

YOUR BRAIN INJURY HANDBOOK



***“Empowering Survivors and Families
to Rebuild Their Lives.”***

**ACQUIRED BRAIN INJURY
NETWORK OF PENNSYLVANIA, INC.**

*.....dedicated to increasing public awareness about acquired
brain injury and to providing support, education, information,
advocacy and other services for individuals with acquired brain
injury and their families.*

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“YOUR BRAIN INJURY HANDBOOK”

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DISCLAIMER

“Your Brain Injury Handbook” was prepared by an organization of survivors and family members to provide limited, general information about brain injury from their perspective. Since each brain injury is unique, the reader is responsible for consulting with appropriate health care and other professionals who can assist in tailoring this general information to meet individual requirements for healing, health, safety, medical treatment, medications, rehabilitation, and other matters.

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PREFACE

The Acquired Brain Injury Network of Pennsylvania, Inc. is an organization of survivors, family members and community supporters focused on “Empowering survivors and family members to rebuild their lives.”

“Your Brain Injury Handbook” is intended to provide general background information on brain injury for affected individuals as well as their families, friends, caregivers, support teams and the general public.

Since this Handbook provides only general information, readers are urged to consult the appropriate professionals before applying this information to themselves or others. Each person with a brain injury presents a unique group of challenges. Since no two people and no two brain injuries are alike, each individual requires an individualized response. One size does not fit all when it comes to brain injury.

Also, since this Handbook reflects the opinions of survivors and family members about brain injury and other fields of interest, you are urged to consult the appropriate professionals in brain injury rehabilitation as well as professionals in the other fields mentioned in this Handbook, before taking action on any of the topics presented.

Many thanks to those who participated in the preparation of this Handbook including: Kim DeKoeyer, Barbara Dively, Shannon Juengst, Peggy Kelly, Stuart Nathans, Sheryll Poris, Joyce Shaffer, Joan Steinberg and Pat Strenk.

Your comments are welcome and will help with ABIN-PA’s periodic revisions.

INTRODUCTION

Brain injury is everywhere and frequently in the news!

Media attention has recently focused on sports concussions and military blast concussions, but you may know of additional examples. Has a neighbor had a stroke? Do you have a relative who experienced memory problems after whiplash or bypass surgery? Has anyone ever spoken to you about feeling “woozy” after a blow to the head, or had a bump from a fall or a lump from walking into a door? Do you know a child who was different after suffering from meningitis or heading a soccer ball?

Most people don't realize that all of these examples represent brain injury.

ABIN-PA would like everyone to understand what brain injury is all about so when it happens, it is not a mystery. Few realize that brain injury affects 1 in 12 Americans.

Whether you are a survivor, family member, professional, or someone who is just trying to understand, we encourage you to enjoy using these pages as a reference.

As you read, keep in mind that brain injury involves an initial event, to which the brain may respond with inflammation and swelling, causing further damage. Medical care may be needed, along with cognitive and physical rest, to heal from this event and minimize long term functional deficits. When physical healing is complete, the brain will organize the long-term repair of any damaged brain cells and their networks. Given enough time and the right circumstances, problems with cognitive (thinking), emotional (feelings), behavioral (actions) and/or physical (bodily) functioning will fade as repair unfolds.

Since everybody knows somebody with a brain injury, everybody needs to understand what brain injury and brain injury recovery are all about!

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1. WHAT IS A BRAIN INJURY?

Can you think of a famous athlete who retired because of a head injury or too many concussions? Has anyone ever spoken to you about the after effects of a blow to the head, a stroke, a bump from a fall, a high fever, or a lump from walking into a door?

An acquired brain injury diagnosis requires:

- 1. an event which occurred after birth was complete,**
- 2. followed by changes in cognitive (thinking), emotional (feelings), behavioral (actions) and/or physical (bodily) functioning that are**
- 3. not due to a neurodegenerative disorder like dementia.**

Changes in cognitive (thinking), emotional (feelings), behavioral (actions) and/or physical (bodily) functioning let us know that some of the brain cells in the networks controlling those functions have stopped signaling. The event itself may be unknown for reasons such as: age, amnesia, ignorance, forgetfulness, no diagnosis, misdiagnosis, or the lack of a witness.

Unfortunately, contrary to the definition above, we now know that brain injury can occur before birth, and that repeated brain injury can cause chronic traumatic encephalopathy (CTE), a neurodegenerative disorder which affects many athletes and has no cure.

The term “acquired” brain injury includes all brain injuries that occurred after birth was complete. One type of acquired brain injury is an anoxic brain injury, caused by a lack of oxygen. Another type of acquired brain injury is a “traumatic” brain injury (TBI) which is caused only by an outside force. There are special federal and state programs which are only available to those with a TBI. Other programs are available to everyone.

Here are the criteria for mild, moderate, and severe traumatic brain injuries (TBIs):

- Mild – Might be unconscious for up to 1 hour. Permanent disability is possible.
- Moderate - Unconscious 1 to 24 hours. Permanent disability is likely.
- Severe - Unconscious over 24 hours. Permanent disability is fairly certain.

Those with an acquired brain injury often have similar problems in cognitive (thinking), emotional (feelings), behavioral (actions) and/or physical (bodily) functioning.

ACQUIRED BRAIN INJURY (all causes)		
Traumatic (TBI) (due to an external force such as assault, fall, whiplash, hit by an object)	Non-traumatic (not due to external force)	
	Anoxic (lack of oxygen – such as a stroke, choking)	All other causes (high fever, poisoning, near electrocution, seizures)

2. INITIAL SIGNS AND SYMPTOMS

Signs are things others observe, while symptoms are complaints that a person reports. If you become aware of any of the signs or symptoms below (especially anything that is unusual for this particular person), always arrange for medical care to rule out increasing pressure in the brain from bleeding or cerebrospinal fluid. Increasing pressure compresses the brain, increasing the risk of disability and death. Since increasing pressure can become life threatening very suddenly, it is very important to get a medical evaluation as soon as signs and/or symptoms are noticed.

Here are some of the signs you may observe that indicate the need for a medical evaluation due to the possibility of a brain injury or another serious condition:

1. answers slowly
2. can't be awakened
3. changes in behavior
4. changes in personality
5. clumsy movements
6. confused
7. dazed or stunned
8. difficulty with arithmetic
9. difficulty with reading
10. difficulty with writing
11. poor memory for events before, during and/or after the time of injury
12. poor memory for recent events
13. poor memory for what was just said
14. unconscious, even briefly
15. unequal pupils or pupils which don't shrink in bright light
16. unsteady or uneven gait
17. unaware of current situation

Here are some of the symptoms a person may complain about that indicate the need for a medical evaluation due to a possible brain injury or some other serious problem:

1. balance or gait problems

2. blurred vision
3. confusion
4. constant hunger or lack of appetite
5. difficulty concentrating
6. difficulty with school, homework, or work
7. dizziness
8. double vision
9. fatigue
10. headache
11. loss of taste or smell
12. memory problems
13. nausea
14. sleepiness or inability to sleep
15. sluggishness
16. weakness

Unfortunately, there is no scan or commercial blood test that captures the disabling microscopic damage of a brain injury. Also, the results of a neurological examination are generally normal. Of course, you can use an X-ray to diagnose a skull fracture or an object penetrating the brain. Also, a CAT scan or MRI will reveal tumors, bleeding into the brain, and distortions from excessive cerebrospinal fluid.

Just remember that every brain injury requires medical attention to rule out the need for life-saving medical care. For example, increased pressure inside the skull due to bleeding, swelling, or excessive cerebrospinal fluid will compress the brain and may cause death as the skull is rigid. For a diagnosis, one could visit the Emergency Room, a neuropsychiatrist, a neuropsychologist, or a physician who knows you well.

Even a mild traumatic brain injury will require cognitive and physical rest plus protection from a “second hit”. After medical recovery, any needed rehabilitation can begin.

3. LATER SIGNS AND SYMPTOMS

Did you know that about 8.5% or 1 in 12 people have a disability due to traumatic brain injury – which is just one type of brain injury? Using this percentage, there would be 1,079,500 individuals with disabling traumatic brain injury in Pennsylvania alone!

The damage caused by a traumatic brain injury is the same as, or very similar to, the damage resulting from any brain injury, regardless of the cause. Can you recognize people with brain injury? Here are some clues.

Look for these physical signs:

1. EYES: uneven eye movements; jerking eye movements, vision seems inconsistent; reacts as if partially blind.
2. HANDS: uncoordinated; weak; slow movements.
3. HEARING: appears deaf or hard of hearing.
4. LIMBS: rigid; weak; spastic; paralyzed; trembling or shaking.
5. SCARS: tracheotomy scar (base of throat); scars or depressions on head, face or neck; head misshapen.
6. SPEECH: difficult; slurred; slow.
7. WALKING: awkward; difficult; uneven gait; stumbling; lurching; struggling on uneven ground.
8. OTHER: extreme fatigue under stress; seizures of various types; difficulty swallowing; brain injury listed on medical bracelet, neck chain or wallet card.

Look for these problems with thinking:

1. disoriented and/or unaware
2. fails to recognize faces, places and/or things
3. ignores change of topics
4. literal or concrete thinking
5. memory issues
6. reacts slowly
7. struggles to find words
8. unable to answer or explain
9. unable to decide
10. unable to follow directions
11. unable to pay attention
12. unable to concentrate
13. unable to rush or go any faster
14. unable to understand

Look for these emotional signs:

1. agitation
2. anxious
3. easily frightened
4. stunned when under stress
5. sudden anger
6. unexpected tears or laughter

Look at how the person is acting:

1. distracted by noise and lights
2. impulsive behavior
3. unpredictable behavior
4. unreasonable response

4. CAUSES

Almost any event can cause a brain injury. These events are easily taken for granted or ignored, but they accumulate. Eventually, a small event may be the final straw and the resulting damage may be great enough to cause a disability. Just remember that any event that is followed by changes in cognitive (thinking), emotional (feelings), behavioral (actions) and/or physical (bodily) functioning has caused neurons to stop signaling.

Events cause brain cell injury in various ways. Here are some examples:

1. Anaphylactic shock – allergy, medication
2. Destruction of brain tissue – brain surgery, fracture, gunshot
3. Electrical interference – lightening, electric shock, radiation, seizure
4. High or low pressure – blast concussion, brain tumor, diving, explosion
5. High or low temperature – fever, frostbite, heat stroke
6. Infection – abscess, bacteria, meningitis, sepsis, virus
7. Lack of blood to carry the oxygen – aneurysm, arteriovenous malformation (AVM), hemorrhage, stroke
8. Lack of glucose – diabetic coma, malnutrition
9. Lack of oxygen (anoxic brain injury) – anesthesia, cardiac arrest, cardiac surgery, choking, near drowning, near suffocation, stroke
10. Lack of water – dehydration
11. Parasites – Lyme disease
12. Physical force (traumatic brain injury) – assault, bicycle or motor vehicle accident, blast, blow, abuse, fall, falling object (baseball, warehouse box), hit by an object (baseball bat, rocks, cinder blocks, two-by-fours), recreation concussion (skateboarding, skiing), shaking, sports concussion, whiplash
13. Poisoning – alcohol, carbon monoxide, chemotherapy, legal or illegal drugs

5. IMPACT OF INJURED BRAIN CELLS

If a skin cell or muscle cell is injured or dies, these cells are quickly replaced and do not affect overall functioning. In contrast, brain cells or neurons are linked into vast networks, connected to each other through their dendrites and axons. One neuron may receive signals from 10,000 other cells.

There are many dendrites on each cell body to receive messages, but only one axon to send a message. Dendrites are like a forest of bushy trees perched on one side of the brain cell or neuron. On the other side of the neuron, there is one single axon which could be microscopic or travel the length of the spinal column. Diffuse axonal injury means that axons throughout the brain have been injured. This is most likely to be the result of a traumatic brain injury involving a shaking force affecting the entire brain as in whiplash or Shaken Baby Syndrome.

Each neuron receives many messages (signals) through its dendrites, decides what action to take, and sends one response (signal) through its solitary axon. Each axon is positioned to “nearly touch” one spot on a dendrite belonging to the next neuron down the line in the network. The location of this “nearly touching” is called the synapse. The neuron signals its axon to release chemical molecules (neurotransmitters) into that synaptic space. After release, the neurotransmitters are collected and used again.

BEFORE BRAIN INJURY

Mental Skills + Feelings + Bodily Functions
(Cognition) (Emotions) (Physical)

This Combination Shapes Your Personal Reality

Your Personal Reality Determines Your Behavior (Action)

When a neuron that is networked with 10,000 other neurons stops functioning, all of its networks will be affected. Important information will be omitted from the decision making process of these networks. Also, cells that fail to receive enough stimulation may become dormant until signals resume.

When a brain cell (neuron) is injured or dies, the structure of the affected neural network (network of brain cells) is compromised and brain chemistry or neurochemistry becomes chaotic. Some of the constant input from eyes, ears, skin, nose, tongue, muscles, organs and receptors for balance, temperature and pressure escapes processing or is processed incorrectly. This biologic disruption produces the familiar signs and symptoms of brain injury. Normal behavior requires the brain to function normally. With these changes in brain function, we have a “new normal” which can be very different, requiring everyone to adjust their expectations, focus on safety and promote brain repair.

6. LONG-TERM EFFECTS

Your brain has 100 billion neurons plus 10 to 50 times as many glial cells for support, nourishment, repair and help in transmitting signals. When injured brain cells fail to send their signals, neural networking breaks down. This change in biologic activity causes observable changes in cognitive (thinking), emotional (feelings), behavioral (actions) and/or physical (bodily) functioning.

After a brain injury, individuals may not realize that they are different and so they may blame their struggles on others. In contrast, others may realize that they are not “themselves” and may be ashamed about their new limitations, grieve their former selves, and be embarrassed at their present state of confusion. This often leads to them to withdraw from social contact and limit their lives to whatever they can manage easily. This new state is the “new normal” and requires long-term personal adjustment, accommodations and rehabilitation. With rehabilitation (formal or informal) the “new normal” will continually shift until recovery is complete. It is extremely important for the person to receive ongoing counseling from brain injury professionals in order to avoid confusing this continuous shifting and related anxiety with mental illness.

The initial medical diagnosis of a mild, moderate, or severe traumatic brain injury refers only to the medical care that will be supplied. Since there is no medical care for mild traumatic brain injury, the individual will generally be sent home from the Emergency Room and merely told to rest. Unfortunately, permanent disability may result from a “mild” traumatic brain injury even though no immediate medical care was necessary.

After medical recovery from the initial event, all three levels of brain injury (mild, moderate or severe) may require long-term rehabilitation. Unfortunately, the amount of the time and the extent of rehabilitation needed to restore function is unpredictable and depends on many factors. The medical severity of the initial injury is only one of the factors influencing the outcome. Other factors include age, education, health, personal determination (found to be the most important factor), family support, funding for rehabilitation, and the number of prior traumatic and non-traumatic brain injuries. When all is said and done, we must provide the best circumstances for the brain to repair itself at the microscopic level, a time-consuming process.

Here are some of the changes in cognitive (thinking), emotional (feelings), behavioral (actions) and/or physical (bodily) functioning that may result from disruption of neural networks:

Cognition (thinking) may be disrupted by missing or incomplete signaling:

Anticipation, answering questions, arithmetic, attention, auditory processing, awareness of others, awareness of self, cause and effect, concentration, conclusions, conversation, decision-making, distraction, focus, following directions, judgment, meaning of words (receptive aphasia), memory (working, short-term, intermediate, long-term), multi-tasking, new learning, organization, pattern recognition, personal identity, planning, prediction, processing speed, reaction time, reading, reasoning, social cues, spatial awareness, understanding, visual processing, word finding (expressive aphasia) and writing.

Emotions (feelings) may be disrupted by missing or incomplete signaling:

Agitation, anxiety, apathy, catastrophic stress reaction, depression, embarrassment, flooding, fright, frustration, grief, irritability, loss of self, mood swings, rage, shame, sudden laughter, sudden tears and terror.

AFTER BRAIN INJURY

**Dead and Injured Neurons
Disrupt Certain Neural Networks**

Causing Chemical Chaos and Missing Signals

Which Result in

Altered Mental Skills (Cognition)	Altered Feelings (Emotions)	Altered Bodily Functions (Physical)
--	--	--

This Combination Creates a Distorted Personal Reality

Distorted Personal Reality Leads to Distorted Behavior (Actions)

Behavior (actions) may be disrupted by missing or incomplete signaling:

Driving ability, egocentricity, family responsibilities, financial management, friendships, hygiene, impulsivity, inertia, parenting, perseveration, social roles, school and work.

Physical (bodily) functions may be disrupted by missing or incomplete signaling:

Appetite, apraxia (unable to initiate), balance, bladder control, blurred vision, bowel control, coma, conversation, coordination, difficulty walking, dizziness, double vision, electrolyte imbalance, gait, headache, hearing, incontinence, light sensitivity, nausea,

motion sensitivity, noise sensitivity, one-sided neglect, paralysis, ringing in the ears, seizures, shaking, sleep schedule, slow or slurred speech, smell, spasticity, sudden and extreme fatigue, swallowing, taste, temperature regulation, thirst, trembling, unequal pupils, unsteady positioning and weakness.

7. CONSEQUENCES

Children

Children need special help because brain injury may interfere with both new learning and with the normal maturation of the brain. The effects of brain injury unfold as the years go by. At first, the differences may appear slight, but the impact generally becomes more pronounced as the child ages. For this reason, it is important to arrange continuing rehabilitation from the beginning, while the reason for such care is still evident to all. As the years go by, the school and physician are less likely to link emerging problems with an earlier injury if treatment has not continued from the date of injury to the present.

On an emotional level, some children will realize that they are not themselves while others will continue to try to do things that are no longer possible. Within a year, friends are likely to be lost and children will do what they must to make new friends. Relatives may also turn away if they believe that the child should have recovered but is being coddled or taking advantage of special treatment.

The idea that children recover more quickly than adults from brain injury is actually a myth. Prior learning allows the child to appear to bounce back when recovering from the medical aspects of the injury, but the functional aspects which prevent new learning must be addressed or the child will fall further behind each year.

Without brain injury rehabilitation, children face the risk of being considered juvenile delinquents. If the child's need for brain injury rehabilitation is not met, 1 in 3 adolescents are arrested within five years of a traumatic brain injury. In addition, three large recent studies found 60% of youth in detention have had a traumatic brain injury.

Children also face the risk of being diverted into the intellectual disability system instead of receiving long-term brain injury rehabilitation. Less than 10% of those with an IQ below 70 by age 22 actually have a genetic neurodevelopmental disorder. Almost all of the rest have had a brain injury through accidents, illness, poisoning or malnutrition and require rehabilitation with the goal of recovery or significant improvement by age 21 when the enhanced childhood coverage under Medical Assistance ends. Beginning at age 21, Medical Assistance no longer covers Cognitive Rehabilitation Therapy (CPT97532), the evidenced-based treatment for restoring cognitive function. Treatment

is available under several other state programs.

Without brain injury rehabilitation, children are also at risk of a mental health misdiagnosis which will further complicate their medical and mental status. Mental health treatment is not considered evidence-based for cognitive recovery from brain injury. Mental health treatment uses medications differently and provides different types of advice and counseling. The side effects of psychiatric medication are greater for someone who does not have a psychiatric condition. Once mislabeled, lifetime mental health treatment may be imposed (generally unsuccessfully), while the lost developmental foundation years under 21 can never be restored and access to brain injury rehabilitation through state programs beginning at age 18 is unlikely.

Adults

Following an acquired brain injury, adults who do not get brain injury rehabilitation are very likely to lose their families, friends, home, career, community role, savings, academic skills, social skills, and parenting skills.

Without rehabilitation, it is more likely that they will utilize publicly funded services for unemployment, homelessness, SSDI (Social Security Disability Income – based on previous contributions), SSI (Supplemental Security Income for those with low income), SNAP (food stamps), mental health, probation, parole, jail, prison, waivers and nursing homes.

Without rehabilitation, 1 in 3 adults will be arrested within 5 years of a traumatic brain injury. While just 8.5% of the general population has had a brain injury, the number is 60% for those in prison, 20% for psychiatric inpatients and 38-63% for those in substance abuse treatment programs (addictiontreatmentmagazine.com). By 15 years post injury, the risk of suicide is five times the rate in the general population, drawing the attention of police, crisis services, and the mental health system under an involuntary commitment (§302).

Senior adults

When seniors experience a brain injury, accurate diagnosis is essential or they will receive a misdiagnosis of mental illness, dementia or Alzheimer's, forever blocking access to brain injury rehabilitation. Further, the rules on restraint will prohibit bed rails and wheelchair seatbelts, resulting in more falls.

All ages

With each traumatic brain injury (TBI), the risk of having an additional TBI increases and the damage is proportionally greater and the recovery time will be longer. The groups with the highest incidence of traumatic brain injury are children and senior adults.

With a series of even mild traumatic brain injuries, there is the risk of chronic traumatic encephalopathy or CTE which has been diagnosed on autopsy in a person as young as 18. CTE is a progressive degenerative brain disorder for which there is no cure.

Traumatic brain injuries may also combine with prior medical events to increase the risk of disability. For example, a very mild whiplash may cause significant impairment if combined with a history of meningitis or a mild stroke.

8. REVERSING THE EFFECTS

Brain plasticity refers to the constant remodeling of the brain that continues from birth to death through the activities of the glial cells. Brain plasticity is responsible for the development of intelligence, the ability to learn new things at any age, and the ability of the brain to reverse the effects of brain injury by repairing itself.

Brain plasticity involves removing dead brain cells, repairing damaged cells, and adjusting or re-routing neural networks. From recent research, we also know that new brain cells may be created as needed.

Brain plasticity is aided by time, passion, determination, and rehabilitation when based on accurate, ongoing assessments.

Enhance plasticity

Brain plasticity is stimulated by activities that are pursued with interest, determination and passion. For this reason, pleasure and individual interests must guide formal and informal rehabilitation. (See “The Brain That Changes Itself” by Norman Doidge, M.D.)

Tips for maximizing your recovery:

1. Notice what you enjoy.
2. Learn what holds your interest.
3. Move away from things that do not hold your interest.
4. Move toward pleasure and interests.
5. Plan activities based on interests.
6. Break activities into small steps.
7. Ask for help if necessary.
8. Set low goals—10% is a success.
9. Change your activities as your interests change.
10. Choose activities that make you happy.

Exercise brings special benefits

Look for programs that provide assistance or a buddy until you are comfortable. Often an organized program will be more helpful, but taking walks or any activity that engages your body will be helpful in promoting brain recovery because it will stimulate the circulation of your blood and improve your outlook, balance and coordination. Several survivors have found companionship and great improvement by participating in triathlon

training groups and competitions.

**RECOVERY FROM BRAIN INJURY THROUGH BRAIN PLASTICITY
UNDER THE DIRECTION OF GLIAL CELLS**

Normal, injured, dead and missing neurons lead to a mix of normal, broken and missing neural networks. Clean-up is handled by glial cells.

CIRCUMSTANCES THAT PROMOTE RE-ROUTING

Time + Assessment + Rehabilitation + Passion + Determination

STIMULATE GLIAL CELLS TO ARRANGE NEW NEURAL NETWORKS

- 1. By retraining for lost cognitive and physical functions**
- 2. By personal adjustment through pacing, acceptance and the constant incorporation of ongoing changes**
- 3. By learning compensatory skills to bypass absent skills**
- 4. By training to use assistive technology to bypass absent skills**
- 5. By learning to re-establish community connections (bank, store)**

**Continually Changing Networks Create a Continually Changing Reality
(Reality under Reconstruction)**

**Continually Changing Reality Causes Unpredictable Behavior While
Impairments are Decreasing (Actions Unpredictable)**

Create a new future

1. Associate with people who respect you and your decisions
2. Apply for all benefits
3. Avoid boring activities that are unnecessary
4. Choose encouraging friends
5. Every day, make the big and little choices required for a new life
6. Get enough food, water, sleep, and rest
7. Take on only as much responsibility as you can handle at the time

9. MINIMIZING CATASTROPHIC STRESS REACTIONS

Who is at risk?

Those with cognitive, emotional, behavioral, and/or physical limitations due to a brain injury may experience an unwelcome biologic “catastrophic stress reaction” (CSR) or “flooding” from excessive demands, including the demands of rehabilitation. This exhausting reaction wastes energy needed for healing, reverses progress, damages self-esteem, interferes with rehabilitation and prolongs recovery. Preventing this reaction is the number one key to recovery. The ability to tolerate stress will increase slowly during recovery and the likelihood of a CSR will eventually fade but never disappear entirely.

What happens?

A CSR involves biologically-driven behavior that is unusual for the individual and beyond their control. After the event runs its course, days may be required for recovery. Behaviors during a CSR may include a frozen state, tears, agitation or violence.

Where will it happen?

Since a catastrophic stress reaction can happen anywhere, it is important to learn which activities, events, or locations are best avoided. For example, crowded stores and loud movies are generally not a good idea. As the brain repairs, less effort will be required to cope with stimulation, so more and more stimulation will be acceptable and the risk of a CSR will be less and less. In the meantime, the brain needs to be protected from excess disturbance.

When will it happen?

The brain shuts down or emotions overflow when the biologic capacity of the brain is exceeded. Think of adding cups of water to a bucket—the last cup is no different from prior cups, but the bucket is now overflowing. Since the cups and bucket are invisible, it is best to err on the side of caution and limit activities on days or weeks when important events are scheduled.

Why will it happen?

A catastrophic stress reaction occurs when the brain is stressed beyond its biologic capacity to respond. Since the cognitive, emotional, behavioral, and physical changes which follow brain injury make even routine tasks much more difficult (or impossible), it is easy to ask too much and overload the brain, resulting in unusual behavior from days in bed to violence. To minimize overload, pay attention to rest, food, water, soothing

activities, signaling, monitoring effort and pacing the day. Learning how to sense an impending overload and forestall an impending CSR is an essential part of brain injury rehabilitation. Those who do not understand and accept their limitations will have a difficult time because they will frequently experience CSRs. For those who do understand, preventing a CSR is their main objective as they go through their day.

Monitor to prevent

Learning the cognitive cost of each situation or recurring task through trial and error is part of the process of recovery. Of course, new activities will always require more effort and temporarily take concentration away from the performance of tasks that were previously mastered. Also, there are daily, weekly and seasonal energy cycles. Do not require participation in extra events or make sudden great changes in daily schedules because the increase in demand can result in months of regression, resembling a prior stage in recovery.

Pace the day, week and seasons

Figure out how many days of the week the person can schedule activities without becoming overwhelmed. Cross off the other days on the calendar for rest. After scheduling one (or two) activities on a particular day, cross off the rest of the day. At times of the year when there are extra demands, other responsibilities and activities will need to be reduced or overload will follow.

Pay attention to the signals

Survivors learn the feelings and sudden difficulties that show stress is rising. They learn to stop what they are doing and switch to another activity, or move into a coasting mode rather than participating. Survivors may need to signal others to walk away to cut short a developing overload. Families must learn to recognize these signals as well as facial expressions, comments and behaviors that warn of impending overload. Once a CSR begins, families learn to step away and say or do nothing until it is over. Professional help will be needed if this strategy is not sufficient.

Soothe away stress

Soothing activities must be available suddenly as needed and also scheduled during the day to keep brain repair at its peak. By decreasing the stress load, the brain is in a relaxed state that allows energy to be directed at healing. This relaxed state also reduces the likelihood of overload. Soothing activities will change over time as more complex options become possible. Soothing activities may progress from time in bed to playing Solitaire to going food shopping as the cognitive cost of each activity declines.

Avoid discussion

A CSR is a biologic reaction just like a seizure that is not under the control of the individual and must run its course. Often, the individual does not remember the event, so questions are not helpful. Attention to rest, food, water and the other factors will help. Consult a neuropsychologist or neuropsychiatrist if these measures are not sufficient.

Here are some soothing strategies that others have used. You will notice that these are

activities which do not involve another person:

Sitting quietly	Lying in bed	Having a shower	Drinking water
Enjoying a pet	Having a snack	Playing Solitaire	Having a meal
Drawing	Taking a walk	Meditating	Doing Yoga
Running	Swimming	Solitary basketball	Knitting
Watching Television	Playing computer games	Cooking	Shopping

10. REHABILITATION

Process

Rehabilitation addresses cognitive, emotional, behavioral and physical challenges and helps survivors and families adjust to a different life.

Rehabilitation is based on various assessments including a neuropsychological evaluation which lists strengths and limitations and provides recommendations. Assessments are repeated periodically so rehabilitation matches current needs.

Therapies are provided by neuropsychologists, occupational therapists, physical therapists, speech and language therapists, and other professionals. Personality, habits, and skills will return slowly with determination and support.

Typical rehabilitation activities include the following:

1. re-training in lost skills such as reading
2. training in compensatory strategies
3. training in assistive technology like reminder watches, communication boards, memory books, date books, computer modifications, etc.
4. counseling to allow processing for grief, anger, and confusion.

How the brain heals

The brain is in charge of its own repair, just like a cut or broken bone must heal itself so that the stitches or the cast can be removed. Unfortunately, the brain must work while it heals. We can't see the healing taking place, but we can notice slow, gradual changes for the better in cognitive (thinking), emotional (feelings), behavioral (actions) and/or physical (bodily) functioning. These improvements result from the self-repair of neurons (brain cells) and neural networks.

We have the ability to promote repair through rest, water, food, interesting activities, and formal therapies such as occupational, physical, cognitive, and speech/language

therapy. Each step is built on prior milestones.

What are “Milestones?”

Beginning at birth, the brain slowly links its neurons or brain cells into the neural networks that allow us to grow up and reach maturity. We mark our barely noticeable progress by milestones such as the first smile, first step, first word, first day of school, driver’s license, graduation, registering to vote, first job, marriage, etc. As yet, there is no pill or treatment that will let us jump from a two-year old brain to a 12-year old brain.

Neural networks

When neurons cannot signal each other following a brain injury, we are prevented from living the life we were enjoying. As the neurons repair, these networks become functional again, and we can resume the activities these networks control such as speaking, swallowing, walking, dancing, driving, having sex, parenting, gardening, swimming, working, planning a vacation, etc. These milestones measure and reveal hidden progress in brain repair.

Brain injury milestones

After brain injury, we re-trace stages in development, repairing the missing links in our neural networks with the help of professionals, family members, and our own determination. Certain milestones tell us that we are ready to tackle the next steps.

1st - Survival—Awake, breathing, swallowing, sitting, walking, etc.

2nd - Activities of Daily Living (ADLs)—Handles hygiene, meals, laundry.

Dressed and is ready to leave the house by 9 a.m.

3rd - Cognition—Can concentrate (30 minutes with distractions), learn, remember.

4th - Behavior—Behavioral agreements with rewards and consequences are sufficient to control verbal aggression, perseveration (persistent repetitive behavior), and poor social skills at home.

5th - Social/Recreation—As behavior improves, behavioral agreements with rewards and consequences are sufficient to control verbal aggression, perseveration and poor social skills in social settings involving other disabled persons and then, with further improvement, in various settings involving the general public.

6th - Academic—Cognitive and social skills are adequate to progress from classes that are online or televised to classes in the community or on college campuses.

7th - Vocational—Job coaching is sufficient to move from volunteer to sheltered work and then to employment with employer incentives while protecting benefits.

11. TERMS AND DEFINITIONS

The world of brain injury has its own vocabulary. While not complete, these definitions will give you a start in understanding what you hear and read.

Anatomy

Axon—Neuron tail which sends signals. From microscopic to several feet long.

Brain Stem—At the top of the spinal cord. Controls heart rate, breathing, etc.

Central Nervous System (CNS)—Includes the brain, spinal cord, and cerebrospinal fluid which cushions them both.

Corpus Callosum—Links brain hemispheres or halves.

Dendrites—Branching extensions of the neuron that receive messages.

Left Cerebral Hemisphere—Enables language, reading, writing, verbal memory, etc.

Neuron—A brain cell including the cell body, many dendrites and one axon.

Right Cerebral Hemisphere—Controls perception of shape, space, emotions, etc.

Medical Diagnosis

Cerebral Edema—Fluid which builds up and squeezes the brain against the skull, its rigid container. May require temporary removal of part of the skull.

Cerebral Hematoma—Bleeding inside the skull which compresses the brain.

Closed Head Injury—skull and dura mater (membrane covering the brain) are intact.

Coma—person does not respond to stimuli but may hear everything.

Concussion, Head Injury, or Traumatic Brain Injury (TBI) – Physical trauma followed by changes in brain function:

- Mild - Unconscious 0 to 1 hour. Permanent impairment is possible.
- Moderate - Unconscious up to 24 hours. Permanent impairment is likely.
- Severe - Unconscious over 24 hours. Permanent impairment is fairly certain.

Coup Contra-Coup Contusion—Bouncing injures opposite sides of the brain.

Diffuse Axonal Injury—stretch, strain, and shearing forces can damage axons throughout the brain (and possibly the spinal cord). This is most likely in a coup contra coup injury where the brain bounces back and forth against the inside of the skull due to an acceleration/deceleration event. Any torque or twisting motion of the head or body will increase the damage.

Left or Right Visual Neglect—unaware of one side, even one side of the body.

Open Head Injury—The skull has been fractured and the membrane covering the brain itself has been damaged or penetrated.

Post-traumatic—Occurring after physical trauma, such as post-traumatic amnesia where an individual has no memory of events right after an accident.

Functional Assessment

Binocular Vision and Accommodation – Tracking. Looking between near and far.

Cognition—the ability to decide, know, multi-task, organize, plan, recognize patterns, remember, solve problems, think, understand.

Field cuts – Absence of vision in one or more parts of the visual field.

Left or Right Visual Neglect—Unaware of things to one side, perhaps even one side of the body. May ignore that side of the body or only eat food on the other side of the plate.

Long-term Memory—older memories are generally intact but retrieval may be difficult.

Neuropsychological evaluation—Measures brain function in cognitive tasks such as pattern recognition, memory, attention, reasoning and sequencing.

Physical Effects of Brain Injury—Any changes in physical function causing paralysis of the voluntary (walking) or involuntary muscles (eye blinking or swallowing).

Short-term Memory Loss—Due to the inability to lay down a memory or lay it down fast enough, the person may be unable to remember what has happened recently or what was just said or done.

Working Memory—Tracks what is happening. Organizes behavior moment to moment and is essential for reading, writing and arithmetic. Allows a person to compare alternatives and reach a decision.

Rehabilitation

Activities of Daily Living (ADL) – independent eating, dressing, bathing, etc.

Allied Health—occupational therapy, physical therapy, speech/language therapy, recreational therapy, cognitive rehabilitation therapy.

Adaptive Equipment/Assistive Technology—devices for independent living such as communication devices, timers, vehicle modifications, walk-in showers.

Cognitive Rehabilitation Therapy (CPT97532) – evidence-based therapy for cognitive recovery. Involves re-learning lost skills when possible, learning new skills and strategies to compensate for lost skills, and learning to cope with losses which can't be addressed yet. As an example, one could re-learn arithmetic skills, learn to use a calculator to compensate for the loss of arithmetic skills, or have someone else pay the bills.

Community Integration—learning the skills needed to return to church, homemaking, parenting, school, social life, work.

Group Home—supervised housing with unrelated individuals.

Instrumental ADLs—independent cooking, driving, shopping, writing checks.

Milestones – achievements that mark the spontaneous return of skills

Medical Tests

Computerized Axial Tomography (CAT Scan)—Multiple x-rays. Cross-section views.

Electroencephalogram (EEG) – records electrical activity in the brain.

Functional Magnetic Resonance Imaging (fMRI) – measures changes in the rate of blood flow and the level of oxygen in the brain in response to brain activity. When an area of the brain is more active, blood flow increases to provide more oxygen. fMRI maps show which part of the brain is involved in a particular activity.

Magnetic Resonance Imagery (MRI)—3-D views using magnetic energy.

Medical Care

Acute Care Hospital—diagnoses and stabilizes the patient.

Nursing Home—A licensed facility which provides supervision and medical care.

Rehabilitation Hospital—Restores essential functions for activities of daily living.

Brief Screening Tools

Glasgow Coma Scale—based on best eye, verbal and motor response for someone emerging from coma.

HELPS Brain Injury Screening Questionnaire—Available free on the web. Asks about events which often cause brain injury and typical symptoms. Widely used.

Mount Sinai Brain Injury Screening Questionnaire (BISQ)—Validated. Not free. Asks about events which often cause brain injury and typical symptoms. May prepay in bulk for online version.

Rancho Los Amigos—Rating scale assesses basic functional performance.

12. PROFESSIONALS WHO CAN HELP

General

Injured brain cells disrupt networks and interfere with cognitive (thinking), emotional (feelings), behavioral (actions) and/or physical (bodily) functioning. Each disrupted network presents an obstacle to your recovery. Professionals can help re-establish breathing, swallowing, hand control, walking, memory, thinking, etc. They can also help survivors: understand and accept their limitations; re-learn academic, social, vocational skills; develop new interests and vocational goals; compensate for deficits; understand, accept and control emotions; minimize fatigue; and avoid cognitive overload and overreaction. To reduce your overall level of disability, you must address each obstacle. These specialists can help.

In the hospital

1. Discharge Planner—finds the right place for further care.
There is no greater responsibility than helping individuals and families with next steps in the long and difficult journey of recovery from brain injury. Survivors and families need help to understand that recovery may be slow, require intense effort, and be incomplete.
 - a. Assess the need and eligibility for further rehabilitation.
 - b. Assess the need for a nursing home.
 - c. Assess the need for Medicare home services (Part A and B).
 - d. Determine the preferences of the individual and family.
 - e. Arrange for adaptive equipment and training if returning home.
 - f. Determine rehabilitation funding sources and begin application process.
 - g. Provide information on the Office of Vocational Rehabilitation.
 - h. Contact the School District for Special Education arrangements and the Intermediate Unit BrainSTEPS Team to plan for school re-entry
2. Insurance Case Manager – monitors progress
3. Neurosurgeon—provides brain and spinal surgery
4. Social Worker—provides information and resolves problems

Medical Assessments

1. Audiologist—hearing
2. Behavioral Optometrist— evaluates functional vision

3. Endocrinologist—hormone imbalance is common after brain injury
4. Ear Nose and Throat Physician—addresses swallowing, breathing, voice problems
5. Neurologist— diagnoses seizures, strokes
6. Neuro-ophthamologist— fits corrective lenses, diagnoses medical problems as revealed through the eyes
7. Neuropsychiatrist—diagnoses brain injury, prescribe medication
8. Neuropsychologist— evaluates and advises on cognition and behavior
9. Physiatrist—plans and supervises physical medicine rehabilitation

Rehabilitation

1. Behavioral Optometrist— restores binocular vision (tracking with two eyes together – 3-D vision) and focusing, provides solutions for “low vision”
2. Cognitive Therapist—restores reading, writing and problem solving
3. Life Skills Coach—retrains for daily activities
4. Occupational Therapist—fine motor, self-help skills, Cognitive Rehabilitation Therapy (CPT97532 Medical Assistance for children), sensory integration
5. Physical Therapist—restores gross motor skills
6. Recreation Therapist—improves cognition and social skills
7. Speech-Language Pathologist - restores speech and cognitive skills

Coordination and Services

1. Case Manager – monitors care and progress
2. Special Needs Coordinator—arranges physical health managed care
3. Supports Coordinator—manages personal waiver services

Financial and Legal

1. Financial Planner—creates plan for lifetime care
2. Lawyer – Personal Injury – paid a percentage of the result
3. Lawyer – Social Security Disability – paid a percentage of the result
4. Lawyer – Tax – paid out of pocket
5. Lawyer—Workers’ Compensation – paid a percentage of the result
6. Special Needs Trust – preserves lifetime public benefits

Independent Living

1. Assistive Technology – equipment for independent living, modifications for home and vehicle, accessible transportation
2. Center for Independent Living—general guidance on available resources
3. Direct Care Workers – assist with mobility, hygiene, and daily activities—available under a Waiver or the local Department of Aging

Children

1. BrainSTEPS – trains teachers, attends IEP meetings—contact Intermediate Unit
2. Occupational Therapist—CPT 97532—Cognitive Rehabilitation Therapy
3. Primary Care Physician – assessment and rehab referrals

4. Special Education—contact the school district/Intermediate Unit

Holistic Alternatives

1. Acupuncture – addresses pain and function with or without needles
 2. Chiropractic – manipulates the spine to relieve pressure on spinal nerves
 3. Homeopathy – addresses cognitive, emotional and physical issues
 4. Hyperbaric oxygen therapy – stimulates brain restoration
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13. FUNDING AND BENEFITS

After a brain injury, years of rehabilitation may be required before people can be self-supporting or even living independently again. During this time, expenses and responsibilities continue—and there is the added cost of needed care – while the extent of recovery remains unknown. Reality lies between total recovery and total disability, so all possible sources of income and benefits must be pursued for financial security.

Affordable Health Care Act

Use marketplace.gov / 800.328.2596 during signup periods, whenever coverage is lost, and whenever there are changes in life circumstances. The average premium is \$69 per month.

Aging Waiver – 60+ (no upper age limit)

This Waiver is offered by the state Department of Aging through the local county Area Agencies on Aging (see the blue pages of your telephone book). This waiver includes personal assistance and some other benefits. The application includes an assessment by the Area Agency on Aging and financial approval by County Assistance. Each county or jointure may have a different name for their local county Area Agency on Aging.

Assistive Technology (AT) – Loans

For low interest, long-term loans to purchase assistive technology, contact:
Pennsylvania Assistive Technology Foundation
888.744.1938 or 484.674.0506

Assistive Technology – Temple’s Institute on Disabilities

Pennsylvania’s Initiative on Assistive Technology has several different programs. Funding for purchase of assistive technology devices may be available through EPSDT or Waiver Programs. Low interest, long-term loans are available through the Pennsylvania Assistive Technology Foundation.

- **Device Demonstrations**—A hands-on opportunity to learn more about different AT devices so individuals can make an informed choice about what will work best for them. For more information, email ATdemo@temple.edu.

- **Device Loans**—Pennsylvanians of any age and ability can borrow AT devices, at no cost, to try at work, school, home or in their neighborhoods. This short-term loan program has a "try before you buy" philosophy, and helps people with disabilities and their families make the right choice of AT devices before they obtain a device. For more information, email ATlend@temple.edu.
- **Device Reutilization**—Previously owned devices are an affordable option instead of buying new equipment. Several options are available to Pennsylvanians, including classified listings of used devices (REEP) and refurbishing programs (Into New Hands, Changing Hands and Liberty ReTreads). For more information, email ATreuse@temple.edu.
- **Training**—Outreach to service providers to increase their AT-related knowledge and skills to better support people with disabilities. For more information, email ATinfo@temple.edu.
- **Technical Assistance**—Outreach to public and private agencies to develop and improve policies related to AT as well as transition from school to work or from nursing home to community living. For more information, email piat@temple.edu.
- **Public Awareness Activities**—Information and referral which educates consumers, via phone, email or letter, about their choices of AT devices and services; AT exhibits and presentations at conferences, group meetings, staff in-services, and other events; and Case Management to help consumers navigate the maze of funding options available to obtain needed AT. For more information, call 1-800-204-7428 (800-204-PIAT) or email ATinfo@temple.edu.

COMMCARE Waiver – 21+ (no upper age limit)

This Waiver is offered by the Department of Public Welfare Office of Long-Term Living through the Pennsylvania Independent Enrollment Broker (IEB). Contact the IEB at 800-550-4227. This waiver is for people with a traumatic brain injury. This waiver includes rehabilitation, some housing options, personal assistance and some other benefits. The application includes a visit from the IEB, an assessment by the Area Agency on Aging, and financial approval by County Assistance.

Commercial Health Insurance

Check your benefits for Cognitive Rehabilitation Therapy or CRT (CPT97532) as this therapy is considered evidence-based for cognitive recovery after brain injury. CRT is covered by many commercial health insurance plans.

Crime Victims Compensation

Search on Victims Compensation PA. File online or call 1.800.233.2339. Expenses of up to \$25,000 are available and this could help pay for brain injury rehabilitation if other funding is not available. Call to find out eligibility criteria.

Financial Planning

Your social worker, attorney, and financial planner can help. Also check these links:

1. ARC Community Trust of PA – www.arctrust.org
2. Certified Financial Planner Board of Standards, Inc. – www.cfp.net
3. NAMI Special Needs Trust (enter into Search engine)

4. Special Needs Alliance—attorneys association for special needs - www.specialneedsalliance.com
5. Wrightslaw.com - “planning for the future”

Head Injury Program – 21+ (no upper age limit)

This program is offered by the Department of Health to those who are not being served by a waiver. Call 717.772.2762 to apply. This program requires a traumatic brain injury which occurred to a Pennsylvania resident after July 2, 1985. The PHIP offers one year of brain injury rehabilitation at a maximum of \$100,000 plus 6 months of transition counseling. One of the waivers may be helpful after the Head Injury Program ends.

Income – Present

1. automobile—lost wages
2. copyrights, patents, royalties
3. disability policy—short or long-term, employer or private
4. dividends - stock
5. employment, wages or business interests – partnership, sole proprietor, business owner, executive with complex benefits
6. interest – bank, CD’s
7. pension—former employer or a private plan, option for spousal continuation
8. Social Security Disability Income
9. Supplemental Security Income

Income – Future

1. accidental death or dismemberment insurance
2. inheritance
3. lawsuits – personal injury, medical malpractice, other
4. Social Security Retirement

Independence Waiver – age 18-59

This Waiver is offered by the Department of Public Welfare Office of Long-Term Living through the Pennsylvania Independent Enrollment Broker (IEB). Contact the IEB at 800-550-4227. This waiver requires limitations in 3 of 5 functional areas and includes personal assistance along with other benefits. The application includes a visit from the IEB, an assessment by the Area Agency on Aging, and financial approval by County Assistance.

Legal Advocacy – all ages (see boxed insert below):

When brain injury causes difficulty with memory and thinking, legal issues are a challenge. Get the very best legal representation, keep a record of phone calls, and organize papers in file folders. Family members or a guardian may need to assist. See boxed insert for some organizations that provide legal advocacy.

Medical Assistance (MA) – 21+ (no upper age limit)

MA is available for low income adults with a disability but does not cover Cognitive Rehabilitation Therapy (CPT97532), the treatment which is evidence-based for the recovery of cognitive function after brain injury.

LEGAL ADVOCACY PROGRAMS

Client Assistance Program - 888.745.2357

For help with state programs such as the Office of Vocational Rehabilitation, etc.

Disability Rights Network – 800.692.7443

For help with special education, Social Security, Ticket-to-Work, Traumatic Brain Injury, etc.

Legal Aid – 800.322.7572

For people with low income.

Legal Clinic for the Disabled – 215.587.3350 (Philadelphia)

For people with disabilities. Will provide contacts statewide.

Pennsylvania Health Law Project – 800.274.3258

For help with publicly funded health plans.

Women’s Law Project – Eastern PA 215.928.9801

Women’s Law Project – Western PA 412.281.2892.

Medical Assistance (MA) – 0-20

MA is available for all disabled children under 21 in Pennsylvania regardless of parent income. Apply through a social worker at the hospital, online through COMPASS or through the County Assistance office. Children whose parents are not low income are called “loophole children”. Under federal Medicaid law, states must provide Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services to all Medicaid-eligible children regardless of the state Medicaid plan and without requiring that a child apply for a waiver. EPSDT includes all necessary services to ameliorate whatever condition the child has under Section 1396d(r)(5).

Under EPSDT, Pennsylvania pays for Cognitive Rehabilitation Therapy (CPT97532) when provided by a licensed occupational therapist to a child under age 21. Cognitive Rehabilitation Therapy is considered evidence-based for cognitive recovery from brain injury. All children with a brain injury should be followed until they are 21 as problems will emerge throughout the years along with maturation. With a physician’s referral, the Special Needs Unit in the physical health managed care plan can assist in finding providers. Contact the Special Needs Unit in the Department of Public Welfare (800.521.6860) for assistance.

Other therapies such as physical therapy, vision therapy and speech/language therapy may also be needed. Medication issues should be handled by a knowledgeable neuropsychiatrist to avoid diversion into the mental health system. Children may also require a neuropsychological assessment for home, school and rehabilitation recommendations. Parents should secure written denials for any denial of service, contact ABIN-PA, and file an appeal.

Medical Benefits

1. Affordable Care Act marketplace – www.healthcare.gov
2. automobile—first party medical benefits
3. CHIP (all children from families who are not Medicaid-eligible)
4. ELKS Nurses—free care coordination if disabled under age 22
5. employee health insurance, or COBRA extension
6. Head Injury Program – Department of Health
7. long-term care policy
8. Medical Assistance—all disabled children regardless of parent income or assets and disabled adults with limited income and assets
9. Medicare—waiting period of 24 months after disability entitlement begins under Social Security Disability — in-home care in Parts A and B
10. private health insurance
11. waivers – Department of Public Welfare
12. Worker’s Compensation (expenses related to an injury on the job)

Medical Malpractice Claims - attorney takes a percentage of the settlement

Medicare

Coverage begins at 65 or two years after entitlement to Social Security Disability benefits begins. Part A covers hospital visits. Part B covers physicians. Part D is for drugs. Part A and B include some in-home care. For Medicare coverage, call 800.633.4227. For Medicare denials, call 800.322.1914.

Motor Vehicle Accidents – if you are at fault

1. Notify your insurance company immediately. Your company pays your medical benefits, uninsured and underinsured motorist claims, lost wages and car repairs.
2. If you are at fault, your insurance company pays for your attorney and any decision against you.
3. As soon as your auto insurance medical benefits are exhausted, you must send all further medical bills to your health insurance plan without delay.

Motor Vehicle Accidents – if you are not at fault

1. Notify your insurance company immediately. Your company pays your medical benefits, uninsured and underinsured motorist claims, lost wages and car repairs.
2. If you are not at fault, find a personal injury lawyer who will get a percentage if you win.
3. As soon as your auto insurance medical benefits are exhausted, you must send all further medical bills to your health insurance plan without delay.
4. When reviewing a settlement offer, consider the lifetime costs, any possible delay before trial, the possible jury outcome and any other factors that are relevant.
5. Consider a Special Needs Trust to protect public benefits.

OBRA Waiver – age 18-59

This Waiver is offered by the Department of Public Welfare Office of Long-Term Living through the Pennsylvania Independent Enrollment Broker (IEB). Contact the IEB at 800-

550-4227. This waiver requires that the person was disabled prior to age 22. This waiver includes rehabilitation, some housing options, personal assistance and some other benefits. The application includes a visit from the IEB, an assessment by the Area Agency on Aging, and financial approval by County Assistance.

Public Benefits

Check income/asset limits, repayment requirements

1. Aging and Disability Resource Centers (LINKS)
2. childcare
3. County Assistance Office
4. County Office on Aging
5. food stamps (SNAP)
6. heating costs (LIHEAP)
7. home modifications, tax rebates
8. HUD Section 8 vouchers
9. Meals on Wheels
10. Medical Assistance Transportation for medical appointments
11. Shared Ride for Persons with Disabilities
12. Temporary Assistance for Needy Families (TANF—with children)
13. waivers—Attendant Care and Independence for in-home care.
14. waivers—COMMCARE and OBRA also include rehabilitation, housing

Private Assets

1. annuities
2. collections – art, coins, stamps
3. home equity
4. investments, IRA's, 401(k) plans
5. life insurance or cash value
6. real estate investments
7. savings, Certificates of Deposit (CD's)
8. trusts

Public Schools – to age 21.

There is a BrainSTEPS Team in every Intermediate Unit to assist teachers to accommodate children with brain injury. Also, Special Education (IEP) and §504 plans provide school accommodations. Graduation can be delayed to age 21. Find a special education attorney for help with a §504 plan or IEP.

Scams

People with disabilities frequently lose money through scams. Avoid prizes, trips, contracts, investments, land sales, inventory, business offers, loan requests and special deals. Don't sign anything or give out personal, banking or credit card details before seeking advice from a long-term trusted relative, friend, advisor or attorney. Consider a guardianship if circumstances warrant - Google "Guardianship in PA Disability Rights Network" for more information.

Social Security

For questions, call 800.772.1213.

Social Security Disability Income (SSDI)

SSDI requires a certain number of paid quarters. SSDI generally involves several rejections and takes several years. Apply through your local Social Security office or online. If rejected, get help from a Social Security attorney. The attorney will be paid a percentage of your benefit. If you are on SSDI and you return to work full or part-time, there are complicated rules for retaining your benefits as long as possible. Contact the Disability Rights Network at 800.692.7443 for information.

Supplemental Security Income

SSI requires disability plus low income and assets. Contact your County Assistance Office. If you are on SSI, there are complicated rules for retaining benefits when working full or part-time. Contact the Disability Rights Network at 800.692.7443 for information.

Workers' Compensation (WC)

WC pays you for lost wages and accident-related bills if you have an injury while on the job. Continue rehabilitation until you recover fully. Continue lost wages as long as possible as complete recovery takes a very long time. You need to restore your cognitive skills, social skills, and stamina before taking a 40 hour per week job that continues month after month without time off. Many survivors do not regain the stamina needed for a full-time job. Since your Workers' Compensation attorney receives a percent of your settlement, you may experience pressure to settle prematurely. Consult a trusted source when deciding when you should settle your case. Some people receive benefits for a lifetime – both income and accident related medical payments.

14. TIPS FOR SURVIVORS

Greetings!

You are now one of the 21 million Americans who live with the effects of brain injury. If you are like most, you will continue to improve each year and build a life of meaning, joy and value. Since 8.5% of Americans have a disability related to traumatic brain injury alone, and there are 12.7 million residents in Pennsylvania, there are more than a million Pennsylvanians who understand what you are going through.

Educate Yourself

Once you have a brain injury, you need to educate yourself about how to deal with it and promote recovery. Visit the ABIN-PA website at www.abin-pa.org and try all the buttons! Check out the Beginner Box. Read our "Stories of Hope." Click on "Buy at Amazon" and search on "brain injury." Also search the Internet for "brain injury" and

“brain injury rehabilitation.” You will find a world of information! Read “The Brain That Changes Itself” by Norman Doidge, M.D. Try out www.givebackorlando.com. Check out the physicians’ toolkit at www.cdc.gov, your Intermediate Unit BrainSTEPS program or brainsteps.net, and also lapublishing.com and lumosity.com.

Get Help

Your determination controls the outcome to a great extent but additional help can be useful:

1. Call the resources listed in this booklet and visit the websites that are mentioned so you have the information needed to modify your rehabilitation plan as your needs change.
2. Let professionals help you identify your strengths, decide what to work on, choose strategies and break activities down into small, easy steps. Be sure the skills of your current brain injury rehabilitation provider match your current needs.
3. Build a support group of people who are committed to your recovery over the long haul—and show you care about them as well!

Aim High

1. Based on animal studies, the brain repairs itself!
2. Enjoy what you can do today and know you will do better shortly.
3. Have patience with others when they try to help you.
4. Make gratitude your attitude.
5. Plan around your limitations so you don’t need to apologize.
6. Sometimes a little extra time is all you need. Don’t rush.
7. Take advantage of hope.

Rely on Your Interests!

Much to everyone’s surprise, interesting activities increase the number of brain cell connections, no matter what the age of the person. Mindless activities don’t help, so pursue activities you are passionate about. Try old hobbies, new hobbies, computer games and workbooks. Find out what you enjoy and find a way to do it—maybe with a little help. This will cause your brain to repair. Stay busy and have fun to promote healing!

Art	Books	Camera	Church	Cooking
Computer	Crafts	Exercise	Family	Food
Travel	Tropical Fish	Fishing	Friends	Games
Magazines	Movies	Music	Pets	Plants
Pool	Sewing	Singing	Sports	Volunteering

Never Give Up

Progress continues every year as the brain remodels from birth to death (brain plasticity). Meanwhile, make each day something to celebrate. Smile! Help others. Try new things. Fortunately, most survivors far exceed the predictions others have made, so make recovery your goal.

That 18 Month Limit?

Fortunately, the brain repairs year after year. Plateaus are temporary. Let us know if you are told that improvement ends at 6, 12 or 18 months. Spread the word—there is no limit and no need to give up!

The Universal Journey to Recovery

1. Be kind to yourself and others.
2. Become aware of your surroundings.
3. Do as much as you can yourself.
4. Enjoy something every day.
5. Get help from people you trust.
6. Give yourself credit for trying.
7. Learn about assistive technology.
8. Put safety first.
9. Promise only what you can deliver.
10. Re-learn what you can.
11. Take responsibilities seriously.
12. Understand your limitations.
13. Work around your limitations.
14. Never give up!

Signs of Success

You will usually be calm, content and eager to start your day. Setbacks will be seen as inevitable but temporary. These signs are your guide to the best path. When you don't know what to do next, or when your rehabilitation providers don't offer a clear direction, look for the path that gives you a sense of satisfaction and encouragement.

Maximize Your Success

1. Celebrate every achievement.
2. Don't create a timeline.
3. Drink water, eat regularly, rest.
4. Focus on easy activities.
5. Focus on your effort, not the outcome.
6. Live gently within your limitations.
7. Rest before and after making an effort.
8. Set success at 10%.

Progress will be Slow

When you first start new activities, familiar activities may not go as well. While your brain is “defragging” for efficiency, you will need to rest. When your brain is repairing deeper structures, progress is often hidden, reaching a plateau, but then leads to sudden improvement.

Your Attitude Is the Key

Don't waste energy on unproductive lines of thought. Stay positive, hopeful and determined. You have a future! You are moving forward every day. Surround yourself

with positive people and focus on the road ahead.

15. TIPS FOR FAMILIES

Choosing to Care

The help of family members is crucial to recovery and a pleasant life. The attitude of the family is the key. At first, families must make a lot of decisions for survivors, but recovery requires survivors to do more and more for themselves—not so easy to watch!

In the Hospital

In formal settings, authority figures are in control but families have an essential role to play. Families have the only familiar faces, the only knowledge of life history and preferences. Families can create a feeling of hope, family warmth and joy for survivors despite outward reality. After coma, survivors report conversations they overheard!

Hospital Discharge

Discharge to home, a parent's home, a rehabilitation provider or a nursing home is based on need and funding. Whatever the location, the family must fill in the gaps and keep the person accountable for whatever tasks they are able to perform. Abilities are rarely clearly evident and change from day to day. Interest and safety are the guides.

Emergency Room

Discharge from a hospital emergency room is generally to home. While further medical care may not be required, the caregiver must watch for immediate signs of trouble as listed on the hospital discharge sheet and return the loved one to the Emergency Department if needed. The caregiver must also watch for changes in cognitive (thinking), emotional (feelings), behavioral (actions) and/or physical (bodily) functioning that may require visiting the primary care physician to arrange for rehabilitation.

Emotions

Families experience a roller coaster of emotions every day, depending on the survivor's level of function at the moment. Waves of fear, gratitude, despair, grief, anger and humor may keep you off balance and exhausted. You may mourn the person you knew and the future you imagined. At the same time, you may be angry that no one is helping or that the survivor isn't kind or doesn't try hard enough. As recovery proceeds, you will be reacting to daily changes and experience two steps forward and from one to three steps back. Go to the ABIN-PA homepage "Beginners Box" for an overview.

Family members are the most important people the survivor has.

They must be sure to get enough rest, eat well and attend to self-care (medical, dental and vision care). They must maintain their cars, homes, bills and friends. They will each

need a circle of support, respite, whatever financial benefits are available, spiritual connections, paid help if needed, changes in other priorities and a forgiving attitude. This is not a short sprint, but a daily marathon.

Impact on Families

Changes due to brain injury often mean that the child or adult acts differently. Learn about brain injury and how recovery unfolds in order to reduce frustration. It is possible that survivors cannot fulfill their normal responsibilities, they may experience alarming fatigue at any time, and their achievements may slide when starting new activities. Everyone will be experiencing a wide range of emotions while trying to work together. Recovery takes a lot of effort over many years and may plateau sporadically.

Of course, family roles and responsibilities must shift to embrace the “new normal.”

- **Spouse/Partner**—May seem like a child or a total stranger. Patience is essential. Personality usually returns. Use coaching, cuing, reminders and supervision. Assure the safety of the survivor and others.
- **Parent**—Children need time with the injured parent and also with loving relatives who can create close relationships. Supervise all childcare by the injured parent to assure safety until parenting skills return. Monitor the ability to make safe decisions, because this ability will change constantly.
- **Child**—Protect from another brain injury (concussion). Arrange long-term rehabilitation through age 21. Use the BrainSTEPS program at school to age 21. Arrange for the transition to adult benefits at 18 and/or 21.
- **Seniors**—Avoid misdiagnosis of dementia, Alzheimer’s or mental illness. Arrange rehabilitation. Monitor medication, diet, weather and hydration.

Celebrate the Journey

Most survivors far exceed the initial predictions made about their lives because the brain keeps repairing itself with stimulation. (“The Brain That Changes Itself”, Norman Doidge, MD.) Keep the big picture in mind. Keep hope and laughter at your fingertips. Use humor and find something to enjoy every day.

Have You Noticed...?	Could You...?
1. Slower thinking.	1. Speak more slowly.
2. Slower reaction time.	2. Wait for answers. Plan for safety.
3. Speech is difficult.	3. Expect short answers.
4. Mind tires easily.	4. Reduce stimulation. Provide rest.
5. Body tires easily.	5. Arrange frequent rest breaks.
6. Decisions are difficult.	6. Offer simple choices slowly.

7. Noise overwhelms.	7. Minimize noise. Provide ear plugs.
8. Becomes confused in a group.	8. Remain close by. Avoid groups.
9. Tasks are not completed.	9. Coach using small steps, cards.
10. Tasks are not familiar.	10. Give shorter/easier tasks.
11. Responsibilities are ignored.	11. Simplify responsibilities.
12. Unable to understand.	12. Gently change the subject.
13. Prefers to be left alone.	13. Assure quiet times.
14. Shows strong interests.	14. Help carry out interests.
15. Easily upset.	15. Rehearse plans. Remain calm.
16. Easily confused.	16. Simplify the situation.
17. Poor memory for recent events.	17. Promote using a memory book.
18. Poor memory for future events.	18. Promote using a date book.
19. People/faces unfamiliar.	19. Use pictures or remind.

16. RETURNING TO WORK

At some point in your recovery, you may want to return to work. At that point, volunteer work may be needed to build stamina. Then, you might try part-time work, a reduced workload, or a shift in job tasks, depending on your progress to date. The Office of Vocational Rehabilitation and one of the waiver programs may be able to assist you with vocational rehabilitation.

Keys to Success

1. ability to do the job
2. accommodations
3. returning to work at the right time
4. social skills

Preparing for success at work

1. Complete your medical treatment.
2. Complete your rehabilitation.
3. Regain your stamina through full or part-time volunteer work with regular hours.
4. Re-establish your social skills in many different settings.
5. Participate in vocational assessment and training.
6. Re-establish any needed academic or vocational skills.
7. Learn how to use needed accommodations and adaptive equipment.
8. Take advantage of pre-vocational training under a waiver.
9. Consider a job coach through the Office of Vocational Rehabilitation.

Job accommodations you may need

1. a “buddy” to help with the rough spots
2. a go-to-person who will always be available to answer any questions
3. advance notice of changes
4. assistive technology
5. calm, quiet location
6. date book
7. safety planning
8. environmental modifications
9. flexible hours to fit best time for mental alertness
10. frequent rest breaks
11. memory book
12. picture directions
13. reminders
14. repeated training
15. simplified social obligations
16. written directions

Barriers to success

1. absence or lateness
2. attitude of other workers
3. changes in job requirements, setting, or supervision
4. irregular transportation
5. poor social skills
6. shift work or irregular hours

Employer Resources

Your local Office of Vocational Rehabilitation has information, resources and programs to help employers hire workers with disabilities and retain workers who become disabled. Check online or in the telephone book blue pages.

Employer Incentives

- Architectural/Transportation Tax Deduction for removing barriers

- On-the-Job Training - specific skills for a specific job
- PA Employment Incentive Tax Credits for hiring recipients of public assistance or OVR services
- Small Business Tax Credit for being accessible
- Work Opportunity Tax Credit (WOTC) for hiring targeted groups (veterans, etc.)

Employee Resources

- Job Accommodation Network - job accommodation suggestions
- Office of Vocational Rehabilitation - evaluation, job training, job placement, and job coaching
- PA CareerLink - general help for job seekers
- PA Head Injury Program - one year of rehab, \$100,000 max.

17. HOLISTIC OPTIONS FOR RECOVERY

Holistic Healing

Conventional medical care saves many lives that would otherwise be lost, but there is often a delay in functional recovery. Once conventional medical care accomplishes what is possible, you may be drawn to explore holistic options. There are many different options, but most stimulate the self-healing capacity of the body.

Here are a few pointers to help you make the best of your situation by respecting the role of medical care while looking for further improvement.

Healing Strategies and Medical Care

Talk to your doctor before trying any holistic healing options. Ask if your plans will interfere with your medical treatment. If your physician doesn't object, try one option at a time so you can tell what is helpful. Keep your doctor aware of any changes.

These forms of healing do not take the place of medical care. Be sure to get the medical treatment you need. Follow the advice and direction of your physician. Do not change your prescription medications without talking to your physician.

A Few Holistic Options

There are many healing options to explore – and you may enjoy lectures, books, or classes as a way to investigate some of these options. Each path has followers and a certain culture which can be very enticing. Remember your own goal of recovery as you explore what is available. You may also be able to learn things that help others, and perhaps you will also make new friends. If you have lost friends due to being somewhat different than they remember, it is very nice to have new friends.

Acupressure	Acupuncture	Alexander Method
Art and Art Therapy	Ayurveda	Behavioral Optometry
Biofeedback	Chiropractic	Cranio-Sacral
Ecological Medicine	Essential Oils	Feldenkrais
Feng Shui	Herbs	Homeopathy
Hyperbaric Oxygen	Interactive Metronome	Jin Shin Jyutsu
LENS Neurofeedback	Massage	Meditation
Music and Music Therapy	Neurofeedback	Nutrition
Oriental Medicine	Organic Whole Foods	Orthomolecular Medicine
Pet Therapy	Polarity	Qi Gong
Recreation Therapy	Reflexology	Reiki
Shiatsu	Sound Therapy	Tai Chi
Therapeutic Riding	Therapeutic Touch	Touch for Health
Trager	VitalStim	Yoga

Hyperbaric Oxygen

In www.abin-pa.org "Library," scroll down to the hyperbaric oxygen section for the SPECT scan report on brain regeneration and the 15 minute video on Curt Allen's 10-month recovery from being totally helpless to walking and joking.

Homeopathy

For the National Institute of Health pilot study on the use of homeopathy for older brain injuries, go to the Journal of Head Trauma Rehabilitation article on the website of the National Center for Homeopathy.

Research Your Holistic Healing Options:

1. Search the Internet.
2. Go to www.abin-pa.org and check out "Links" and "Alternatives."
3. Ask for personal recommendations.
4. Attend classes or seminars.
5. Read books.
6. Interview practitioners.
7. Ask your physician.

Questions to Ask A Practitioner

1. Are there any contraindications?
2. How many sessions are needed to find out if this is helpful?
3. What is the cost of each session?
4. What is the total cost for all the sessions I will need?
5. Will you be asking me to pay the cost for more than one session at a time?
6. Are there added costs?
7. Will there be papers to sign? (Ask someone to review these with you.)

Questions to Ask Yourself:

1. Does my physician object?

2. Can I afford this treatment?
 3. Do I have the stamina to undergo this treatment?
 4. How long shall I plan to try this choice?
 5. Should I really pay for more than one session at a time?
 6. Should I really sign anything?
-
-

18. DOMESTIC VIOLENCE CAUSES AND FOLLOWS BRAIN INJURY

PA Coalition Against Domestic Violence

6400 Flank Drive, Suite 1300
Harrisburg PA 17112

PH: 1.800.932.4632; TTY:1.800.553.2508; FAX: 1.717.671.8149

LEGAL OFFICE: 1.888.235.3425

TTY: 1.800.553.2508; FAX: 1.717.671.5542

NATIONAL: 1.800.537.2238

TTY: 1.800.553.2508; FAX: 1.717.545.9456

SERVICES BY COUNTY:

www.pcadv.org/Find-Help/Domestic-Violence-Services-By-County.asp

Domestic abuse often causes brain injury

Research indicates 66% of residents at one shelter had a concussion or traumatic brain injury in the prior 12 months. Two women at that shelter had ten (10) concussions during that period of time. All of these women need an evaluation to determine whether they require brain injury rehabilitation. Their counselors may need special training, because this injury generally interferes with conversation, decisions, memory, planning, reading, writing and math.

Many domestic abusers have had a prior brain injury.

One study indicated that 48% of batterers (but only 8.5% of the general population) had a history of concussion or brain injury. A prior brain injury will interfere with anger-management programs and other services for batterers and will therefore have a negative effect on a victim's safety. Batterers should be referred for a brain injury evaluations and any necessary brain injury rehabilitation to prevent further battering.

Long term disability higher after "second hit"

Having a second impact before the first brain injury has healed will greatly increase the risk of permanent deficits and may even cause death. Medical attention for each brain injury is essential. Some authorities urge three months without any danger of re-injury.

Things to consider

1st – Location – Get to a safe place where help is available.

2nd - Medical Care – Get medical care to rule out bleeding in the brain, a skull fracture, spinal fractures, etc.

3rd – Rest – Plan sufficient cognitive and physical rest to avoid long term disability.

4th – Accommodations – Provide necessary accommodations within shelter and counseling programs.

5th – Safety Plans – Prepare a safety plans that brain injury survivor will be able to follow to prevent a “second hit”.

6th – Funding – Arrange funding for medical care and brain injury rehabilitation under health insurance, Medicaid, Medicare, the Pennsylvania Head Injury Program, the Office of Vocational Rehabilitation, the COMMCARE Waiver, Crime Victims’ Compensation, and Victims’ Services.

19. SENIOR FALLS AND BRAIN INJURY

Falls lead to brain injury!

According to the Centers for Disease Control and Prevention, “People age 75 and older have the highest rates of TBI-related hospitalization and death. In addition, they recover more slowly and die more often from these injuries than do younger people.” Falls are the greatest cause of brain injury in seniors (www.cdc.gov).

Take steps to prevent falls at home:

1. Clear objects from floors and steps.
2. Create clear pathways.
3. Do not walk over wires or cords.
4. Fix loose handrails on steps.
5. Install grab bars for tub, toilet.
6. Remove or tape down loose rugs.
7. Replace burned out light bulbs.
8. Replace loose or torn carpet.
9. Use a tub mat or non-slip strips.
10. Wear an alarm device to call for help.

Keep yourself safe!

1. Schedule a medication review with your doctor and your pharmacist to prevent drug interactions, drowsiness and dizziness.
2. If you are using a blood thinner, see the doctor for every bump or blow because you may have internal bleeding.

3. Consider exercise and strength training to improve balance and decrease falls.
4. Keep vision appointments up to date to prevent falls.

Get good care

Many physicians are uninformed and may confuse brain injury with dementia. Instead, see a neuropsychologist or a neuropsychiatrist for diagnosis and treatment.

Tips for recovery

1. Address substance abuse.
2. Be careful with prescription drugs.
3. Consider a support group.
4. Create a personal support circle.
5. Focus on personal interests daily.
6. Get plenty of rest and sleep.
7. Get the funding you need for rehabilitation.
8. Have water, fruits and vegetables.
9. Keep trying—accept errors.
10. Learn about brain injury.
11. Prevent further brain injuries.

More information

Go to www.cdc.gov to order these free brochures: “Preventing Traumatic Brain Injury in Older Adults” and “Check for Safety: A Home Fall Prevention Checklist for Older Adults”. Share this information with your friends and family.

20. SPORTS CONCUSSION and STUDENT ATHLETES

SB 200—Safety in Youth Sports Act—July 1, 2012

“Establishing standards for managing concussions and traumatic brain injuries to student athletes; assigning duties to the Department of Health and the Department of Education; and imposing penalties.” For the full text of the bill, Google “PA Safety in Youth Sports” and choose the “pa portal” url. This Act applies to public schools, but it is hoped that the requirements will be followed in all sports programs for children.

Pennsylvania Schools and Sports Concussion Compliance

To learn more about what schools are doing, check your nearest high school website for sports concussion information and possibly pre-season baseline testing, Return-to-Class and Return-to-Sports protocols. Coaches, parents, and athletes now have certain required activities. Also, after a possible concussion, returning to games or practice

must be approved by an “appropriate medical professional.” Compliance with this Act will prevent “second hits.” Right now, this Act applies only to public schools, but the hope is that the requirements will be followed in all sports programs for children.

The “Second Hit”

Each season, 10% of athletes in contact sports have concussions which injure nerve cells in the brain. While the brain is still repairing that damage, the next concussion is called a “Second Hit.” Damage from a “Second Hit” can result in death, greater disability, or a much longer recovery period. Coaches, staff, families and team members who care about each other will make sure the injured player takes the time needed for recovery to prevent a “Second Hit” or concussion before the first injury has healed.

Assess Needs

After a player is removed from play due to a concussion, changes in cognitive (thinking), emotional (feelings), behavioral (actions) and/or physical (bodily) functioning may be noticed. At that time, cognitive and physical rest, medical attention, brain injury rehabilitation, and school accommodations are needed. Medical Assistance will pay for Cognitive Rehabilitation Therapy, the evidence based treatment that reverses cognitive loss (CPT Code 97532). The BrainSTEPS Program in the Intermediate Unit will assist the school with temporary or long- term school accommodations, including a §504 plan or IEP.

Heads Up CDC Training

Go to cdc.gov/concussion/sports for free online coach’s training and many free resources on recognizing and responding to a concussion.

21. SUICIDE RISK and PREVENTION

**National Suicide Prevention Lifeline
1-800-273-8255**

Signs indicating suicide risk are common after brain injury:

1. breakdown in relationships, disconnected from others
2. depression or hopelessness
3. feeling of being a burden
4. isolation from friends, family
5. legal problems or difficulties at work or with finances

The risk of death by suicide is higher after brain injury:

1. four times higher after a severe traumatic brain injury
2. five times higher by the 15th year after a mild concussion

3. twenty five percent of those who attempt suicide post injury will try again
4. worse with pre-injury substance misuse, mental illness or aggressive personality

Some myths of suicide

1. Asking someone if they are thinking about suicide will only give them “ideas.”
2. Improvement after a suicidal crisis means the risk is over.
3. Most suicides occur with little or no warning.
4. Surviving an attempt means there was no intent to die.

Preventive Measures

1. If someone seems upset, ask if they are contemplating suicide. If so get the help they need as quickly as possible.
2. Keep potential means of suicide like ropes, toxic materials, and knives securely locked away to decrease impulsive suicidal acts.
3. Remove firearms and ammunition from the home. If removal is not possible, store them separately in break-in proof locked containers with the firearms disassembled.
4. Monitor medication carefully because many suicide deaths and attempts involve self-poisoning.

Warning signs that indicate the need for immediate help:

1. giving away valued possessions
2. looking for a weapon, pills, poison, or another way to kill oneself
3. obsessing about suicide or death through talking, writing or drawing
4. settling up affairs, making a will, making funeral arrangements
5. stating a specific plan of how and when suicide will occur
6. threatening to hurt or kill oneself

If someone is suicidal

1. Don't leave them alone.
2. Say that you are getting help.
3. Call 911 for immediate help.
4. For support and guidance, call 1.800.273.8255, the National Suicide Prevention Lifeline.

Involuntary commitment

Mental health care may be needed but does not address brain injury.

Factors which decrease the risk of suicide:

1. ability to seek help when needed
2. coping and problem solving skills
3. no use of alcohol or drugs
4. strong family and social ties

Focus on rehabilitation

1. Connect children with rehabilitation and the BrainSTEPS program.

2. Get the Head Injury Program (21), OBRA (18) or COMMCARE (21) Waiver.
3. Assess cognitive, emotional, behavioral and physical changes.
4. Form a rehabilitation plan based on interests and goals.
5. Maintain a steady program of rehabilitation with periodic review.

22. CLIENTS, CUSTOMERS, PARISHIONERS AND PATIENTS

What will you notice as you relate to this person?

Those with brain injury may have difficulty asking for information or explaining their needs. They may not see well or fail to understand your explanation or your directions. They may not be able to answer your questions or remember events. They might be startled by unexpected information or confused by rapid speech or conversations around them. They may easily feel upset and then behave in unexpected ways. They will be grateful if you can remain calm as they are re-learning how to act in the world. Someone with a serious brain injury may require five to ten years or more to re-learn what was lost.

How to make a person with brain injury more comfortable:

1. Minimize standing.
2. Avoid talking in a noisy place, in crowds, or around bright lights.
3. Don't get too close to the person or touch the person.
4. Face the person at all times when speaking with them.
5. Speak directly to the person.
6. Speak slowly and calmly.
7. Ask what help is needed.
8. Give information in small steps and repeat each step until it is accomplished.
9. Ask "Do you understand?"
10. Repeat brief explanations often.
11. Ask short questions and allow as much time as possible for an answer.
12. Wait patiently for a response.
13. Use distracting hand gestures only when needed.
14. Go with the person.
15. Show the person what to do.
16. Ask "Can you do this?"
17. Give written directions for anything you expect the person to do again.
18. Offer to have a buddy assist the person and stay with them until they leave.
19. Have a buddy call or send reminders as needed.
20. Use advance assisted boarding for buses, planes and trains.

21. Check comfort frequently.
22. Call for assistance if needed.

23. CRIMINAL JUSTICE: DIVERSION OR ACCOMMODATION

Screening and Diversion

Just as with mental health and drug abuse treatment, rehabilitation for brain injury reduces repeat arrests. The HELPS brain injury screening tool is available free online. Positives should be evaluated further to assess needs. Those age 21 or older with traumatic brain injury can apply for rehabilitation under the PA Head Injury Program (717.772.2762— \$100,000 over one year) or the COMMCARE Waiver (877.550.4227— lifetime benefits), both of which offer housing. For any disability before age 22, those 18 or older can apply for the OBRA Waiver (877.550.4227). The Attendant Care and Independence Waivers are also available but include no housing and limited rehabilitation.

How is it treated?

Survivors require help to learn about their injury, adjust emotionally to new limitations, re-train for lost skills, learn compensatory strategies and overcome fatigue. Some need coaching and cueing for everyday activities, and help with tasks like driving, shopping, cleaning or cooking. Some will need 24/7 supervision to be safe and protected from exploitation. Unfortunately, most do not get evidence-based care but are considered intellectually disabled, delinquent, mentally ill, incorrigible or demented. Evidence-based rehabilitation is being added to insurance plans but most survivors have had none.

Accommodations

Rules are of little use for those unable to learn or recall them. For inmates with brain injury, difficulties and recidivism can be reduced through identification, rehabilitation and changes in the environment and program. Coaching and cueing will also be needed.

Prevent overload

Survivors easily experience cognitive overload, resulting in a biologic event called a catastrophic stress reaction (CSR). A CSR is marked by a change in behavior (loss of speech or motion, tears, anguish, screaming or violence) which must run its course to discharge the overload. (Avoid talking to or touching the survivor.) Afterwards, the survivor may need hours or days to recover from exhaustion; otherwise, a slight stress may cause another CSR. Some factors to monitor are noise, light, moving objects, new learning, rushing, crowds, emotional situations, change, fatigue, and excess cognitive

demands. Simple routines including food, water, and rest are best. Each additional brain injury or even well-chosen psychiatric medications can make behavior worse (consult a neuropsychiatrist).

24. EMPLOYEES AT WORK

Returning to Work

Hospitalization or rest at home may be all that is needed to return to work. Others may require medical care, rehabilitation, volunteer work, part-time, or less difficult tasks during the period of recovery.

What can employers do?

Upon return to work, you can help your employee be more effective by minimizing distractions, emotional reactions, and unnecessary effort so the employee can focus on the job. Being back at work, if not too soon, will help your employee continue to regain former skills. The brain repairs as a result of effort and determination.

Suggestions for employers

1. Provide a calm, quiet setting.
2. Remind others to speak slowly.
3. Give shorter/easier tasks.
4. Explain events and tasks clearly.
5. Limit the choices involved.
6. Expect short answers.
7. Coach using small steps, cards.
8. Permit pictures or other reminders.
9. Permit frequent rest breaks.
10. Simplify the social situation.
11. Simplify job responsibilities.
12. Stay calm and speak calmly.
13. Postpone confusing conversations.
14. Assign a "buddy" for navigation.
15. Minimize noise and motion.
16. Make clear safety plans and involve a buddy if necessary.
17. Permit assistive technology.
18. Offer environmental modifications.
19. Permit use of a memory book.
20. Support using a date book.
21. Make any changes very slowly.
22. Understand limitations.
23. Build on strengths.

24. Restructure work schedule for most attentive times of day.

Employer Resources

Your local Office of Vocational Rehabilitation has information, resources and programs to help you hire and retain workers with disabilities. The Job Accommodation Network has suggests for possible accommodations. Check online or the telephone book blue pages.

Employer Incentives

- Architectural/Transportation Tax Deduction for removing barriers.
- On-the-Job Training for specific skills training for a specific job.
- PA Employment Incentive Tax Credit for hiring a recipient of public assistance or OVR services.
- Small Business Tax Credit for being accessible.
- Work Opportunity Tax Credit (WOTC) for hiring those in targeted groups (veterans, etc.)

Keys to success

1. Clear, simple expectations
2. Clear, simple rules
3. Encouragement and praise
4. Patience
5. Problem-solving together
6. Team approach
7. Accountability for all involved

25. INTELLECTUAL DISABILITY

Who is considered intellectually disabled?

To qualify for the Person/Family Directed Support Waiver and the Consolidated Mental Retardation Waiver which begin at age 3, a person must be considered intellectually disabled. This is an administrative determination requiring a person to have established both an IQ and a functional capacity below 70 prior to the age of 22, regardless of the cause. Those whose IQ and functional capacity drop below 70 after age 21 are not considered intellectually disabled and are not eligible for these waivers.

What are the causes of intellectual disability?

There are many causes for low IQ and low functional capacity prior to age 22. These causes include insufficient sensory stimulation, heredity, genetic neurodevelopmental disorders and also accidents, illness, poisoning or malnutrition. In the case of accidents, illness, poisoning or malnutrition, the person experienced structural damage or was

exposed to inappropriate force, pressure, temperature, oxygen, blood flow or glucose in a way that interfered with the normal metabolism and biochemistry of the brain.

How is IQ distributed among those with intellectual disability?

15% have an IQ from 0-55 and 85% have an IQ from 55-70.

What proportion may have a brain injury?

Among those with an IQ from 0-55, 60% have a neurodevelopmental disorder which permanently limits their IQ. From 55-70, neurodevelopmental disorders are infrequent.

Provide evidence-based programming:

1. Provide screening, neuropsychological assessment and rehabilitation for those with an IQ of 50-70 who do not have a genetic disorder.
 2. Provide evidence-based services for those with brain injury according to the recognized standards for brain injury rehabilitation.
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26. JUVENILE JUSTICE

Screening

Upon police contact, careful screening for a pre-existing brain injury is essential because three recent, very large studies found that 60% of youth in detention have had a traumatic brain injury. A brain injury diagnosis is so important because poor judgment due to a brain injury will continue until addressed by rehabilitation and/or other programs that improve problem solving. The number of persons with brain injury in prison shows that the problem becomes greater as people age. Prison studies have found that 80+% of adult inmates have had a traumatic brain injury. Other research shows that, for almost all inmates, the brain injury occurred prior to any known offenses.

If youth were provided with brain injury rehabilitation at the time of injury, or at least whenever they are identified by the juvenile justice system, the prevalence of traumatic brain injury in youth detention and adult prison should drop closer to the general population where 8.5% or 1 in 12 have a disability due to a traumatic brain injury. Of course, youth and adults have brain injuries from many other causes which may also play a role in juvenile and criminal justice involvement.

Recovery protocol:

- 1st - HELPS Brain Injury Screening Tool or another screening tool
- 2nd - Neuropsychological assessment
- 3rd - MD physiatrist assessment
- 4th - Rehabilitation Team Planning
- 5th - Family Training

6th - BrainSTEPS (Intermediate Unit) involvement with teachers and planning
7th - Transition planning for adult system from ages 14 to 21

You Can Help!

1. Arrange frequent rest breaks.
2. Assure quiet times.
3. Coach using small steps, cards.
4. Explain what is happening.
5. Expect short answers.
6. Gently change the subject to divert.
7. Give shorter/easier tasks.
8. Help carry out interests.
9. Minimize noise.
10. Offer simple choices.
11. Plan for safety.
12. Promote using a date book.
13. Promote using a memory book.
14. Reduce stimulation.
15. Speak more slowly.
16. Remain calm.
17. Remain close by.
18. Simplify responsibilities.
19. Simplify the situation.
20. Use pictures or remind.

Juvenile Justice Research and Projects

1. Beckworth, B. P. (2013, October). *TBI juvenile justice partnership pilot project*. Presented at the National Association of State Head Injury Administrators State of the States Annual Conference.
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27. MENTAL HEALTH

Link to Mental Illness

Behavior changes, suicide attempts, arrest or substance abuse may lead survivors to mental/behavioral health professionals. This may result in misdiagnosis or medication errors.

Recovery

Recovery requires medical treatment for the precipitating event and medical rehabilitation for cognitive, emotional, behavioral, or physical impairments. Cognitive and physical rest after a brain injury will decrease functional impairment. Cognitive Rehabilitation Therapy (CPT97532) is evidence-based for cognitive recovery.

Psychosocial factors

Behavior and personality changes present the greatest challenges after brain injury due to: worsening of pre-injury mental illness; changes in intelligence; impact of cognitive or physical change on emotional, social, and behavioral reactions; emotional trauma; or a reaction to the incident which caused the injury.

Comparison

Similar to an emotional disturbance:

1. Difficulty regulating mood
2. Reduced self-control

Unlike an emotional disturbance:

1. Change in physical functions
2. Ignores rewards, punishments
3. Loss of academics, causation
4. Lost memory, procedures, skills
5. More impulsive, irritated, confused, and/or disinhibited
6. Over-sensitivity to change, noise, temperature, light, movement
7. Unaware of deficits, slowness

Professionals providing treatment for brain injury recovery:

1. Occupational Therapists, Physical Therapists, Speech and Language Therapists, and Cognitive Rehabilitation Therapists
 2. Neuropsychologists—diagnose, assess deficits, counsel
 3. Neuropsychiatrists—diagnose, manage behavioral medications
 4. Psychiatrists – physicians who specialize in rehabilitation
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28. STUDENTS IN THE CLASSROOM

Identification

If classroom teachers have been taught the signs and symptoms of brain injury, the child's teacher may observe a sudden change in the child or notice the symptoms of a prior brain injury. The school nurse or coach may also identify a concussion. For new injuries, a hospital or parent may reach out to the school. For a mild injury, a watch and wait approach will involve the school nurse and guidance staff.

Accommodations through the BrainSTEPS Teams

Every Intermediate Unit has a BrainSTEPS Team to help schools and teachers accommodate students with brain injury (brainsteps.net). The teacher and family will have assistance in understanding needs, creating a §504 plan or preparing an IEP. The Team will provide strategies based on the needs of the child, such as "errorless learning" and reducing the cognitive load to relieve the child.

Recovery

Cognitive and physical rest during medical recovery decreases functional disability.

Cognitive and physical rest means no cognitive or physical activities:

Cognitive activities include: work, school, homework, tutoring, music lessons, television, telephone or cell phone, other electronic equipment, bill paying, computer use, computer games, reading, board games, playing cards, hobbies, religious activities, shopping, unnecessary medical or dental appointments, meetings and social situations.

Physical activities include: housework, driving, errands, sports, walking, running, yoga, lifting, stooping, and other activities requiring physical movement.

After the period of cognitive and physical rest is complete, evidence-based Cognitive Rehabilitation Therapy (CPT 97532) may be used to improve functional recovery, along with other necessary therapies. The Special Needs Unit of the physical health plan will help arrange care using a referral from the physician.

Examples of Differences from Other Disabilities

LEARNING DISABILITIES: Obvious contrast with prior abilities. Wide ability gaps. New learning difficult. Old facts more often retained. No insight. Loss of friends. Lack of self-control. Greater memory deficits. New "self." Inappropriate behaviors.

INTELLECTUAL DISABILITIES: No prior special education. Inconsistent learning rate. More inconsistent behavior. New "self." IQ score taps prior learning so may not reflect

current learning potential.

EMOTIONAL DISTURBANCE: Limited awareness of deficits. Oversensitive to change. Oversensitive to sensory stimuli (noise, light, temperature, motion). More impulsivity, confusion, and/or disinhibition. Poor recognition of cause and effect. Less responsive to rewards and punishments.

Misdiagnosis carries a heavy price:

1. blocks access to care which research has shown is effective or “evidence-based” for those with brain injury
2. imposes care that has not been tested on those with brain injury and may create chaos and exhaustion
3. interferes with recovery through the impact of medications and counseling which have not been validated as being effective for those with brain injury
4. destroys lives and families by interfering with the recovery of the brain, imposing side effects, and providing advice which is not appropriate for this condition
5. increases disability and state costs through a lifetime of inappropriate care

29. VICTIMS, SUSPECTS AND INMATES

Impact on others

A victim, suspect or inmate with an old or new brain injury may not be able to follow directions or give a statement. They may not remember or understand events. They usually can't think fast enough to respond to questions, conversation, rapid speech, noises, new situations, quick changes or commands. They may easily get upset or confused and then act in unexpected or unusual ways.

Divert into treatment

The HELPS brain injury screening tool is online. Traumatic brain injury rehabilitation is funded by the PA Head Injury Program (717-772-2762) and the COMMCARE Waiver (717-772-2762). Call for other resources.

Cognitive signs you may observe

1. can't follow directions
2. can't rush or go any faster
3. can't understand or decide
4. concrete thinking
5. disoriented and/or unaware
6. doesn't answer or explain
7. doesn't pay attention

8. doesn't recognize or react to events, faces, places or things
9. ignores change of topics
10. memory problems
11. thinks or reacts slowly
12. struggles to find words

Physical signs you may observe

1. appears deaf or hard of hearing
2. awkward, difficulty walking, uneven gait or stumbling
3. balance is uncertain when standing or sitting
4. brain injury listed on medical bracelet, chain or wallet card
5. confusion on uneven ground
6. extreme fatigue under stress
7. eyes don't line up together
8. limb is rigid, weak, spastic, or paralyzed
9. reacts as if partially blind
10. scars on head, head misshapen
11. seizures of various types including periods of absence
12. speech difficult or slurred
13. swallowing difficult
14. tracheotomy scar (base of throat)
15. trembling or shaking

Emotional signs you may observe

1. agitated in a group
2. anxious or easily frightened
3. gets angry without warning
4. stunned when under stress
5. tears or laughter at unusual times

Unusual behavior you may observe

1. behavior unpredictable
2. distracted by noise and lights
3. ignores responsibilities
4. impulsive
5. response not reasonable

Strategies you might find helpful:

1. Minimize sirens, flashing lights.
2. Move slowly and calmly if possible.
3. Don't get any closer than necessary.
4. Speak firmly but gently.
5. Use only 2—5 words at a time.
6. Wait 3—5 seconds for an answer or response when possible.
7. Ask one part questions.
8. Give one step directions.

9. Repeat each direction until that step is complete (coaching).
 10. Ask "Do you understand?"
 11. Ask "Can you do this?"
 12. Use hand gestures only when necessary.
 13. Call contact on wallet card or number on medical jewelry.
 14. Seat the person to reduce fatigue and focus attention.
 15. Test for substances, not for balance or mental acuity.
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30. AGENCIES AND ORGANIZATIONS

1. Acquired Brain Injury Network of Pennsylvania, Inc. [1.800.516.8052](tel:1.800.516.8052)
2. Aging and Disability Resource Centers [1.866.286.3636](tel:1.866.286.3636) – 15 across PA – information on all aging and disability services.
3. Area Agency on Aging – [blue pages](#) – in every county – information, services
4. Brain Injury Association of America www.biausa.org
5. Brain Injury Association of Pennsylvania Resource Line [1.800.444.6443](tel:1.800.444.6443)
6. BrainSTEPS Program – [Intermediate Unit](#) – helps teachers plan program
7. CareerLink – [blue pages](#) – help with finding employment
8. Centers for Independent Living [1.717.920.0530](tel:1.717.920.0530) – 18 centers – for all disabilities
9. CHIP Health Insurance [1.800.986.5437](tel:1.800.986.5437) – for all children to age 19 with parents above Medical Assistance financial limits (Affordable Care Act may revise).
10. County Assistance Offices – [blue pages](#) – there is no county programming for brain injury recovery but services are available for food stamps, heating assistance, intellectual disabilities, children, Medical Assistance, mental illness and seniors.
11. Department of Health Head Injury Program [1.717.772.2762](tel:1.717.772.2762) – 1 year, \$100,000 max
12. Disability Rights Network [1.800.692.7443](tel:1.800.692.7443) – TBI, Special Education, SSD, etc.
13. Elks Nurses (PA) [1.814.781.7860](tel:1.814.781.7860) – case management if disabled before age 22
14. Legal Aid (PA) [1.800.322.7572](tel:1.800.322.7572) – refers to local legal aid office, low income required
15. Meals on Wheels – www.mealcall.org – meals delivered to your home
16. Medical Assistance [1.866.542.3015](tel:1.866.542.3015) – or County Assistance Office – Low income

- disabled adults, all disabled children – Special Needs Unit at [1.800.521.6860](tel:1.800.521.6860)
17. Medicare Coverage [1.800.633.4227](tel:1.800.633.4227) – Parts A and B include in-home services
18. Medicare Denials [1.800.322.1914](tel:1.800.322.1914)
19. Office of Vocational Rehab – [blue pages](#) – assessment, job coaching
20. Pennsylvania Health Law Project [1.800.274.3258](tel:1.800.274.3258) – government funded health plans
21. Social Security [1.800.772.1213](tel:1.800.772.1213) – retirement, disabled (SSDI), low income (SSI)
22. Special Education Consult Line [1.800.879.2301](tel:1.800.879.2301) – Department of Education – rights
23. Special Kids Network [1.800.986.4550](tel:1.800.986.4550) – resources for children with special needs
24. Support Groups – www.abin-pa.org, Support Groups – 51 independent groups
25. Waiver Enrollment [1.877.550.4227](tel:1.877.550.4227) – Independent Enrollment Broker – help at home and other services through the Independence and Attendant Care Waivers. Both the COMMCARE and OBRA Waivers also include rehabilitation and supported housing.
26. Waiver Complaints [1.800.757.5042](tel:1.800.757.5042) – Office of Long Term Living
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31. REFERENCES

Centers for Disease Control and Prevention - extensive materials - www.cdc.gov.

Lash Publishing - www.lapublishing - Books for children through professionals.

"Recommendations for Best Practice in Cognitive Rehabilitation Therapy: Acquired Brain Injury" - www.societyforcognitiverehab.org/index.php - Standards.

"Systemic Approach to Social Work Practice: Working with Clients with Traumatic Brain Injury", Strutchen and Clark. www.brainline.org - Baylor College of Medicine.

"The Brain That Changes Itself" by Norman Doidge, M.D. - Amazon.

"Treating Clients with Traumatic Brain Injury" - SAMHSA Technical Advisory - www.samhsa.gov/samhsanewsletter/Volume_19_Number_2/TraumaticBrainInjury.aspx.

32. ABIN-PA BROCHURES (Alphabetical)

1. ABIN-PA Would be Happy to Assist You with Brain Injury Issues
2. Anatomy, Diagnosis and Assessment Terms Used in Brain Injury
3. Building a New Life after Brain Injury
4. Caregiver Tips and Strategies for Brain Injury Recovery
5. Changes in Family Roles after Brain Injury
6. Changes in Your Loved One after Brain Injury
7. Clients, Customers, Parishioners and Patients with Brain Injury
8. Consumers of Intellectual Disability Services with Brain Injury
9. Consumers of Mental Health Services with Brain Injury
10. Discharge Planning for Those with Brain Injury
11. Diversion and Accommodation with the Criminal Justice System
12. Domestic Violence Causes and Follows Brain Injury
13. Effects and Consequences Following Brain Injury
14. Employees in the Workplace with Brain Injury
15. Enhance Brain Plasticity to Restore Brain Function
16. Everybody Knows Somebody with a Brain Injury
17. Holistic Options for Brain Injury Recovery
18. Legal Issues Requiring Attention after Brain Injury
19. Maximizing Income and Benefits for Brain Injury Recovery
20. Milestones Measure Progress in Recovery from Brain Injury
21. Minimizing Catastrophic Stress Reactions after Brain Injury
22. Minimizing the Challenges that may Follow Brain Injury
23. Returning to Work after Brain Injury
24. Senior Falls Lead to Disabling Brain Injury
25. Simple Tips and Strategies for Living More Easily with Brain Injury
26. Sports Concussions and Student Athletes
27. Students in the Classroom with Brain Injury
28. Suicide Risk and Prevention after Brain Injury
29. Victims, Suspects and Inmates with Disabling Brain Injury
30. Youth in the Juvenile Justice System with Disabling Brain Injury

33. ABIN-PA BROCHURES (By Topics)

General

ABIN-PA Would be Happy to Assist You with Brain Injury Issues
Effects and Consequences Following Brain Injury
Everybody Knows Somebody with a Brain Injury
Legal Issues Requiring Attention after Brain Injury
Maximizing Income and Benefits for Brain Injury Recovery
Minimizing Catastrophic Stress Reactions after Brain Injury

Survivors

Building a New Life after Brain Injury
Simple Tips and Strategies for Living More Easily with Brain Injury

Family

Caregiver Tips and Strategies for Brain Injury Recovery
Changes in Family Roles after Brain Injury
Changes in Your Loved One after Brain Injury

Recovery

Anatomy, Diagnosis and Assessment Terms Used in Brain Injury
Discharge Planning for Those with Brain Injury
Enhance Brain Plasticity to Restore Brain Function
Holistic Options for Brain Injury Recovery
Milestones Measure Progress in Recovery from Brain Injury
Minimizing the Challenges that may Follow Brain Injury
Returning to Work after Brain Injury

Prevention

Domestic Violence Causes and Follows Brain Injury
Senior Falls Lead to Disabling Brain Injury
Sports Concussions and Student Athletes
Suicide Risk and Prevention after Brain Injury

ADA Accommodations

Clients, Customers, Parishioners and Patients with Brain Injury
Consumers of Intellectual Disability Services with Brain Injury
Consumers of Mental Health Services with Brain Injury
Diversion and Accommodation within Criminal Justice System
Employees in the Workplace with Brain Injury
Students in the Classroom with Brain Injury
Victims, Suspects and Inmates with Disabling Brain Injury
Youth in the Juvenile Justice System with Disabling Brain Injury

33. ABIN-PA SERVICES

History

ABIN-PA was organized as a nonprofit 501(c)(3) corporation in 2007 by brain injury survivors and family members. We provide a website, advocacy, free newsletter, InfoLine and training. We also represent the brain injury community by responding to state government requests for comments and stakeholder participation.

Mission

ABIN-PA is dedicated to increasing public awareness about acquired brain injury and to providing support, information, education, advocacy and other services for individuals with acquired brain injury and their families.

Website

The www.abin-pa.org website is silent and motionless with simple navigation. It includes a Store, Brochures, Our Stories, Newsletters, Links, a Rehab Facility Search, Resources, Support Groups and Advocacy Groups. The Library includes a TV interview, a state DVD and a hyperbaric oxygen video. Brochures and a 24-page booklet called "Building a New Life after Brain Injury" can be downloaded for free. This "2014 Brain Injury Notebook" and brochures can also be ordered from the store.

InfoLine

ABIN-PA assists callers with resource information and advocacy. Callers include survivors, families, social workers, attorneys, parole officers, providers and others. You are welcome to call for information or assistance. You can also request literature.

Free Monthly Newsletter

ABIN-PA has 1,297 newsletter subscribers by email or land mail, including survivors, family members, friends, and community members. Many also contribute articles. You can sign up for the newsletter on the website or contact ABIN-PA by calling or sending an email. You can always print copies from the website to share with others. Perhaps you might want to send in an article or place an advertisement!

ABIN-PA E-list

Emails on ABIN-PA matters and disability topics from many sources go out frequently to the 334 members of ABIN-PA's E-list. You can choose the E-list when you sign up as a newsletter subscriber. Subscribers should contact ABIN-PA to add the E-list.

PeerConnect Partners

Periodically, survivor to survivor and family member to family member matches are

made for phone and email support.

Advocacy - Individual

ABIN-PA helps individuals understand their rights and the benefits that may be available to them. Literature can be sent to professionals who are trying to assist. ABIN-PA can also make phone calls, send emails or attend meetings with your written permission.

Advocacy - Systems

ABIN-PA works on issues that affect the brain injury community as a whole such as:

- an accurate portrayal of concussions in the field of entertainment
- Medical Assistance for outpatient and residential brain injury rehabilitation
- access to waiver programs for rehabilitation and support
- screening, diversion into rehabilitation and ADA accommodations within the court system, prison, probation and programs for mental health, intellectual disability, homelessness and substance abuse
- equal state funding for equally disabled residents regardless of age or diagnosis
- routine brain injury screening during annual childhood physical examinations

Programs

ABIN-PA provides short talks, annual luncheons, a holistic conference, programs, focus groups, seminars, panel speakers and workshops. We also train staff for programs that serve individuals with brain injury.

Literature

ABIN-PA offers 30 brochures, "Building A New Life After Brain Injury: A Peer to Peer Training" (24 pages), and "Your Brain Injury Handbook" (60+ pages).

**Help yourself by helping others.
Get involved with ABIN-PA and make a difference!**



ACQUIRED BRAIN INJURY NETWORK OF PENNSYLVANIA, INC.

"Empowering Survivors and Families to Rebuild Their Lives."

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