant:

Name of Other Clinicians:

Phone/Email:

Other Clinicians:

Phone/Email:

ABI Team:

Name:

Phone/Email:

Name:

Phone/Email:

Pharmacy:

Name:

Phone/Email:

Other Important Contacts:

Name:

Phone/Email:

Name:

Phone/Email:

Name:

Phone/Email:

Important Medical Information and Events:

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ACQUIRED BRAIN INJURY IRELAND

Understanding Acquired Brain Injury

The Brain and How it Works

The brain is responsible for everything we do. It controls all movements, sensations, speech, thoughts, and emotions. Surprisingly, for such an important structure, the brain is very soft, almost the consistency of firm gelatin.

The brain (Figure 1) would be easily injured if it was not contained by the skull, the boney covering of the brain. The brain is made up of two halves, the right and left hemispheres. The right hemisphere controls the the left side of the brain and the left hemisphere controls the right side of the brain.

Within the hemisphere are sections called lobes. There are 4 lobes, they work together, yet each has special functions. The cerebellum, the lower part of the brain located in the back of the skull, controls coordination. The brain stem connects the brain and spinal cord and controls basic life-sustaining functions such as heart rate and breathing.

Parts of the Human Brain

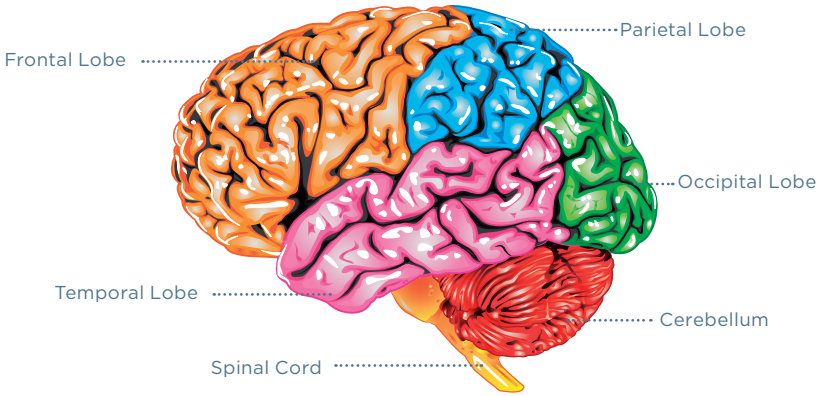


Fig. 1

Acquired Brain Injury

An **acquired brain injury (ABI)** is an injury to the brain that has occurred after birth and is not hereditary, congenital, or degenerative. Causes of an acquired brain injury can be but are not limited to: tumours, blood clots, strokes, seizures or infections.

A type of ABI is a **traumatic brain injury (TBI)**. This is any injury to the brain caused by a blow or jolt to the head or a penetrating head injury that disrupts the normal functioning of the brain. Not all blows or jolts to the head result in a TBI. Common causes of TBI are motor vehicle crashes, falls, or assaults. The injuries are categorised according to severity as mild, moderate, or severe and could be both a closed head injury or open head injury. In most injuries, damage occurs immediately when forces are exerted on the brain.

There is a rich network of nerve cells called neurons, communicating with each other to perform functions. An injury to the connections can interfere with the brain's ability to function as efficiently as it did prior to the injury.

Sometimes bleeding occurs, which results in additional damage to the surrounding brain tissue. In most injuries, the brain responds by swelling. Since the brain is enclosed by the rigid skull, swelling in one area can result in pressure and additional damage to the surrounding areas.

Skull fractures or breaks in the bone surrounding the brain, may occur with or without damage to the underlying brain. The bone itself will heal over time. Additional treatment may be required if there is damage to the brain beneath the fracture.

A **Concussion** is a mild traumatic brain injury, caused by a blow to the head, disrupting or interfering with a person's normal functioning. When a concussion takes place the brain suddenly shifts, shakes or rotates. Concussion is difficult to diagnose, hence clinical and neuropsychological assessment are so important. Concussion can often be presented in its most obvious form, such as passing out or feeling light-headed. Other symptoms can be of a milder format, and so harder to diagnose. These symptoms may be:

- Headache or pressure
- Nausea
- Balance problems or dizziness
- Double or blurry vision
- Sensitivity to light

- Sensitivity to noise
- Feeling sluggish, hazy, foggy or groggy
- Concentration or memory problems
- Confusion
- Does not 'feel right' or is 'feeling down'

Prevention and Observation: Most people with a concussion will recover quickly and fully. However for some people signs and symptoms of concussion can last for days, weeks or longer; emphasising the necessity of observation post-injury.

In a contusion, a part of the brain is bruised and develops small areas of bleeding and swelling that can be seen on tests. People with contusions often complain of headaches, nausea and slow thinking. People with contusions must be watched closely for signs of additional swelling, bleeding, or further injury of the brain.

Sometimes opposite sides of the brain are injured when the brain first strikes one side of the skull during an impact, and bounces back against the opposite side of the skull, for example, when you bang your head upon impact in a car accident. This is called a **coup contrecoup** injury (Figure 3).

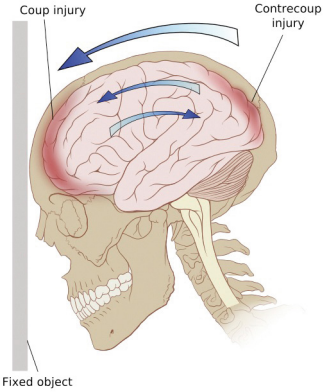


Figure 3

A subdural hematoma is a collection of blood outside the brain. Commonly known as a **brain haemorrhage**. The bleeding and increased pressure on the brain from a subdural haematoma can be life-threatening. Some subdural haematomas stop and resolve spontaneously; others require surgical drainage.

Anoxia and Hypoxia

Anoxia is a condition in which there is an **absence** of oxygen supply to the brain tissue. Hypoxia is a condition in which there is a **decrease** of oxygen to the brain tissue.

Anoxia and hypoxia may be caused by a number of events, such as smoke or carbon monoxide inhalation, high altitude exposure, strangulation, anaesthetic accidents, or poisoning. In severe cases of anoxia and hypoxia, the person is often (in a state of unconsciousness) for periods ranging from hours to days, weeks, or months.

Effects of Acquired Brain Injury

It is hard to predict what changes are likely to occur as a result of an acquired brain injury. Each person is unique. The effects of brain injury are not always apparent. Brain Injury is often called "the silent epidemic" because thousands of people with a brain injury have symptoms that are not generally evident to others.

> *"It is hard to predict what changes are likely to occur as a result of a brain injury. Each person is unique."*

The changes experienced after a brain injury depend on a number of factors including:

- Pre-injury: educational and vocational history, health history, history of alcohol and substance abuse, intellectual ability
- Injury characteristics: severity of the injury, secondary complications
- Available medical and rehabilitation resources
- Emotional reaction to the injury and it's effects
- Family and social support

Common problems associated with injury to the brain may include:

- **Motor:** weakness or paralysis or one side of the body (also known as hemiplegia), poor balance and coordination (or ataxia), less endurance, abnormal muscle tone and stiffness

- **Problems with** hearing, vision, taste, smell, touch, knowing the relationship of the body to fixed objects
- **Difficulty understanding speech** and difficulty in expressing thought (also known as aphasia).
- **Executive functioning:** thinking, reasoning, paying attention, judgment, problem-solving
- **Memory and learning:** problems with short term memory, slower learning, limitations in learning, difficulty with retrieval of long term memory
- **Behavioural:** angry outbursts, inability to control behaviour
- **Emotional changes:** moody, easily frustrated, anxious, impatient, angry, depressed and low self-esteem.

In addition, a person with a brain injury might find changes in basic bodily functions. These include:

- Body temperature
- Level of alertness
- Swallowing
- Bowel and bladder function
- Sleep patterns
- Endurance for physical and metal activities
- Sexual function

Seizures may occur after a brain injury. They may happen immediately or much later. It is difficult to predict if a person will develop seizures, after a brain injury.

Following a brain injury, damage to the optic nerve and other parts of the brain can result in a visual blind spot, partial vision loss, and/or one or more types of visual deficits.

Visual challenges after brain injury can be overlooked early on, as more severe and life-threatening injuries sustained from the brain injury are treated. People with brain injury should undergo a vision evaluation as soon as possible after injury. Even if problems with vision are not perceived, challenges may be present and can have an extensive impact on life and rehabilitation efforts.

Brain Injury Severity

What is a Coma?

When we hear the word "coma" many of us think of a person in a state of complete unawareness. In reality, coma simply means unconsciousness, of which there are varying levels. The injured person may be in a deeply unconscious state where no amount of stimulation will elicit a response. However, in other cases a person who is in a coma may move, make noises or respond to stimulation.

The process of recovery from coma is gradual. The injured person will typically emerge rather than suddenly wake-up from this state, becoming progressively responsive to their environment and eventually regaining full consciousness.

While a person is in a coma, individual members of the medical team may conduct a number of assessments. The Glasgow Coma Scale (GCS) is universally used upon admission to determine the depth of the coma, and periodically thereafter to determine a more accurate duration of coma.

The Scale has 3 categories: 1) Eye Opening; **2)** Best Motor Response; and **3)** Verbal Response. Each of these categories is scored from 1 to 15. The lower the total score on admission, the more severe the injury is assumed to be. The length of time a person remains in a state of coma is considered a reliable indication of the extent of damage that remains causing long-term difficulties.

Glasgow Coma Scale		
Behavior	**Response**	**Score**
Eye opening response	Spontaneously	4
	To Speech	3
	To Pain	2
	No Response	1
Best verbal response	Oriented to time, place and person	5
	Confused	4
	Inappropriate words	3
	Incomprehensible sounds	2
	No Response	1
Best motor response	Obeys commands	6
	Moves to localized pain	5
	Flexion withdrawal from pain	4
	Abnormal flexion (decorticate)	3
	Abnormal extension (decerebrate)	2
	No response	1
Total Score:		
	Best reponse *Comatose client* *Totally unresponsive*	15 8 or less 3

What is Post-Traumatic Amnesia?

Post-traumatic amnesia (PTA) is the period of time following a brain injury when the person appears conscious and awake, but is confused and does not have continuous memory for ongoing events. The person forgets what happened minutes, hours or days before. The person may also be disoriented to person (familiar faces), time (time of day, week, month or year) and place (where do they live).

Post-Traumatic Amnesia and Brain Injury

PTA is assessed in a variety of ways by professionals. During PTA there may be isolated “islands” of memory, when the person appears to be oriented and retaining information, but these are not continuous.

The duration of PTA provides information on the severity of the brain injury and in combination with other measures is used to estimate prognosis. Longer durations of PTA are associated with poorer outcomes and may be linked to the likelihood of emotional and behavioural problems after brain injury.

Loss of Consciousness and Brain Injury

One way to tell if a brain injury is serious is the amount of time someone was unconscious afterwards. If someone was not knocked out at all or if someone lost consciousness for less than 30 minutes, then the injury would most likely be mild in nature. Although someone may have some symptoms, there would probably be little injury to the brain and complete recovery would be expected. Most people who have a brain injury fall into this category. The longer someone is unconscious, the longer the recovery usually takes. If someone was knocked out for more than 30 minutes but less than 24 hours, the injuries would most likely be moderate. Returning to normal would probably take sometime and require rehabilitation.

A person with an ABI who lost consciousness for more than 24 hours have suffered a severe injury. Although many people with an ABI make a full recovery even after a severe head trauma, symptoms can often last for some time. Treatment at a rehabilitation hospital is usually recommended and can help recovery.

Child and Adolescent Brain Injury

When discussing brain injury, especially in children and adolescents, it is useful to first understand brain development.

There are 6 broadly recognised stages of cognitive development:

Birth to 2 years: The sensory-motor Stage
This is the stage where a child learns and experiences very much through touch, feel and exploration.

2 to 7 years: The pre-operational stage
Language goes through a rapid period of growth during this stage. More complex problem-solving skills are beginning to develop.

7 to 11 years: The concrete operational stage
A more logical type of thinking begins at this stage, for example a questioning of Santa and the tooth fairy.

11 to 13 years: The formal operational stage
Abstract thinking increases, for example the ability to understand and complete difficult Maths problems.

14 to 17 years: Adolescence
The focus becomes more about how others perceive them, greater awareness to their development.

18 to 21 years: Late Adolescence to early adulthood
Most cognitive skills are established at this point and an increase maturation of the frontal lobes.

Brain Injury

Brain injury for a child or adolescent poses different challenges and an appreciation for child development. A child's brain continues to grow and develop in a process started from conception through late adolescence. The adult brain is fully developed with critical nerve pathways already established and interconnected. An injury to a young brain affects recovery and ongoing development.

Please remember any information that you read merely summarises injury and recovery. More detailed information should be obtained from your GP or paediatric treatment providers and brain injury resources

Rehabilitation can help towards the healing process by providing stimulation and activities to restore injured skill areas. If the injury is such that areas of the brain cannot perform their typical function, surrounding areas may be recruited through stimulation and practice, to assume some roles of the injured area.

The Effects of Childhood Brain Injury

The effects of a brain injury varies from child to child. This is partly because every brain injury differs in type and severity. In addition, recovery from a brain injury is complex and is affected by many non-injury factors, such as the child's age at the time of the injury, pre-injury functioning and family supports.

The recovery process is complex and health care providers cannot predict the precise outcome for a specific child. Some risk factors are known to increase the likelihood of certain types of outcomes. For example, more severe brain injury is associated with greater likelihood of impairment.

Given that the child's brain is developing over a number of years, it is important to appreciate that needs and challenges may change over time. This calls for a higher degree of diligence in monitoring the effects and readiness of a brain injury in order to adapt the environment to meet a change in needs that may emerge. Things may appear fine until the child hits a milestone. Parents can often forget an accident that happened years before and not link the behavior and accident.

Stages of Adjustment for Families (family can move in and out between these stages)	
Stage I:	The shock of the injury dominates. Hopes for full recovery. Repressed feeling and denial of severity.
Stage II:	Recognition of the severity of the injury. Helplessness and frustration.
Stage III:	Start to get annoyed with individual. Family expects full independence. Still comparing 'before & after' realities. Start to recognise the reality of impairments. Start information seeking about brain injury.
Stage IV:	Realism of situation sets in. Family begins to get exhausted. Reduction of time with loved one. Bereavement-like emotions and stages occurring.
Stage V:	Profound sadness. Families grieve and can experience guilt with grieving. Mourn the loss of loved one's personality. This can occur as disenfranchised grief (unacknowledged by society) and/or ambiguous loss (no resolution, finality, ritual or clarity).
Stage VI:	Greater understanding of the situation. Understand the person may never be the same. Begins to accept loved one's condition. Can now address needs of the entire family unit.

Children with brain Injury – The Challenges

One of the biggest challenges facing an individual following a brain injury is learning to accept new abilities and realities, no matter how altered they may seem.

This conflict between the "old vs. new" self is especially problematic for the older children and adolescents who may have had a clear image of who they were before the brain injury. This issue is less noticeable for children who experience their injuries at an early age, since they have less awareness of themselves prior to the brain injury.

- Difficulty accepting changes is self relative to peers – A related challenge for a child is accepting changes that make them feel different to their peers. For example, speech.
- Cognitive changes viewed as differentiating the child from peers include memory problems (forgetting conversation topics or names), learning difficulties (having special education services or being slower in learning) and processing speed (trouble keeping up with conversations)
- Anger control and emotional lability – Emotional lability refers to rapid, volatile shifts in mood with more intense reactions than expected. Anger control issues often occur when a child is less able to tolerate frustration, reason about situations, and the ability to moderate their emotional and behavioural reaction.

Sexual Self and Being

After a brain injury, teenagers may feel more self-conscious and vulnerable to the influence of others. Their ability to read social cues and make important social judgments may be affected by brain injury. Parents need to develop effective communication with their teens to foster discussion about good decisions. Parents need to also ensure that teens are knowledgeable about pregnancy and sexually transmitted diseases.

Emotions and Behaviours

A brain injury may cause changes in cognitive functioning, and these issues often trigger inappropriate behaviour typically related to:

- Overstimulation
- Fatigue
- Unexpected Changes, for example a change in plans or schedule.

Interactions with peers, family members and others are often affected by a brain injury. Children with brain injury might display the following behaviours:

- Decreased Social Skills: taking turns in groups and staying on topic
- Decreased Awareness of Social Cues
- Being distracted in Noisy Surroundings
- Bossy and Argumentative
- Poor Responsibility and Dependency
- Inappropriate Sexual Behaviour and/or language
- Suggestibility: A child with a brain injury might be more easily led or influenced by peers.

Parents and Guardians as Advocates

In *What Psychotherapists Should Know About Disability*, Rhoda Olkin writes, "With the predominant focus on negative attitudes toward disability there is less understanding of positive, caring, loving, intimate relationships between an able-bodied person and person with a disability."

Parents and guardians need to be advocates for their child who have experienced a brain injury and provide watchful attention and intervention. From recovery and beyond, parents will need to monitor their child's needs in all areas of life and well-being: physically, socially, emotionally, and academically.

However, it is vital that parents also work with their child to help them learn to speak out regarding their own needs. Parents are vital in helping their child interpret the injury event and its impact and helping their child integrate the experience into his or her life in a way that fosters self-worth and growth. As the child moves through adolescence into adulthood, parents are encouraged to teach their child to become independent as a self-advocate.

With the help of family and the larger rehabilitation community the young person will become adept, identifying and using accommodations and resources to work toward reaching short and long term goals.

Brain Injury and the Aging Brain

The transition into late adulthood is accompanied by a number of physical, psychological and social changes. In addition to offering opportunities for personal growth and life enrichment, advancing age is also associated with diminished sensory functioning including problems with hearing. It is also linked with the onset of vision and chronic medical conditions like diabetes, heart disease and orthopaedic conditions such as arthritis.

Adults age 65 and older are also at increased risk for experiencing a brain injury. Older adults striking their head on the ground or some other hard object following a fall, is the leading cause for these injuries. In addition to the sensory deficits and chronic medical conditions that are common with age, medication side effects may also compromise the physical functioning of older adults and contribute to the increased risk for falls and brain injury.

While a brain injury can happen at any age and in a number of ways, it is known that older adults are confronted with unique challenges following a brain injury. For example, older adults have been found to experience an increased incidence of posttraumatic infection and seizures, subdural haematomas (bleeding in the subdural space) and delayed neurosurgical complications following moderate to severe brain injury.

> *"Try to accept the person with the brain injury as they are today. They may, in fact, be much more content than us."*
>
> Anna Maria, Killarney

Common Outcomes of Brain Injury

A brain injury can impact any aspect of a person's being, including their cognitive and emotional functioning, personality and behavior. The vulnerability of certain areas of the brain following a brain injury often contribute to a multitude of symptoms that includes deficits in attention, speed of processing and behavioural responding, learning, expressive and receptive language functioning, memory and problem-solving abilities.

Depression, anxiety, irritability, impulsivity and sudden bursts of crying for no reason are also relatively common among older adults with a history of brain injury. When compared to younger survivors of brain injury, older adults with a history of brain injury may be at an increased risk for the delayed onset of depression and anxiety.

Distinguishing brain injury related cognitive impairments from the effects of other medical conditions common in older adults may be difficult. For example, hypertension has been associated with general cognitive dysfunction, including memory impairment.

Cardiovascular disease can compromise speed of processing, attention expressive language and memory. Congestive heart failure can contribute to a significant decline in cognitive functioning, including impaired attention.

Deficits in cognitive processing speed and memory are common in elderly survivors of stroke. While brain injury related cognitive deficits would be expected to improve as recovery progresses, impairments related to other medical conditions may not respond to rehabilitation interventions.

Also, some adults who incur a brain injury have a history of cognitive difficulties that were not recognised prior to their brain injury. However, following their brain injury, these preexisting cognitive deficits may be intensified.

Tips For Carers

- Encouraging and assisting a person who has had a brain injury to focus on a single task at a time and avoid "multi-tasking" when possible may promote cognitive efficiency by minimising demands on divided attention.
- Allowing a person with a brain injury appropriate time to process information and express thoughts may alleviate frustration and ensure that their needs are identified. Encouraging the use of memory strategies and cognitive aids such as a daily organiser and prioritising checklists may promote their level of independence.
- Challenges in social skills and decreased social activity are also common following brain injury. Try to encourage "small group" social settings as opposed to large family events or parties.
- Assessment and treatment of psychiatric conditions (such as depression and anxiety) are a primary concern following brain injury. A psychological evaluation by a qualified health professional who is familiar with brain injury is important to clarify the emotional well-being of a person who has sustained a brain injury.
- Having a brain injury increases the risk of future brain injury. Take measures to address sensory challenges (through hearing aids and glasses) and health conditions (such as High Blood Pressure), evaluating the necessity and side effects of medications and promoting improved physical and emotional well-being, should be initiated to minimise the risk of a future brain injury.

Tips: Messages a Person with an Acquired Brain Injury Need You to Know

Time and Rest
I need extra time to rest than I used to. I'm not being lazy. I not only get physically tired, but I get "brain tired." It is very difficult and tiring for my brain to think, process and organize. Tiredness makes it even harder to think.

My Stamina
My Endurance changes at times. Even though I may look good or "all better" on the outside. Some days are better than others.

My Brain Injury Rehabilitation
Brain injury rehabilitation takes a very long time. Rehabilitation can take years, it continues long after formal rehabilitation has ended. Please know that I can't be the person I used to be, even if I look like it.

Overstimulating for Me
I am not being difficult if I don't like social situations. Crowds, confusion and loud sounds quickly overload my brain, I can't always filter sounds like I used to. Smaller groups are better for me.

Please Be Patient
If there is more than one person talking I may seem uninterested. I have trouble following when there are several people talking, it can be exhausting for me to try to follow. I'm not dumb or rude, my brain can get overloaded.

I Need a Break
If we are talking and I tell you that I need to stop, I need to stop NOW! I am not avoiding you, I actually need to take a break from all of the thinking and processing. I promise I will be able to rejoin the conversation later and take up the topic.

I'm Not Myself
Try to notice the circumstances if a behaviour problem arises which is out of character for you or you are not yourself. Behaviour problems are often signs of my difficulty coping with an issue to a situation. It could be a number of things, I'm tired, confused, in pain, possibly the noise level.

Brain Injury and the Family

A brain injury can affect the whole family, while it's important to note family members play a vital role in the rehabilitation process, every family is unique and has different ways, such as:

- Ways of communicating
- Traditions/rituals
- Resources
- History
- Coping strategies
- Cultural backgrounds

There are many changes a neurological condition can bring to the family unit:

- Role Changes
- Practical Changes (mobility, finance)
- Life cycle changes
- Idea of an 'altered future'
- Prolonged care giving
- Social Isolation
- Relationship changes

These changes are uninvited and often unwelcome. Psychologically, families may feel:

- Bewilderment
- Frustration
- Guilt
- Fear
- Depression

> *"A brain injury doesn't happen just to the person, it happens to the whole family."*
>
> Acquired Brain Injury Ireland
> Family Carer

Caring For The Carer

Carer's Emotional Health

During this challenging time of increased responsibility, decreased time available and competing demands, emotional health and wellbeing is what allows you to cope and deal with life's situations. Most of us take emotional and mental health for granted and only focus on it when problems occur. But like physical health, it requires attention to build and maintain.

A carer's emotional health is very important. Chronic stress that doesn't go away can lead to health problems. There are many different tools that can help you achieve balance in your life, with time to relax, enjoy relationships, work and have fun.

First, ask yourself, 'Am I stressed?' Learn to recognise signs of stress:

- Tiredness
- Irritability
- Sadness
- Avoidance
- Over eating

Most of us have particular telltale signs that we are feeling under pressure or we are beginning to get stressed. Make sure you:

- Check in with yourself
- Learn your personal tell tale signs

Secondly, ask yourself, 'Why Am I Stressed?' Try to identify what in particular is causing your current stress levels, for example:

- You have too much to do
- Family disagreements
- Feelings of inadequacy
- Feeling unsupported

Be honest with yourself. Then identify what you can and cannot change.

Remember, we can only change ourselves; we cannot change another person.

Remember, we can only change ourselves; we cannot change another person.

Tips for Caring for Yourself

Problem Solving

Ask yourself:

- "What can I do about it?"
- Make a list of possible solutions
  - Choose one option
- Set a goal:
  - Small and manageable
  - Give yourself a timeframe
  - Break down bigger goals into smaller more attainable pieces
- Try it Out
- Ask yourself, 'Did it Work?'
- If necessary try something else

Requesting and Accepting Help

Sometimes we need help in certain situations, but we set up barriers that stop us from asking:

- Pride
- Avoiding burdening others
- Protecting the person with an ABI
- I will do it the best
- Sense of duty and responsibility
- Embarrassed or ashamed about not coping

What we need to do:

- Asking for help is natural. It is a sign of maturity and reflects personal strength
- Ask for exactly what you need
- Divide tasks down – lighten the load
- Consider who is ideal to help – fit the task with the person
- Build and widen your circles of support
- The answer 'no' may only mean – not now.
- Be clear and specific. Don't hint or hope the person will guess what you need, They can not read your mind!
- Return the favour when you can

Share

It's ok, to talk about your situation with someone.

- Choose someone you trust
- Be honest
- Talk to a professional
- Talk about other things with others. It's also ok to talk about something other than brain injury or your loved one
- See friends and extended family members as often as possible – keep up the pattern of social interaction
- **DON'T FORGET TO LAUGH**

Remember Yourself

Always remember that you have needs as well. Don't forget that you are an important person; you are every little bit as important as the person with the brain injury. Remember:

- You are human
  - You are not perfect
  - You have limitations
- Do something for yourself everyday
- Treat yourself every now and again

Most Importantly:

- There is no perfect way to deal with any situation
- Be forgiving of yourself
- Above all be gentle to yourself

Relaxation Techniques for the Carer

Breathing Exercises

Breathing deeply is a quick way to relax. You can do it almost any place and time you need to relieve stress. Deep breathing helps maintain a sense of calm and is part of almost all relaxation and meditation techniques. The key is to breathe deeply from your abdomen, rather than shallowly from your lungs and get as much fresh air and oxygen into your lungs as possible.

Instructions

1. Sit or lie down in a comfortable position
2. Put one hand on your stomach (and the other on your chest if possible)
3. Feel your breathing for a short time, noticing the rise and fall of your stomach
4. Breathe in (inhale) deeply through your nose. As you breathe in, the hand on your stomach should rise (and the one on your chest should move very little)
5. Breathe out (exhale) through your mouth – push out as much air as you can and feel your stomach tighten as it flattens. Again the hand on your stomach should move (your chest shouldn't move much)
6. Be sure that you empty out all the air and then pause
7. Try to inhale to the count of 10 and then exhale to the count 10 – this helps to slow your breathing
8. Repeat this breathing for several minutes. If you are lying down, you can put a small book on your stomach and try to breathe so it rises as you inhale and falls when you exhale

Muscle Relaxation

Muscle relaxation techniques are easy to do. Combining muscle relaxation with deep breathing can be even more effective in relieving stress. Some studies have shown that people find muscle relaxation useful for helping them to fall asleep.

Instructions

1. Lie down in a comfortable position with your arms slightly out to the side and legs straight.
2. Concentrating on each body part, one at a time, you will tense your muscles as tight as you can, hold them for 10 seconds, then release and completely relax
3. Start with your head and face – you'll move down through your body to your feet and toes:
   - Raise your eyebrows as high as you can and hold for 10 seconds and then release
   - Smile as wide and hard as you can, hold for 10 seconds and then release
   - Touch your chin to your chest, hold and then release
   - Raise your shoulders as high as you can, hold and then release
   - Force your arms straight making them unbendable, hold and then release
   - Make fists, hold and then release
   - Tighten your stomach, hold and release
   - Force your legs straight, hold and then release
   - Bend your ankles, pointing your toes at your knees, hold and then release
   - Curl your toes, hold and then release
4. After relaxing each body part, notice how heavy each part feels when it is totally relaxed
5. When completed, continue performing the deep breathing

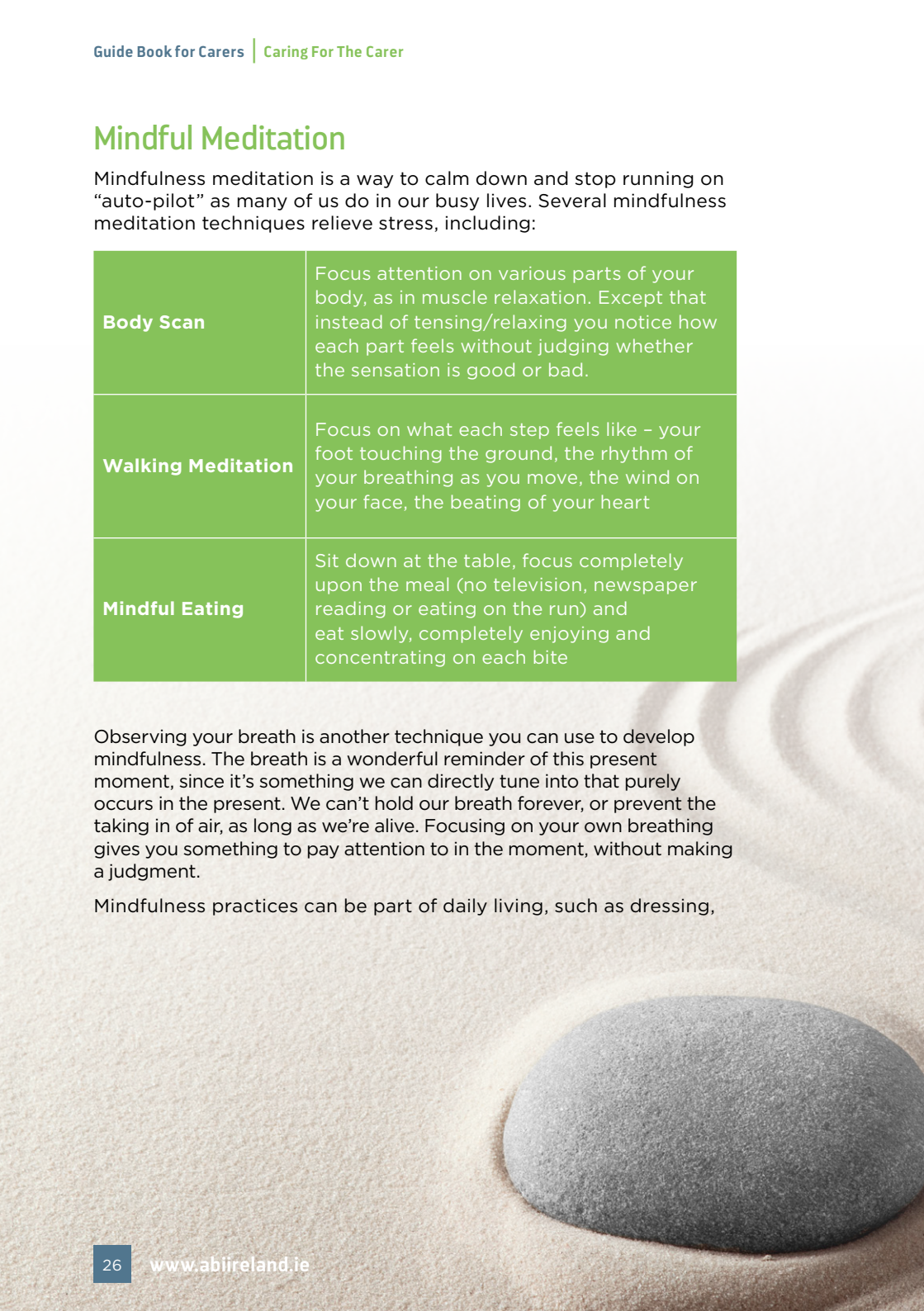
Mindful Meditation

Mindfulness meditation is a way to calm down and stop running on "auto-pilot" as many of us do in our busy lives. Several mindfulness meditation techniques relieve stress, including:

Body Scan	Focus attention on various parts of your body, as in muscle relaxation. Except that instead of tensing/relaxing you notice how each part feels without judging whether the sensation is good or bad.
Walking Meditation	Focus on what each step feels like – your foot touching the ground, the rhythm of your breathing as you move, the wind on your face, the beating of your heart
Mindful Eating	Sit down at the table, focus completely upon the meal (no television, newspaper reading or eating on the run) and eat slowly, completely enjoying and concentrating on each bite

Observing your breath is another technique you can use to develop mindfulness. The breath is a wonderful reminder of this present moment, since it's something we can directly tune into that purely occurs in the present. We can't hold our breath forever, or prevent the taking in of air, as long as we're alive. Focusing on your own breathing gives you something to pay attention to in the moment, without making a judgment.

Mindfulness practices can be part of daily living, such as dressing,



walking and brushing teeth. Setting aside a few minutes each day will build and stabilise mindfulness. Over time, the benefits gained from mindfulness are: a clearer mind and less stressed body, a greater sense of pleasure in ordinary things and fuller appreciation of life.

You might think that meditation sounds like day dreaming, but that's not the case. If you try it, you'll see that maintaining your concentration and bringing your mind back to the present when it starts to drift off takes effort. You'll get better at it over time. Practised regularly, it actually changes the brain. The areas involved in joy and relaxation strengthen, while those involved in negativity and stress weaken.

As you try to focus the mind and pay attention, you'll be amazed to see how your mind jumps and wanders around planning, dreaming and remembering. Over time, with repeated practice, the mind begins to settle down. Learning to recogise when the mind is wandering is considered a breakthrough in changing the old pattern of automatic pilot – if you can see that your mind is somewhere far away, you can bring your attention back to the present.

Keeping a Diary

Writing down personal experiences, thoughts and feelings. It often provides an emotional release and leads to valuable insights, whether in the moment or after reflection and review. Sometimes keeping a diary just chronicles daily activities and values. It may even evolve into a personal memoir.

Why Writing in a Diary is Beneficial
Keeping a diary is a powerful form of writing down your personal thoughts and feelings without anybody ever needing to know. Perfect spelling, grammar or artistic skills aren't necessary. It can be handwritten on paper or typed on a computer. It can be like a scrapbook as well, with photos and notes from others.

Keeping a diary offers a flexible, low-cost, creative way to help cope with the worries, concerns, questions, challenges and feelings of isolation that may come with being a Carer for a person with an ABI.

Just taking the time to write down your thoughts can give you a break from the demands of your carer responsibilities. In turn, these positive benefits may be passed along to the person you are caring for. Self-discovery and solutions to challenging issues occur when maintaining a diary, reviewing entries and reflecting on them. Practical plans may even be put into place as a result of journal notes.

Getting Started Using Prompts
It's quite easy to start a diary. One way is to start to get feelings or thoughts flowing, something as simple as:

- "I feel..."
- "Today I want..."
- "I love you, but..."
- "If I am honest with myself, I am..."

On With Life Support Groups

On With Life is open to family members and friends caring for a loved one with a brain injury. To find out more, see **www.abiireland.ie**

Emergency Plan

Who will provide care in an emergency? It's not possible to prevent every illness, even if you are paying close attention to your health. A Carer's illness impacts both the Carer and the person with an ABI. Plan in case you get sick. This provides peace of mind and assures the person's ongoing care.

Supportive relationships are especially important in a time of emergency. The quality and close connection of social supports is more important than having lots of individuals involved. Staying in routine touch with supportive friends and family via quick notes or calls fosters a healthy connection.

Contact and Carer Information

It's a good idea to keep all contact information – names, phone numbers, email and/or home addresses – for family and friends up-to-date and easily available. Having this information on display at home makes it possible for someone else to make calls if you cannot. A special list can identify people who have agreed to step in for caring support, if you, the Carer, fall ill.

It is best to keep crucial carer information up-to-date and accessible:

- In-home diary's
- Medical contacts and appointments
- Medication lists

- Every-day activities information
- Nutritional requirements including allergies
- Other important information about the person with an ABI

Anyone stepping in as a Carer will want to know these details. The person's Rehabilitation Team also needs to have up-to-date information. You may want to consider keeping vital information on your mobile phone and mobile devices.

Helping Children to Cope

As you are learning to adjust in the Carer role, the children are also in a state of transition. In this section we will discuss:

- Why it is important to consider the needs of the children, the effects an ABI has on the injured person's children and parenting after the person returns home.
- We'll also discuss tips for communicating with the children about the changes in the person and at home and ways to help children cope with their feelings.

Remember:

- Spending one to one time (special time) with a child, it can strengthen the relationship between parent and child.
- Balance your stress. Sometimes during stressful times we may not recognise that our children may not be getting enough attention.
- Adjustment Period: The children need time to adjust to the new situation, so allow them that time.

Challenges Children and Families Face

When communicating with your child it is important to be aware of the many challenges they face. Often there is a shift in attention from them to the person with an ABI at home and they don't fully understand. Outside of the home, they recognise that their peers are not going through the same changes and they may have no one with whom they can identify.

Furthermore, children may misunderstand the nature of the changes in the person. For example, it may be difficult for them to understand that a change in their personality or interests is related to the physical injury. Or they may misunderstand the nature of the injury itself.

Changing schedules and lack of familiar routines can also leave children feeling disoriented and lost. Every child has different needs and different ways of coping.

Children's Emotions

Over time, the condition and abilities of the person with an ABI may change and the child's level of understanding will also change, so ongoing attention to communication is important. You can help your child understand that it's normal to feel the full range of emotions – sad, angry, fearful, dismissive and happy.

Children often experience conflicting emotions. Although happy to

have their parent or sibling back home, children can resent losing the attention they were used to having and have difficulty dealing with so much, go to the person with the ABI. At the same time they experience guilt at feeling resentment and ambivalence.

They may be upset that the life they know has been disrupted and may experience depression, anxiety or fearfulness.

They also may feel embarrassed if their parent looks or acts differently from others. Depending on their understanding of the circumstances, they may feel a desire to take revenge on someone for hurting "my Mummy or my Daddy". They may even feel they don't have a right to be happy if mummy or daddy doesn't seem happy.

Communicating with Children

It's natural to want to shield children from unpleasant information, but doing that often backfires. Even babies pick up on emotional changes in the family. Children sense something bad has happened and become worried or frightened if they don't know what it is. Children often imagine that it's worse than it is. Here are some suggested approaches:

- Talk to your child about the situation as soon as possible. Do it when you feel calm enough and you won't be interrupted.
- Whatever your child's age, sit together and talk at eye level – if you are calm your child will be better able to take in what you say. Use language your child can understand – don't provide details to a child who isn't ready to hear them yet. Take cues from your child – the questions asked, the topics brought up, to know the right time and how much to share.
- Use props for young children – five year olds, for example, may find it helpful if you use a doll or puppet to show where the person is injured.
- Tell your child what's being done for the injured parent – it's important for a child to know that the person is getting the best of care.
- Reassure your children that you are safe and they will be cared for and kept safe.
- Give your children opportunities to have fun.
- Let your child's school know what is happening at home so they may also help you to recognise when the child needs support.

Helping Your Children Respond to Others

If your children are of young school-age (pre 10), friends, family and neighbours may continue to ask how the person with an ABI-their parent- is doing. Families often find it helpful to have a response ready – something brief, clear and easily repeated when needed. For example:

> *"My mum had an accident. She was in the hospital for six months and now she's in the NRH. We just moved into this neighbourhood and I'm getting used to a new school and making new friends. I'm playing hurling, as well."*

Parents can help children tell the caring adults in their lives- teachers, coaches, neighbours – what they need to know about the family injury.

Recognising for Signs of Depression

The moods of adolescents and teens typically are like the wind. They can be pleasantly breezy and calm and then suddenly whip into a howling rage. Aside from the teen moodiness, serious depression is a real possibility. Parents can help children through depression by looking for these symptoms and providing them with professional help:

- Change in sleeping patterns
- Change in eating habits
- Acting out behavior, especially in the form of aggression
- Withdrawal/isolation – reluctance to go out with friends
- Lack of joy in doing things
- Moodiness
- Too much television/computer use
- Decline in school performance

Communicating with Adolescents

Adolescents can be challenging throughout the recovery process. Between the ages of 9 and 12, children are most concerned with peers and fitting in. They compare their family to others. Some adolescents are willing and able to help; others need more prompting. Here is some sample language for this age group:

"Daddy had a brain injury after a car accident. It caused changes to the way his brain works. He needs a lot of rehabilitation to learn how to do things again. He has trouble with his feelings sometimes. It isn't about you. It's hard to be patient and understanding. I know you get angry and frustrated, too. We need to keep talking about it."

"Mammy is getting rehab so she can do all the things she used to be able to do. I'm sure you get frustrated sometimes when she needs help with something quite simple. It would be great if she didn't have this problem, but we all need to work together to get things done around here. I appreciate your help and when you're done helping, maybe you'd like to have a friend over."

Communicating with Teens

Normal development for teens is to become increasingly independent, but now they're pulled back into the family. Although intellectually capable of understanding the details of the injury and family situation, they're not ready to be a "substitute" adult. They can become irritable and "act out" – take risks such as drinking, drugs, or driving recklessly. Staying in communication is really important. Here are two examples of what to say to a teen:

"You know that Dad has an ABI due to his stroke. He gets cranky and moody when he is tired. I know sometimes you're the recipient of his frustration and that he takes it out on you because of your pink hair. Try to understand that he loves you and is doing the best he can to cope. And he doesn't love you any less – it's just hard."

"Mum's injury gets her in a bad way sometimes. I'm sure it's no fun to come home to a moody parent who hasn't gotten out of bed all day and that you are embarrassed that the house isn't always kept up. But, she's getting help though Acquired Brain Injury Ireland and on good days things are pretty much back to normal. It's hard to be patient, but we all need to hang in there together to get this to work for all of us. I worry about you and wonder if you are getting depressed? Would you like to talk with a therapist about the stress you're under because of all of this?"

"*Finding My Way: A Teen's Guide to Living with a Parent Who Has Experienced Trauma*", by Dr. Michele Sherman and DeAnne Sherman is a helpful book for teenagers.

Glossary of Terms

Acquired Brain Injury (ABI)
An injury to the brain occurring after birth that is not hereditary, congenital or degenerative; does not refer to brain injuries induced by birth trauma.

Advocacy
Assist, support and represent the person and promote the best interest of his/her health, welfare and well-being.

Amygdala
Close to the hippocampus, the amygdala is a "fight or flight" structure closely tied with emotional memories.

Anoxia
Stop in oxygen getting to the brain.

Aphasia
Difficulty in understanding and expression of spoken or written language.

Apraxia
Impaired planning of muscle movements.

Ataxia
Impaired coordination of movements.

Atrophy
Partial or complete wasting of a part of the body.

Axon
A long, slim "wire" in the neuron that transmits signals from one cell body to another via junctions known as synapses.

Basal Ganglia
Four nerve cell clusters of the basal ganglia or "nerve knots" help handle physical movements by relaying information from the cerebral cortex to the brainstem and cerebellum.

Brain Stem
Located at the top of the spinal column, the brain stem relays information in and out of the brain. It is like the "point person" for all incoming and outgoing information and basic life functions. The brainstem contains many of the centres for the senses of hearing, touch, taste, and balance. It does not affect sight and smell.

Cerebellum
Located in the lower back section of the brain, the cerebellum is the "movement" part of the brain that coordinates, modulate and stores all body movement.

Closed Head Injury
Skull is intact after an injury to the head

Cognition
Conscious process of knowing or being aware of thoughts or perceptions, including understanding and reasoning.

Community Skills
Abilities that enable someone to live and function safely in the community.

Cortex
"Thinking" part of the brain.

Coup-contrecoup
Effect where injury can occur to the brain at the site of impact as well as on the opposite side. The head stops abruptly and the brain collides with the inside of the skull

Diffuse Head Injury, is the most common and devastating type of brain injury, meaning the injury occurs over a widespread area for example a concussion. This injury may be mild to severe. It may cause various difficulties with memory, processing speed, attention and reasoning.

Empathy
Ability to identify with and understand another person's feelings or difficulties.

Focal Injury, is an injury that is a result of a direct mechanical force, for example a gun shot or a penetrating would to the head. This injury affects a specific area of the brain. The difficulties from a focal injury are often more specific and may affect one area such as language or perceptions.

Frontal Lobes
The frontal lobes of the brain can be divided into a narrow motor "strip" which curves over the top of the head like a hairband and the prefrontal cortex, which are the much larger parts of the frontal lobes, anterior to the motor strip.

Haematomas
Collection of blood trapped in the tissues of the skin or in an organ.

Hemiparesis
Weakness of one side of the body

Hemiplegia
Paralysis of one side of the body

Hippocampus
A paired-organ, one on each side of the brain, sitting within the temporal lobes, "between your ears" so to speak. Most commonly associated with memory functioning.

Hypertension
Elevated blood pressure exceeding 140/90 mm Hg.

Hypothalamus
Control centre for hunger, thirst, sexual response, endocrine levels and temperature regulation. Also involved in many complex responses like anger, tiredness, memory and calmness. Serves as the "conductor" of a person's emotional orchestra.

Hypoxia
Decreased amount of oxygen getting to the brain.

Integration
Based on the expectation that people fit in, be alike and reach for similar standards.

Medulla
First area in the lower part of the brain stem which is involved in many basic living functions. It contains reflex centres which control many involuntary functions such as breathing, heart rate, blood pressure, swallowing, vomiting and sneezing.

Memory Problems
Considered the most disabling consequences the most disabling consequence of brain injury, impaired memory affects a person's ability to learn, retain, and use new information and may significantly affect a person's ability to live independently.

Meninges
Three membranes that cover the brain, containing the Dura mater, Arachnoid and Pia mater layers.

NeuroRehabilitation
Is a complex medical process which aims to aid recovery from a nervous system injury, and to minimize and/or compensate for any functional alterations resulting from it.

Neurons
Billions and billions of tiny brain cells making up the nervous system which are the "communicators". Each neuron has a cell body, axon and dendrites.

Occipital lobes
The primary visual centre which is located as far away from the eyes as possible in the back of the skull.

Open Head Injury
Skull is broken and the brain is exposed after an injury to the head.

Parietal Lobes
The parietal lobes sit behind the frontal lobes where we find the primary sensory strip poised like a hairband, posterior to the motor strip. The parietal lobes respond to sensory information such as touch, heat, pain, and are responsible for one's sense of body awareness.

Partial Seizures
Arise from disturbances in specific, localized areas of one hemisphere of the brain; sub classified as simple partial or complex partial seizures.

Pia mater
One of the membranes that covers the brain. It consists of tender matter which moulds around every tiny crook and crevice on the brain's surface.

Pons
Bridge of nerve fibres, just above the medulla, that connect the cerebral cortex and cerebellum.

Prefrontal Cortex
Located at the very front part of the frontal lobes (right over one's eyebrows), the prefrontal cortex contains many of the neurons we associate with the broad spectrum of human behavior.

Seizures
Abnormal disorderly discharge of electrical activity in the nerve cells of the brain.

Simple Partial Seizures
Simple partial seizures (a type of focal seizure) have no alteration or loss of consciousness. Abnormal, localized electrical activity in the motor area of the brain may result in motor symptoms such as stiffening or jerking of muscles (e.g. face, hand, side of mouth, finger, foot)

Spasticity
Involuntary increase in muscle tone (tension) that causes the muscle to resist being stretched.

Subdural Haematomas
Bleeding into the space between the dura matar and the arachnoid layers of the meninges.

Tardive Dyskinesia
Side effect of antipsychotic medications resulting in involuntary movement disorder characterized by lip smacking, rhythmic darting of the tongue, chewing movements, aimless movements of the arms and legs and in severe cases, difficulty breathing and swallowing.

Temporal Lobes
Rest on both sides of the brain and are the centres for language, hearing, and may be where memories are permanently stored.

Thalamus
Sits on the very top of the brain stem just beneath the cortex. Acts as a major relay station for incoming and outgoing sensory information. Each sense (except smell) relays its impulses through the thalamus.

Tonic
Excessive muscle tension/contraction.

Tonic-clonic Seizures
Formerly known as grand mal, there is an abrupt loss of consciousness. Body stiffens in tonic contraction at onset. Person may cry out, drop unconscious to the ground, roll up eyes or turn to the side and bite tongue.

Traumatic Brain Injury (TBI)
An alteration in brain function, or other evidence of brain pathology, caused by an external force.

Contact our services

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Area Office 1:

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Area Office 2K:

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Acquired Brain Injury Resources

Acquired Brain Injury Ireland
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Email: hello@abiireland.ie
Website: www.abiireland.ie

National Rehabilitation Hospital
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Telephone: 01 235 5000
Website: www.nrh.ie

Epilepsy Ireland
Head office
249 Crumlin Road
Crumlin, Dublin 12
Telephone: 01 455 7500
Email: info@epilepsy.ie
Website: www.epilepsy.ie

Family Carers Ireland
Market Square,
Tullamore,
Co Offaly, Ireland,
24/7 Careline on 1800 240724.
Email: careline@familycarers.ie
Website: www.familycarers.ie

Headway Ireland
Blackhall Green,
Off Blackhall Place,
Dublin 7.
Telephone: 01 604 0800
Helpline 1800 400478
Website: www.headway.ie

Irish Heart Foundation,
17-19 Rathmines Road Lower
Dublin
Telephone: 01 668 5001
Email: info@irishheart.ie
Website: www.irishheart.ie
www.stroke.ie

National Advocacy Service for People with Disabilities
National Office,
C/O Citizens Information Board
George's Quay House
43 Townsend Street
Dublin 2
Telephone: 0761 07 3000
Email: info@advocacy.ie
Website: www.advocacy.ie

National Council for the Blind Ireland
Head Office
Whitworth Road
Drumcondra
Dublin 9
Telephone: 01 830 7033
Website: www.ncbi.ie

Useful Websites:

Citizens Information Board
www.citizensinformation.ie

Education & Science
www.education.ie

Health Service Executive
www.hse.ie

Irish Wheelchair Association
www.iwa.ie

National Learning Network
www.rehab.ie/national-learning-network/

National counselling organisation
www.iacp.ie

National Society of Chartered Physiotherapists
www.iscp.ie

National Speech and Language Therapy organisation
www.iaslt.ie

National Occupational Therapy organisation
www.aoti.ie

National Epilepsy
www.epilepsy.ie

National Diabetes
www.diabetes.ie

Social & Family Affairs
www.welfare.ie

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Notes

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