



Brain Injury Family Training #1

**For family members of adults who
have recently experienced brain
injuries and reside in Maine**

Prepared by the
Muskie School of Public Service



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Introduction

This training is intended for family members and loved ones of adults who have recently experienced brain injuries and reside in Maine.

Topics covered include:

- Brain injury basics
- Hospitalization and rehabilitation
- Preparing for a survivor's return home
- Supports and resources in Maine
- The role of the family in rehabilitation and recovery

This training is organized so you can go through it at your own pace and begin with whatever topic or section is most important to you.

Section 1: Understanding brain injury

Section 2: Hospitalization

Section 3: Rehabilitation

Section 4: Preparing for a survivor's return home

Section 5: Supports and resources for family members

Section 6: Supports, resources, and services for survivors

Section 1: Understanding Brain Injury

Background:

The human brain performs an amazing number of tasks. Our brains make us aware of ourselves and our environments. Brains process sensory information (sights, scents, sounds) and control our motor function as well as our breathing, blood pressure, body temperature, and heart rates.

Every thought, feeling, or memory begins in our brain. Our brains help us construct identities and communicate who we are.

When the brain is injured or damaged, the effect can be devastating. A brain injury may impact many areas of functioning and very often changes the way a survivor sees and thinks about him or herself.

While there are many different types of brain injuries and many different outcomes, for most survivors and family members life is not the same after a brain injury.

In this section, we will describe different types of brain injuries and explore some of the changes a brain injury may cause.

Types of Brain Injuries:

Every person's brain is unique. Every brain injury is different and produces different effects. The effects of brain injury depend on a combination of factors including how the injury happened, the part of the brain that was injured, and the severity of injury.

Acquired Brain Injury (ABI): An acquired brain injury (ABI) is an injury to the brain that has occurred after birth and is not hereditary or due to a degenerative condition, such as dementia or Alzheimer's.

An acquired brain injury may be caused by stroke, near drowning, insufficient or no oxygen (i.e. hypoxic or anoxic brain injury), brain tumors, neurotoxins, electric shock or lightning, or an injury. An acquired brain injury can be either traumatic or non-traumatic.

Traumatic Brain Injury (TBI): A traumatic brain injury (TBI) is a disruption in brain function caused by an external force, such as bump, blow, or jolt. Common causes of TBI include gunshot wounds, motor vehicle crashes, sports injuries, assaults, and falls.

Source: Brain Injury Association of America, <http://www.biausa.org/about-brain-injury.htm>

Stroke

One common type of non-traumatic brain injury is a **stroke**.

A stroke occurs when blood flow to the brain is interrupted and the brain does not get the oxygen it needs. About 87 percent of strokes are caused by a blood clot that blocks blood

flow to part of the brain (*ischemic*). Strokes may also occur when a burst blood vessel in the brain causes a bleed (*hemorrhagic*).

Two types of weakened blood vessels usually cause bleeds in the brain.

- An **aneurysm** is a ballooning of a weakened region of a blood vessel. If left untreated, the aneurysm continues to balloon and weaken until it ruptures and bleeds into the brain.
- An **arteriovenous malformation** (AVM) is a cluster of abnormally formed blood vessels. Any one of these vessels can rupture, also causing bleeding into the brain.

TIAs (transient ischemic attacks) are sometimes called “mini strokes” and are caused by a temporary blood clot that clears on its own. Symptoms go away after a few minutes and usually cause no permanent damage. TIAs should be taken very seriously. They can be a warning of a larger and more serious stroke to come.

Source: American Stroke Association

http://www.strokeassociation.org/STROKEORG/AboutStroke/TypesofStroke/Types-of-Stroke_UCM_308531_SubHomePage.jsp

Traumatic Brain Injury

Traumatic Brain Injuries are categorized depending on whether the injury was an *Open Head Injury* or *Closed Head Injury*.

Open Head Injury:

An open head injury, sometimes called a **penetrating head injury**, results when an object breaks through the skull and enters the brain.

Open head injuries can be caused by bullets and other fast-moving objects like flying glass and debris. They can also be caused by knives, other weapons, and skull fragments that penetrate the brain once the skull has been fractured.

Open head injuries usually affect a specific area of the brain, the part where the penetrating object strikes. They can be just as severe as closed head injuries.

Closed Head Injury:

A closed head injury occurs when there is a blow to the brain or when the head strikes a stationary object, such as during a fall. **The skull remains intact**, but inside the skull, the brain twists, turns, and bumps around, resulting in damage not just to the spot of initial impact but to other areas as well.

Because of this moving and twisting, the brain is often bruised or damaged in many places.

Another concern with closed head injuries is brain swelling. Since the brain is contained within the skull, there is no place for it to go when it swells. Instead, pressure builds, and

brain tissues may compress, causing further injury. This is often referred to as ***increased intracranial pressure***.

A period of unconsciousness may follow a closed head injury and may last for minutes, days, or months.

Concussion:

A concussion is the most common type of traumatic brain injury and is generally considered to be a mild brain injury. Concussions are caused by head trauma that causes the head and brain to move back and forth, stretching and damaging brain cells and causing chemical changes within the brain. Concussions can happen with open or closed head injuries and may or may not result in loss of consciousness.

Concussions are usually not life threatening but the effects can still be serious. While the brain recovers from concussion, it is particularly susceptible to damage. Concussions may result in loss of memory of events occurring around the time of trauma and may cause neurological deficits that may or may not go away with time.

Traumatic Brain Injury – Causes

According to the Federal Centers for Disease Control, falls cause 40 percent of all traumatic brain injuries. About 15 percent are caused by unintentional blunt trauma (being struck by or striking an object), and about 14 percent are caused by motor vehicle accidents. About 10 percent of all traumatic brain injuries are due to assault.

- Falls (40.5%)
- Other/Unknown (19%)
- Struck by/against events (15.5%)
- Motor Vehicle-traffic crashes (14.3%)
- Assaults (10.7 %)

Source: Centers for Disease Control, Traumatic Brain Injury and Concussion, https://www.cdc.gov/traumaticbraininjury/get_the_facts.html

Prognosis

When will I know the impact of the brain injury?

In the first hours, days, and weeks after a brain injury, it is difficult for doctors to predict how a brain injury will impact the survivor. Doctors may offer general predictions. For example, one basic rule of thumb is that the longer a coma lasts, the less likely an individual is to fully recover.

However, doctors may also advise family members to “wait and see.” This answer can be frustrating, but it is often the most accurate response. **Each brain injury is unique**, and it may be impossible for anyone to understand the full impact of a brain injury for months or even years.

The extent to which basic functions, like walking and speaking, are lost or recovered will likely depend on a number of variables, including the survivor's pre-existing personality, the quality and types of services available, the survivor's age, the length of time spent in a coma, and the involvement of family and other supports.

Source: Brain Injury: A Family Guide, Brain Injury Association of Florida

Mild, Moderate, and Severe

You may be told that your family member has a **mild, moderate, or severe** brain injury. You may wonder what this means.

Emergency personnel and first responders typically determine the severity of an initial brain injury by using an assessment tool called the **Glasgow Coma Scale** (GCS). The Glasgow Coma Scale collects information about a person's level of consciousness after a head injury. It measures things like whether or not a person can open his or her eyes, respond to stimuli, speak, move, or makes sounds. This information is then used to classify an initial injury as mild, moderate, or severe.

It is important to note that the Glasgow Coma Scale focuses on the initial level of brain injury. ***There may be no correlation between the initial Glasgow Coma Scale score and initial level of brain injury and a person's short or long term recovery or functional abilities.***

Even brain injuries that are initially classified as mild may have a severe and significant impact on a person's life. Likewise, an individual originally diagnosed with a severe brain injury may, in time, relearn skills like reading, writing, and walking---skills the survivor was told she or he would never recover.

Key Point

The initial classification of a brain injury as mild, moderate, or severe does not necessarily predict the life impact of that injury.

Source: Brain Injury Association of America, <http://www.biausa.org/about-brain-injury.htm>

Common Long-Term Consequences of Brain Injury

What can you expect long term?

A brain injury disrupts brain function. When brain cells are damaged, they can no longer send information to other cells in typical ways. This causes **changes** in a person's behavior and abilities.

As we've said, the effects of brain injury vary greatly depending on the location and severity of injury. Still, you may have questions about how your family member or loved one may be impacted.

As you embark on this journey of understanding and support, it can be helpful to understand some of the common long-term consequences of brain injury.

Emotional and Behavioral Changes:

- Mood swings
- Anxiety
- Depression
- Restlessness
- Lack of motivation
- Difficulty controlling emotions
- Increased irritability and frustration
- Difficulty with social skills
- Difficulty empathizing with others
- Inappropriate and/or aggressive behavior
- Grief over the loss of one's good health

Physical Impairments

- Speech difficulties
- Muscle coordination problems
- Full or partial paralysis
- Visual impairments and changes to hearing, touch, taste
- Seizures
- Sleep problems
- Headaches
- Fatigue and weakness
- Balance
- Spasticity
- Continence

Cognitive Impairments

- Memory deficits
- Impaired concentration
- Slowed thinking
- Limited attention span
- Difficulty learning new things
- Difficulty understanding abstract concepts
- Difficulty initiating activities
- Partial or complete loss of reading and writing skills
- Speech and language problems, including communication deficits and loss of vocabulary

Recovering from a Brain Injury

Brain injury is not an acute, or short-term, condition. Most survivors do not suddenly recover after a couple of days or weeks. The effects of brain injuries may stay with

survivors for years and sometimes forever, significantly changing relationships, employment, finances, recreational activities, and identities.

Determined and persistent brain injury survivors may recover skills and abilities, like reading, writing, and even walking, months and/or years after their initial injury and treatment.

Because of the long-term nature of brain injury, recovery, for many survivors, is about ***discovering a new normal*** and ***rebuilding and accepting a new sense of self***.

As you support a loved one or family member who has recently experienced a brain injury, it may be helpful to keep in mind that she has just had her world turned upside down.

As hard as it can be to accept this, it may not be possible for the survivor to go back to being who she was before. The survivor may feel more supported and less alone if you can try to understand this.

Experiencing a Brain Injury is Like Falling into a Sinkhole

Written by Ralph Poland a Brain Injury Survivor

Imagine you are strolling along in your life, looking towards the horizon and your future Goals, Aspirations, and Ambitions. In a flash, the ground beneath you drops out and you go down with it.

Once the dust settles, you struggle to dig yourself out and find yourself standing at the bottom of a Very Dark, Deep, Isolated, Lonely, and Unstable Sinkhole.

At some point, you notice other elements of your former life crashing down around you. You see these elements scattered in unrepairable pieces or partially buried nearby.

A sense of isolation - Anger - Bitterness – Confusion - Depression - Fear - Frustration - and, of feeling Overwhelmed, until finally you reach the stage of Acceptance.

When you look up, you notice more and more aspects of your former life caving in around you. It seems like anything left of your former life is haphazardly hanging overhead. You try to grab at these pieces of your life in a desperate attempt to climb your way up and out of the hole and pull yourself back to something that feels normal. But, everything you grab, also comes crashing down around you.

Meanwhile, your friends and family stand at the sinkhole opening and look down at you with Bewilderment. They are unable to offer you any kind of Help/Hope as you start to search for ways to begin to climb back out of the Horrible Sinkhole and resume your former life.

Over time, strangers, rescuers, slowly appear and drop Ropes down to you. Some ropes only help you climb up a certain extent, while other ropes help a great deal more. Still, you find it very difficult to gain a footing and climb up further. But eventually, many of those strangers, rescuers, (including Therapists, Doctors, Nurses, CNAs, family members, friends, and Dietitians) offer you some Strategies that help you slowly begin to climb up out of the hole towards daylight.

Finally, months or years later, you struggle your way up and out and eventually reach the top. Even then, it is challenging to climb from the hole and find stable ground to stand on. Daily, you discover that the bit of ground you are standing on is shifting

It is only when you have a moment to enjoy looking up that you feel the warmth of the sun as you take in a breath of fresh air and reflect on all you have achieved post brain injury. From here, you realize the sky is the limit.

Section 2: Hospitalization

Survivors of serious brain injuries typically spend time in the hospital immediately following their injuries. They may be in a coma or may drift in and out of consciousness. They may be surrounded by life-saving medical equipment and attached to multiple IV lines and monitors. They may be receiving treatment for other-related injuries, such as broken bones or burns or bruises. They may be subject to numerous medical tests and scans.

The hospital can be an extremely stressful setting for family members. There is much uncertainty and worry about your loved one's future. It can be difficult to process all the information you are receiving while remembering the names and roles of medical professionals playing a part in your loved one's care. It can be hard to keep track of your questions and make sure they get answered.

In this section, we'll provide tips for navigating your time in a hospital setting.

Care Team Members

Most hospitals use a team approach to provide care to patients with brain injuries. Each team member has a unique and important job to do.

At first, it may be hard to tell who does what and to whom you should direct certain questions. The following is a list of professionals who may be part of the team during various stages of the initial recovery process.

Neurologist – A neurologist is a doctor who specializes in the diagnosis and treatment of disorders of the brain, spinal cord, and peripheral nerves. Neurologists often work closely with neurosurgeons but do not perform surgery.

Neuropsychologist – A neuropsychologist is a psychologist with specialized training in the relationships between the brain and behavior. Neuropsychological testing is often recommended after a brain injury to identify strengths and weaknesses in a person's thinking skills. A neuropsychologist may also help with emotional and behavioral problems.

Neurosurgeon – A neurosurgeon is a surgeon who specializes in the diagnosis and surgical treatment of diseases and conditions of the nervous systems (i.e. brain, spinal cord, and peripheral nerves).

Occupational Therapist – Occupational therapists work with patients to rebuild their functional and cognitive living skills for self-care, homemaking, social participation, sensory processing, leisure activities, organizing and managing life, integration into the community, and preparing to return to work.

Occupational therapists also assess the need for assistive technology (AT) and adaptive devices that will improve the functional capacity of the individual in areas of education, independent living, working, and being in the community.

Physiatrist – A physiatrist is a doctor who is primarily concerned with evaluating the impact of the brain injury on the functioning of the patient's body (i.e. not just the brain) and helping the patient to overcome any disability that has occurred.

Physical Therapist – A physical therapist is a healthcare professional who helps patients improve and restore their movement. A physical therapist may also work with an

unconscious patient to prevent further deterioration and loss of muscle. This is done by moving the arms and legs (called Range of Motion) and exercising unused muscles.

Rehabilitation Nurse – A rehabilitation nurse has special training in how to support patients with chronic conditions as they move through the process of rehabilitation. A rehabilitation nurse may help set goals for independent functioning and activities of daily living, encourage self-care, and focus on preventing complications or further disability.

Respiratory Therapist – A respiratory therapist is concerned with helping the patient breathe better so further complications don't occur. If the patient is on a respirator, the respiratory therapist is responsible for maintaining the equipment. If the patient is unable to cough up secretions, the respiratory therapist may assist by lowering the head, tapping the back, and suctioning the patient.

Social Worker/Case Manager – A social worker, or case manager, meets with patients and family members to discuss concerns and may act as a go-between between the care team and family. The social worker can provide copies of medical records to take home before discharge.

A social worker can also be a useful resource as you and your loved one begin to examine brain injury services and apply for public benefits, such as Social Security Disability Insurance (SSDI), MaineCare, and others. Your social worker can answer questions about service availability as well as legal protections and arrangements such as guardianship, durable power of attorney, and more. If you plan to file an accident law suit, make sure to ask for more information about Special Needs Trusts.

Speech Therapist – A speech therapist helps patients regain skills around producing and understanding language. Speech therapists also assess a person's need for assistive technology to support and enhance communication.

Others: Depending on the types of injuries and complications that have occurred, the lead physician may bring other specialists on board, such as infectious disease control, ear, nose, and throat, oral surgery, or orthopedics. Vocational rehabilitation counselors may be on staff at rehabilitation hospitals to assist the injured person with skills and barriers related to independent living and employment. Additionally, you may want to contact your insurance provider and ask for a patient advocate to help you better understand which services are paid for.

Sources:

Brain Injury: A Family Guide, Brain Injury Association of Florida

Brain Injury & Stroke Resource Directory, Brain Injury Association of America – Maine, First Edition.

Tips for Interacting with the Care Team

- ✓ **Write down questions** so you don't forget them.
- ✓ **Be persistent.** You may need to ask questions several times before they are answered or before the answer is clear to you.

- ✓ At the same time, remember that **some questions cannot be answered right away**. Doctors may not know yet how this injury will affect your loved one.
- ✓ Be prepared for some difficult information.
- ✓ But **don't lose hope** if you are told your loved one will never walk or speak or work again. In many cases, it is too early to know whether or not this is true. Some professionals may not realize this kind of information is not helpful at this time.
- ✓ Ask different specialists to leave their business cards behind so you can remember names and keep track of roles. Keep cards in a bag or small box or make a chart of everyone's names and titles and their role in your loved one's care.
- ✓ **Don't give up if someone tells you no**. A hospital is a busy and stressful place to work. Some staff may be too busy to help you and may tell you something is not possible. It's okay to be persistent and keep asking until you or your loved one gets what is needed.
- ✓ Nurses and therapists can be excellent resources. If you are feeling uncertain about how to interact with or support your loved one, ask one of the nurses for concrete suggestions.
- ✓ Ask if there are activities you can assist with, like feeding or grooming. **Loving care from family members is important in the recovery process**. It is also a good way to spend time with the patient while learning about their needs and how to care for them.
- ✓ You may be able to ask a physical therapist to show you how to perform range-of-motion (ROM) exercises so you can help maintain a loved one's strength and function while he or she remains in bed.
- ✓ A good day of progress may be followed by a down day. This is very common and does not signify a permanent loss of a function or skill.

Sources:

Brain Injury: A Family Guide, Brain Injury Association of Florida

Challenges, Changes, and Choices: A Brain Injury Guide for Families and Caregivers, Brain Injury Association of America. Found at: <http://www.biausa.org/brain-injury-community.htm>

Tips for Supporting the Survivor

*Tips were shared by Ralph Poland,
a Maine brain injury survivor*

- ✓ **Be sensitive about the words you use** when speaking to the survivor.

- ✓ When attempting to explain what happened to the survivor, be gentle and keep it simple. The survivor's impaired cognitive skills may prevent him from understanding what is being explained to him. **Too much information can be overwhelming.**
- ✓ Because the survivor in many cases feels all alone and separated from the world, remind her that the doctors, nurses, CNAs, and therapists, as well as family/loved ones, are all working as a team to better understand her circumstances and support her.
- ✓ **Avoid saying things like, "You can't" or "You won't" or "You never will."** Saying any of these things can strip away a person's hope of ever regaining his or her former abilities.
- ✓ It is even a good idea to avoid saying these things and talking negatively around a survivor who is in a coma. Some survivors have shared experiences of being aware of what was going on around them while they were in a coma. For these reasons, conversations about the patient's condition being "hopeless" or "terrible" should take place in another room where the patient will not hear them.
- ✓ Along these same lines, talking to a survivor who is in a coma, even if it is only small talk, can be comforting to the survivor. **Talk about current events, friends, family.** Reassure him everything is being done to help.
- ✓ **Be supportive.** If you notice that a survivor is doing something, such as making eye contact or purposefully moving, for the first-time since the brain injury, point it out and use it to encourage the survivor about the progress she is making.
- ✓ Remember, **there are no clear answers early on.** A lot depends on the survivor. That is why everyone needs to remain supportive and encouraging as the survivor tries to heal and find the "certain spark" that will motivate him to move forward and become engaged in his own rehabilitation and therapies.

*** Special thanks to Ralph Poland, Survivor, for his insights and experiences*

Tips for Managing Your Stress and Preparing for the Next Steps

- ✓ **Ask family and friends to help with chores** you are unable to leave the hospital to do. Most people want to help. They just need an assignment. Some tasks friends may be able to assist with include:
 - Laundry
 - Preparing meals
 - Driving carpools
 - Taking care of small children
 - Taking care of pets
- ✓ Try to get enough **sleep** and **eat** properly.
- ✓ Recharge yourself in whatever way is meaningful to you.

- ✓ **Supporting a loved one with a brain injury is a marathon not a sprint.** You will need your health and emotional well-being for a long time to come so make sure you take time to take care of yourself.
- ✓ Purchase a binder or notebook and begin recording all critical information, such as:
 - Dates of hospital stays
 - Medication changes
 - Dates of medication changes
 - Doctors involved in various decisions and procedures
 - Requests made to care team
 - Request fulfilled
 - Notes about patient improvements
- ✓ **Begin gathering information** you will need to manage insurance claims, determine eligibility for various government programs, and file any recommended litigation. Try to collect as many of the following as possible:
 - Social Security card (application for Social Security Administration programs should begin at once-check with the social services department of the hospital)
 - Insurance card(s) (a copy of all policies in force, if possible)
 - Driver's license
 - Birth certificate
 - School records
 - Work records (if filing for Workers' Compensation)
 - Tax returns from the past year
 - Information about family assets (important when applying for various governmental programs)
 - Accident reports (if applicable)

Collecting documents and records can be overwhelming, so it is best to start as soon as you can. For more on government programs your loved one may be eligible for, see **Section 6: Supports, Resources, and Services for Survivors.**

Source: Challenges, Changes, and Choices: A Brain Injury Guide for Families and Caregivers, Brain Injury Association of America. Found at: <http://www.biausa.org/brain-injury-community.htm>

Section 3: Rehabilitation

Once your loved one is medically stable, the focus of care and treatment will likely shift to rehabilitation.

Rehabilitation is the process of helping a person achieve the highest level of functioning, independence, and quality of life possible after a serious injury or disability.

In contrast to early hospital care, which likely focused on medical problems, rehabilitation focuses on restoring and improving an individual's physical strength and mobility, communication skills, thinking and reasoning skills, and acceptance of his or her new condition and limitations.

In most cases, a hospital physician, social worker and/or case manager will help advise you on what type of rehabilitation services and/or programs your loved one may need around the time he or she is preparing to leave the hospital.

What Does Rehabilitation Look Like?

Rehabilitation services and supports are specialized based on the unique needs and strengths of the brain injury survivor. Services may include:

- Cognitive therapy
- Speech/language therapy
- Physical therapy
- Occupational therapy
- Neurobehavioral therapy
- Vocational rehabilitation
- Neuropsychological testing
- Counseling
- Recreational therapy
- Respiratory therapy

Source: brainline.org, "Brain Injury Rehabilitation", Found at:
http://www.brainline.org/landing_pages/categories/rehabilitation.html

How Do You Know What Types of Rehabilitation Services are Necessary?

A neuropsychologist will usually do a **neuropsychological assessment** to determine what abilities the individual has lost as a result of the injury and what deficits he or she may have now.

The information gathered during this noninvasive, task-oriented evaluation helps the individual and family better understand how the injury has affected the survivor's intellectual functioning. It also provides valuable information about the kinds of supports and rehabilitation services the survivor now needs.

As the survivor progresses, his or her needs will change. Rehabilitation services and treatment plans will need to change too.

Source: *Challenges, Changes, and Choices: A Brain Injury Guide for Families and Caregivers*, Brain Injury Association of America. Found at: <http://www.biausa.org/brain-injury-community.htm>

Rehabilitation Settings

Rehabilitation services are delivered in a range of settings. Some of the different types of settings include:

- **Acute rehabilitation** – an intensive rehabilitation program that treats patient as they become medically stable.
- **Transitional living programs** – nonmedical residential programs that teach skills for community living and prepare individuals for maximum independence.
- **Long-term care and supervised living programs** – residential facilities that provide care and rehabilitation to people with brain injuries who are not able to live independently.
- **Behavior management programs** – typically community-based (i.e. not residential) programs that teach self-control and appropriate social behaviors.
- **Day treatment programs** – provide rehabilitation during the day so the person can return home at night.

Source: Family Caregiver Alliance, "Traumatic Brain Injury." Published on www.caregiver.org

Tips for Selecting a Rehabilitation Provider

Excerpted and updated from *Guide to Selecting and Monitoring Brain Injury Rehabilitation*
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- **An informed consumer makes the best consumer.** Do your research before making major decisions.
- **You know your needs best.** Professionals can help provide the information you need to make choices, but your loved one and you should ultimately decide what works best.
- **Be curious.** Ask questions. Learn about programs, their staff and service philosophy and methodology.
- **Learn from others.** Try to talk to individuals who have participated in different programs you are considering. Brain injury support groups are often a good place to find people who have experience with a program or service you are considering.
- **Explore more than one program.** Whenever possible, look into a wide range of services. The closest one or the one which offers the most services is not necessarily the one that will best meet your needs.

- **Listen to your instincts.** Don't make a decision until you are ready. If you are unsure or uncomfortable, find someone who has no stake in the decision to help you sort things out. Be aware of anyone who tries to pressure you.
- **Get it in writing.** Keep records of who you spoke to and when. Get any commitments for services (the types and quantities to be provided as well as the costs) in writing before you choose.
- **Looks are not everything.** The qualities of services should not be judged by how nice the facilities or marketing materials look.
- **The ultimate goal is self-determination.** Brain injury programs and services should promote self-determination to the fullest extent possible and maximize integration in the community.
- **Know your financial situation.** Find out about public or private benefits your loved one may be eligible for and apply promptly. Depending upon what kind of services are needed, you will want to talk with the insurance carrier, managed care organization,, or other health care payer to find out how much it will pay, for what services, and under what conditions. Ask about deductibles and co-pays. Get a copy of the policy or plan and re-read it.
- **The customer is always right.** The person with the brain injury receiving services should be satisfied with the services provided. If not, it may be time to look into other options.

More Questions to Ask Rehabilitation Providers

The Brain Injury Association of America's **Guide to Selecting and Monitoring Brain Injury Rehabilitation Programs** is a great starting point for figuring out what questions to ask a rehabilitation provider and how to compare and contrast different services and facilities.

<http://bianj.org/wp-content/uploads/2014/09/GuidetoSelectingandMonitoringRehab.pdf>

The National Stroke Association also has a **Guide to Choosing Stroke Rehabilitation Services**.

https://www.stroke.org/sites/default/files/resources/NSAFactSheet_ChoosingaStrokeRehabProvider_2014.pdf

Section 4: Preparing for a Survivor's Return Home

At some point, the survivor will likely be ready to return home for short visits or permanently. This can be a source of excitement and anxiety for the injured person and his or her family members.

On the one hand, it may feel more relaxing and liberating for the survivor to spend time at home. On the other hand, a return home poses new emotional, behavioral, and physical challenges.

The survivor may not be fully aware of the impact of his or her injuries until he or she attempts to resume old routines (like personal care, cooking, or organizing and initiating daily activities) and discovers how difficult it can be to complete tasks that were once simple. It is not unusual for new behavioral challenges to emerge during this transitional time. We will spend more time discussing how family members can support survivors to manage and cope with behavioral and cognitive challenges in the next Family Member Training (#2).

In this section, we will focus on assessing and preparing the survivor's home so it is safe for his or her eventual return.

The ideas and tips in this section are adapted from Debbie Hartzler's article, "Home, Safe Home: Caregiver and Client Tips," which appeared in The Challenge! (Fall 2015) Volume 9, Issue 4, produced by Brain Injury Association of America. This article can be found at: <http://www.biausa.org/brain-injury-publications.htm>

Take Inventory and Make Some Changes

The most pressing home-safety concerns for persons with brain injuries and their caregivers are: (1) access into the home and (2) safety in the bathroom. Navigating stairs and slippery surfaces can be challenging for people who have impaired judgment, decreased concentration, decreased motor control, vision changes, and/or impaired balance due to a brain injury. Because of this, persons with brain injuries are especially susceptible to falls.

You may want to consider:

- Installing a ramp in the garage or to the front door so individuals can avoid stairs.
- Installing a stair lift.
- Installing grab-bars in the bathroom, along with hand-held showers, wall-mounted shower seats, comfort-height or wall-mounted toilets, and/or sloped vanities.
- Removing a bath tub and replacing it with a barrier free shower.
- Asking the rehab facility to do a home visit for safety – what do they think needs to be done? Occupational and physical therapists can offer advice on equipment and techniques to make personal care and mobility easier and safer.
- Setting up an Assistive Technology (AT) Consultation. For more information, visit: <http://mainecite.org/at-consultants-in-maine/>

Other things to consider:

- **Impulsivity:** Is your loved one acting impulsively? Do you need to hide keys or install door alarms?
- **Wandering:** How will you deal with wandering?
- **Mental health assistance:** You may want to set up an appointment for intake to get counseling services started as soon as your loved one returns home.

Decrease Home Hazards

In addition to considering some of the changes mentioned above, it is a good idea to scan the survivor's home environment for other hazards that could complicate and contribute to falls. Here are some basic suggestions to think about. Please note that any home modifications should be customized for the individual and his or her specific needs and risks.

Lighting:

- Use brighter bulbs
- Install additional lighting in darker areas
- Light paths at night and maximize natural light by day
- Use wall switches and plugs for easier access
- Relocate light switches and plugs for easier access

Flooring

- Remove trip hazards, like throw rugs, cords, and clutter
- Replace carpet with low pile, dense carpet, or hard-surface flooring
- Highlight any raised thresholds with brightly colored tape
- Use non-slip tile and no-wax flooring products
- Secure area rugs with double-sided tape

Stairs:

- Install handrails on both sides of the stairs
- Ensure good lighting with switches at the top and bottom of the stairs
- Add reflective tape or contrasting color to the edge of the step
- Ensure the stairs have smooth non-slip surfaces

Storage

- Store frequently used items at a height between your shoulders and knees in the kitchen, bedroom, bathroom and shower
- Install pull-down shelving and hanging rods in closets
- Use lever-style door handles and D-ring pulls on cabinets and drawers

Assistive Technology

Assistive Technology (AT) can have a significant impact on the lives of people with brain injuries. AT can improve the functional capacity of a person in the areas of education, living independently, employment, and community life.

AT may be a customized device or bought commercially. Examples of AT include: a talking alarm clock, transfer bars, a shower safety seat, tablets and smart phones with special apps, smart home technology (e.g. remote monitoring or remote door unlocking), smart watch, medication organizers, standing wheelchair, stair glide, or platform lift.

AT services include Assessment, Device Demonstrations, Device Loans, and Equipment Reuse. For AT services in Maine, visit www.mainecite.org.

Section 5: Supports and Resources for Family Members

A Brain Injury Affects an Entire Family

When a brain injury happens, a family changes forever.

Family members may feel traumatized by the initial experience of watching their loved one in a hospital, surrounded by many doctors and life-saving machines. They may worry about their loved one's future and their own future as well, and they may feel overwhelmed by all the new caregiving and financial responsibilities suddenly placed upon them.

Even the strongest families are challenged by the many changes and stresses brought about by a serious brain injury.

Common Stressors and Changes

If the person who was injured was the primary breadwinner, someone new will need to step into this role. Quiet family members may be forced to speak up and advocate on their loved one's behalf. Family members who may not be natural nurturers may suddenly find themselves responsible for providing substantial care to their loved-one many hours a day. Children may need to care for parents. Parents may need to devote significantly more time and energy to an injured child than a non-injured one. These major role changes and reversals may cause family members to feel extremely stressed, overburdened, resentful, and/or guilty.

Financial stresses, caused by medical bills, insurance deductibles, and/or the loss of the ability for a breadwinner to work, can add to a family's burdens.

Caregivers may no longer have the flexibility to engage in their usual friendships and activities outside the home.

As families adapt and change and begin to accept the fact that their loved-one's brain injury is not just going to go away, it is natural for family members to experience feelings of grief and loss and sadness.

Grief

A serious brain injury alters a person. It is natural for family members to mourn the loss of the person they knew before.

Mourning the loss of the person they knew is an important part of the process of coming to accept and appreciate who the brain injured person is now.

Most people go through a grieving process that includes some or all of the following stages:

1. Denial: "No, this couldn't have happened to us..."
2. Anger and frustration: "I can't believe she let him climb up that ladder. It's all her fault."

“Those doctors have no idea what they’re doing. They’re not helping one bit.”

3. Depression and withdrawal: Family members may find it hard to care for themselves physically and emotionally. They may feel lonely and alone when friends who were once supportive become less involved as the rehabilitation and recovery processes continue on and on. Disconnected from friends and outside activities, family members may feel hopeless and fall into despair.
4. Acceptance: Grieving is a challenging and difficult process. However, over time, both the family and the survivor should begin to accept what has happened and the changes that have resulted. Acceptance leads to healing. In good time, both the family and the survivor should shift their focuses from what is lost to what remains and how the highest quality of life can be built upon one’s strengths and capabilities.

Source: *Brain Injury: A Family Guide*, Brain Injury Association of Florida

Tips for Minimizing Stress

Family members should:

- **Be aware of the needs of other family members.** Spouses, siblings, children, need to know they have not been forgotten. It is so easy to focus only on the needs of the injured survivor but other family members have needs as well.
- **Stay in contact with friends** and continue to participate in social and recreational activities. When you don’t allow yourself an opportunity to recharge with people and activities you enjoy, it is easy to burn-out and lose your ability to support others who need you.
- **Work out a rotating visitation schedule** with other friends and family members that allows the primary caregiver to step away and take a break.
- **Ask and accept help from others.** Remember, people who care about you truly want to help and are often looking for your permission to do so. Members of your support network may be able to run errands, help communicate updates to other friends and family member, assist with childcare or pet-care, and/or bring over meals.

There are a number of websites that can help you share updates and coordinate help from select friends and community members. Caring Bridge (www.caringbridge.org) is one such site.

- **Express feelings and do not try to keep everything inside.** It is normal to feel a range of feelings after a loved one is injured, including anger, guilt, sadness, fear, and denial. There is no such thing as a “wrong” feeling. Remember, your family has just been through a lot. Talk to other family members, social workers, ministers, case managers, nurses, or anyone with whom you feel comfortable.
- Professional counseling can help families work through challenges and stresses and find ways to move forward. You may find it helpful to seek out others in similar

situations through support groups, senior centers, professional counselors, and either private or publicly funded services.

Source: Brain Injury: A Family Guide, Brain Injury Association of Florida

Maine Support Groups

Maine has a number of brain injury support groups throughout the State for family members who would like to connect and hear from others who have gone through similar experiences. Some of these groups are in person and some occur over the phone. Some are geared specifically towards family members and caregivers and others are for survivors or for both survivors and family members.

The Brain Injury Association of America - Maine Chapter maintains an updated list of the State's support groups on their website. <http://www.biausa.org/Maine/supportgroups.htm>

For more information on available support groups, you can also call the Maine Brain Injury Information Center at 1-800-444-6443 or email Mainebraininjuryinfo@biausa.org.

Brain Injury Association of America - Maine Chapter (BIAA-ME) Resources and Services

BIAA-ME provides advocacy, education, and information about brain injury to all those in need. BIAA-ME offers a number of supports for family members and survivors, such as:

- A free monthly e-Newsletter to keep Mainers informed about important issues and BIAA-ME events. Contact BIAMaine@biausa.org to subscribe.
- The Maine Brain Injury Information Center, a toll-free helpline, where individuals can call with questions and receive personalized information about available supports, services, and resources. Toll-free phone: 1-800-444-6443 or email: Mainebraininjuryinfo@biausa.org.
- Social, recreation, and outreach programs, such as resource fairs and adult summer camp experiences, when resources and community interest permits.
- Survivor/family stories, found at: <http://www.biausa.org/Maine/Our-Stories>
- Maine's Brain Injury & Stroke Resource Directory which includes brief descriptions and contact information for services and supports ranging from adaptive equipment and assistive technology to advocacy, transportation, rehabilitation and community programs.

You can download a copy of this guide on BIAA-ME's website.
<http://www.biausa.org/Maine/index.htm>

To request a hard copy of the directory, please email: BIAMaine@biausa.org.

Importance of Family in Recovery Process

Your family member may get the best medical and rehabilitation care in the world, and still his or her circle of supports will be incomplete if he or she does not have your loving support, encouragement, patience, and acceptance.

It may take a long time for the survivor to recover pre-injury physical and cognitive functions, and some skills and functions may never be fully recovered. "Families of persons with brain injuries must adjust to the fact that the recovery process is a 'slow labor of love' for everyone involved." **

You may experience many different feelings, including grief, frustration, and guilt. And this is okay. However, ultimately, your role, and the role of other family members, is to be as understanding and patient as possible while still taking care of your own health and well-being. It is also essential that you recognize, encourage, and celebrate the survivor's progress and small steps forward.

***Source: Brain Injury: A Family Guide, Brain Injury Association of Florida*

Section 6: Supports and Services for Survivors

It can be stressful and overwhelming to sort out what medical and rehabilitation services are available for your loved one and how to pay for them. Eligibility criteria may be difficult to understand, and the required application processes may be lengthy and confusing.

You, the family member, will need patience and persistence to help your loved one identify and apply for the supports and services he or she needs.

In this section, we'll provide an introduction to key public programs that provide financial assistance, medical and rehabilitation services, and legal services and advocacy. You will likely still need to do more research and follow-up with state and federal agencies for more information.

Public Programs Offering Direct Financial Support

The most widely used financial-support programs are those provided by the Social Security Administration (SSA). The Social Security Administration manages two cash benefit programs for people with disabilities.

- ***Social Security Disability Insurance (SSDI)*** provides disability insurance benefits for workers who have contributed to Social Security while working and become disabled or blind before reaching retirement age.

To be considered "disabled" a worker must (1) be unable to do any work and (2) have a disability that is expected to last for at least one year or result in death. Additionally, a worker must have worked a certain number of quarters (periods of three months) in order to be eligible for this benefit. The monthly SSDI payment is based on wages earned at the time the worker was injured.

- ***Supplemental Security Income (SSI)*** provides monthly cash income to low-income persons with *limited* work history and resources on the basis of age and disability. Everyone who qualifies for this program receives the same amount of money.

How to apply?

To get more information or apply for benefits, contact your local Social Security office. Applications may also be filed online. Social Security offices in Maine can be found at: <https://www.ssa.gov/boston/ME.htm>

Tips for applying:

Be aware that over 60% of first-time applications are denied. Be prepared to appeal the denial and consider engaging a disability attorney to advocate on your behalf. There are multiple steps in the appeal process, beginning with a request for reconsideration, moving onto a hearing before an administrative law judge (an ALJ), and ultimately, if needed, a hearing in Federal court. The success rates for people who have a hearing before an ALJ are nearly 60%, largely because applicants have representation from a disability attorney or a non-attorney disability advocate.

Public Programs to Pay for Health Services

MaineCare

MaineCare (Maine's Medicaid Program) is a health insurance program managed by the Maine Department of Health and Human Services (DHHS). It pays for the medical expenses of people who are unable to pay some or all of their own medical expenses.

MaineCare is intended for individuals with low income and limited resources. There are provisions in place which allow the program to offer special services and different eligibility requirements for adults and children with disabilities.

For adults with a disability, MaineCare eligibility is based on income and medical criteria/disability status. Individuals who qualify for Social Security Income (SSI) payments are generally automatically eligible for MaineCare.

MaineCare can fund a range of medical and long-term support services that are essential to adults living with brain injuries, such as inpatient hospital care, home health services, prescription drugs, therapies, and personal care aides that assist with self-care and household tasks and facilitate independent living.

The Office of Family Independence determines financial eligibility: Medical Assistance, including MaineCare, Cub Care and Medically Needy programs, and provides payment to health care providers.

Eligibility is determined by the Office of Family Independence. Bill payment and other activity are done by the Office of MaineCare Services.

To apply for MaineCare, contact the Maine Department of Health and Human Services or visit a local office. An eligibility specialist will help determine whether you are eligible and answer questions about the application process and benefits.

Office of MaineCare Services Office of Family Independence

11 State House Station,
Augusta, Maine 04333-0011
Toll-free phone: 1 (855) 797-4357, 1 (800) 442-6003
(207) 624-4168
Website: www.maine.gov/dhhs/ofi

Maine Waiver Programs for Adults with Brain Injury

MaineCare has two Medicaid Waiver programs that can help people with brain injuries.

- Brain Injury Waiver, and
- Other-Related Conditions (ORC) Waiver.

Brain Injury Waiver (Section 18)

Home and Community Based Services for Adults with Brain Injury

MaineCare's Brain Injury Waiver program provides community-based services to eligible adults who are age 18 or older with an acquired brain injury.

In order to be eligible for this benefit package, an individual must meet an institutional level of care but choose to receive services in the community.

Covered community services include:

- Assistive technology,
- Care coordination,
- Community/work reintegration,
- Self-care/home reintegration,
- Home support,
- Work support, employment, specialist services, career planning, and more.

As part of each application, the Office of Aging and Disability Services requires an evaluation by a neuropsychologist or psychiatrist along with a Brain Injury Waiver assessment by the state's Assessing Services Agency to determine eligibility. If eligible, a completed application is forwarded to the Office of Aging and Disability Services (OADS). OADS will assign a care monitor who will work with the individual to select the service package and providers.

Office of Aging and Disability Services
Maine Department of Health and Human Services
41 Anthony Avenue
State House Station 11
Augusta, ME 04333-0011
(207) 287-6656

For information on how to apply:

<http://www.maine.gov/dhhs/oads/home-support/brain-injury/apply.html>

Other Related Conditions (ORC) Waiver (Section 20)

Home and Community Based Services for Adults with Other Related Conditions

MaineCare's Other Related Conditions Waiver offers a comprehensive benefit package to eligible adults who are age 21 or older with cerebral palsy, epilepsy, or any other condition (other than mental illness) that requires treatment similar to persons with intellectual disabilities.

To be eligible, the person must meet an institutional level of care but choose to receive services in the community. Additionally, the person's condition must be expected to continue indefinitely and must result in substantial limitations in three or more major life activities (i.e. self-care, understanding & use of language, learning, mobility, self-direction, and capacity for independent living.)

Community services may include:

- Home support,

- Physical, occupational, and/or speech therapy,
- Community and work supports,
- Assistive technology, and more.

Services are individualized in order to help the person live as independently as possible and meet their needs and personal goals.

To apply, complete an Other Related Conditions application and submit to the Maine Office of Aging and Disability Services (OADS). An assessment by the state's Assessing Services Agency will be conducted to determine eligibility. If the person is determined to be eligible for this waiver program, OADS will assign a care monitor who will work with the individual to select the service package and providers.

Office of Aging and Disability Services
 Maine Department of Health and Human Services
 41 Anthony Avenue
 State House Station 11
 Augusta, ME 04333-0011
 (207) 287-6656

For information on how to apply:

<http://www.maine.gov/dhhs/oads/home-support/brain-injury/apply.html>

MaineCare Outpatient Neurorehabilitation Services

MaineCare also offers outpatient neurorehabilitation treatment at nine clinics throughout the state. These clinics provide physical, occupational and speech therapies and other services to help individuals with brain injuries recover their physical, communicative and cognitive abilities.

To be considered for this, individuals must be eligible for MaineCare and have a diagnosed brain injury. Individuals who are not eligible for MaineCare may also receive services from these programs.

Tips for Securing Financial Support and Health Services:

- Obtain a copy of all medical records and doctors' summaries.
- Make copies of all pertinent documents required for eligibility applications. Do not ever give anyone the original documents.
- Remember, apply for Social Security Administration (SSA) programs as soon as possible.
- **Don't get discouraged easily.** Social Security Disability Insurance (SSDI) is often fraught with delays and denials. After a second denial, you should contact an attorney specializing in Social Security law.
- If the injury occurred on the job, immediately notify Worker's Compensation. Worker's Compensation is a type of insurance provided by employers for employees

who are injured while working. To get more information about Maine's policies and laws, contact your regional Worker's Compensation Board office.

<http://www.maine.gov/wcb/Departments/regions/index.html>

- If health insurance is provided through the survivor's employer, make every effort to continue coverage without interruption under COBRA until another health insurance plan is put in place.

Source: Challenges, Changes, and Choices: A Brain Injury Guide for Families and Caregivers, Brain Injury Association of America. Found at: <http://www.biausa.org/brain-injury-community.htm>

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- Social, recreation, and outreach programs, such as resource fairs and adult summer camp experiences, when resources and community interest permits.
- Survivor/family stories, found at: <http://www.biausa.org/Maine/Our-Stories>
- Maine's Brain Injury & Stroke Resource Directory which includes brief descriptions and contact information for services and supports ranging from adaptive equipment and assistive technology to advocacy, transportation, rehabilitation and community programs.

You can download a copy of this guide on BIAA-ME's website.

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Maine Support Groups

Maine has a number of brain injury support groups throughout the State for survivors, family members/caregivers, and friends who would like to connect with others facing similar challenges.

The Brain Injury Association of America - Maine Chapter maintains an updated list of the State's support groups on their website. <http://www.biausa.org/Maine/supportgroups.htm>

For more information on available support groups, you can also call the Maine Brain Injury Information Center at 1-800-444-6443 or email Mainebraininjuryinfo@biausa.org.

Brain Injury Voices

Brain Injury Voices is an active volunteer group of brain injury survivors in Maine who are "paying it forward" by:

- **Educating** medical professionals and the general public about brain injury from the survivor point of view,
- **Advocating** for the importance of brain injury rehabilitation, and
- **Supporting** survivors and families through peer mentoring.

Their website includes contact information as well as links to informative websites on living with a brain injury and recommended books by both medical professionals and survivors. For more information, visit: www.braininjuryvoices.org.

Legal and Advocacy Resources

In addition to the programs and supports we've already mentioned, Maine has several organizations that provide free legal and advocacy services.

The Maine Volunteer Lawyers Project provides free legal information, assistance, and representation to Mainers with low incomes facing civil legal issues. Find more information at www.vlp.org or 1-800-442-4293.

Pine Tree Legal Assistance is another source of free legal services to low-income Mainers. They can be contacted, at www.ptla.org.

Disability Rights Maine protects and advocates for the rights of individuals with brain injuries and other disabilities. For more information, contact: <http://drme.org/> or 1-800-452-1948.

Maine Long-Term Care Ombudsman Program advocates for the quality of life and care of people living in nursing facilities and assisted housing programs, such as residential care facilities and assisted living. For assistance or information, contact: <https://www.maineombudsman.org/> or 1-800-499-0229.

Additional Links & Resources

American Stroke Association

<http://www.strokeassociation.org/STROKEORG/>

Brain Injury Association of America

<http://www.biausa.org/>

Brain Injury Association of America – Maine Chapter

<http://www.biausa.org/maine>

Neurobehavioral Services

Office of Aging and Disability Services

Maine Department of Health and Human Services

<http://www.maine.gov/dhhs/oads/home-support/brain-injury/index.html>

Brain Injury Voices

<http://www.braininjuryvoices.org/>

Brainline

<http://www.brainline.org/>

Caring Bridge

www.caringbridge.org

Disability Rights Maine

<http://drme.org/>

Family Caregiver Alliance

<https://www.caregiver.org/>

MaineCare Services Office of Family Independence

Maine Department of Health and Human Services

<http://www.maine.gov/dhhs/ofi>

Maine Cite

<http://mainecite.org/>

Maine Long-Term Care Ombudsmen Program

<https://www.maineombudsman.org/>

Maine Volunteer Lawyers Project

<http://www.vlp.org/>

Pine Tree Legal Assistance

<http://ptla.org/>

Social Security Administration Disability Programs

<https://www.ssa.gov/disability/>

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