# Brain Injury GUIDE



# NORTH DAKOTA BRAIN INJURY NETWORK

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# About the North Dakota Brain Injury Network

After a brain injury, there often are difficult decisions to make. The North Dakota Brain Injury Network (NDBIN) provides information and support to individuals with brain injury, their family members and various service providers and agencies.

Our resource facilitators assist with navigating the service system and provide technical assistance in finding the right resources for each individual.

We offer outreach and education to increase public awareness of brain injury, as well as peer support by connecting people with others who have experienced a brain injury. We provide virtual education and on-site training to facilities and organizations.

All of our services are FREE.

www.facebook.com/ndbin Toll Free: 1(885) 866-1884 www.ndbin.org

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# What Is Brain Injury?

Brain injuries can happen to anyone. They do not discriminate among races, age groups, or genders. A brain injury is damage to living brain tissue caused by an external or internal insult. Some causes of brain injuries include a blow to the head, excessive force such as shaking or whiplash, bleeding inside the brain, inflammation/swelling, or an infection. This may result in temporary or permanent cognitive, physical, behavioral, and/or emotional changes.



Nontraumatic brain injury Anoxia (lack of oxygen), infections, strokes, tumors, substance exposure

Traumatic brain injury (TBI) Falls, crashes, abuse, assaults, sports



# Some injuries are severe and others are mild. Concussions are a mild form of brain injury and are common.

There may or may not be a period of unconsciousness immediately following the event. No two brains are the same, the results of a brain injury, which can affect various areas of the brain depending on the type and severity of accident, vary widely from person to person.



# **TBI Severity Continuum**

Mild	<ul> <li>75-90% of TBIs</li> <li>Loss of Consciousness less than 30min</li> <li>Up to 15% have long term impairments</li> </ul>
Moderate	<ul> <li>10-30% of TBIs</li> <li>Loss of Consciousness between 30min-24hrs</li> <li>Up to 30-50% have long term impairments</li> </ul>
Severe	<ul> <li>5-10% of TBIs</li> <li>Loss of Consciousness greater than 24hrs</li> <li>Up to 80% have long term impairments</li> </ul>

# About Brain Injury

An estimated 5.3 million Americans currently live with disabilities as a result of brain injuries, according to the Centers for Disease Control and Prevention. This translates to almost 14,000 North Dakotans living with disabilities due to brain injuries. The brain is one of the most complex and least understood organs in the body. Each brain injury is unique.



The brain controls everything we do, say, think, and feel. It controls the functions that keep us alive: breathing, circulation, digestion, hormones, and the immune system. It is through the brain that we experience emotion and personal expression. Even the slightest brain injuries can bring about drastic changes in a person. Some injuries are so minor that the person does not require medical attention and the injury remains undetected for a long period of time. Regardless of the degree of injury, it is important to be aware of how a person's brain can change.

Many survivors physically appear to be as they were before the injury. Cognitive deficits (memory, organization, motivation, processing speed, etc.) and personality changes are what typically manifest, but these changes often are not acknowledged as results from the injury. It is difficult for people close to the survivor to recognize deficits because on the outside, the person appears to have recovered. This gives the impression that the survivor should also be acting and speaking as they would have before experiencing the injury. Although a person may recover medically, pre-injury cognition may not completely return.

After sustaining a brain injury, medical, and psychological issues are often identified. Seizures are a common neurological effect, but other systems in the body such as digestive, respiratory, and cardiovascular, can be impacted as well. Negative feelings, attitudes, and poor coping skills can result not only from the realization of the injury severity, but with the difficulties of being accepting of post injury life, thus mental illness and substance abuse are also common following a brain injury.

A common myth is that when the brain is injured, it can mend completely – like a broken arm. Unfortunately, brain cells do not regenerate like skin or bone cells. Rehabilitating from a brain injury takes time because damaged cells need to relearn how to do things while the brain uses healthy cells to compensate.

While it is important to understand changes that may have a negative impact, the best resources for recovery are an individual's current strengths, abilities, and interests. As many individuals with brain injury have said: "It's not about what you lost. It's about how you use what you have left!"

# Common Changes Following a Brain Injury

It is often said that no two individuals experience the consequences of brain injury in the same manner. The effects of a brain injury varies and depends not only on the location and severity of the injury and length of coma, but also on the individual's age at the time of injury, as well as educational and vocational history and social support. Below are some deficits commonly found across physical, cognitive, and behavioral domains that are associated with brain injury.

# Behavioral

- Depression, grief over loss of ability, or chemical changes caused by the injury
- Anxiety, restlessness, agitation
- Lower tolerance for stress
- Irritability, frustration, impatience
- Mood swings
- Impulsiveness and lack of inhibition
- Emotional flatness and passivity

# Cognitive

- Short-term or long-term memory loss
- Slowed processing of information
- Impaired judgment
- Trouble concentrating or paying attention
- Difficulty keeping up with conversation; trouble finding words
- Spatial disorientation
- Difficulty organizing or problem solving
- Inability to do more than one thing at a time
- Impaired understanding of deficits

# Physical

- Seizures
- Fatigue, increased need for sleep
- Insomnia
- Sensory loss or impairment
- Blurred or double vision
- Headaches or migraines
- Trouble with balance and dizziness
- Decreased motor abilities
- Sexual dysfunction
- Muscle control and balance problems
- Ringing in the ears
- Hormonal changes

# Symptom Checklist

Following is a checklist to keep track of your symptoms after a brain injury. Share the information with individuals close to you and providers with whom you are working.

# Thinking:

- Do you more frequently forget names, numbers, appointments, or things you said you would do?
- Is it harder to follow a conversation amongst several people?
- Is it harder to follow the plot of a movie or remember what a speaker said?
- Do you often re-read something you just read because you cannot remember?
- Do you get lost more easily?
- Do people tell you they didn't know what you meant by something you said? Or that you used a different word than you think you used?
- Is it more difficult to remember what you should be doing next?
- Is it harder to learn a new procedure or task?
- Is it harder to write notes while a speaker goes on to a new topic?
- Do you sometimes forget to plan for something important?

#### **Emotions:**

- Do you laugh or cry more often or at times that are not appropriate?
- Do you lose your temper or get impatient more easily?
- Have you recently had problems on a job or serious arguments with others? Does your spouse, close friend, or child get angry with you more often or seem afraid of you?
- Are you sadder or more depressed than before?
- Do you get restless, irritated, or agitated more often?
- Do you have more trouble sleeping?

### **Physical Changes:**

- Does noise bother you more than before?
- Do you lose your balance more often?
- Do you have blurred or double vision?
- Do you have headaches more often?
- Do you find that you can't smell or taste things as well as before?
- Is speech more difficult or do people find it difficult to understand your words?
- Have you had seizures?

# **Tips for Healing**

As you continue through your recovery, there are things you can do for yourself to help in your journey.

## Take care of your health:

- Eat well.
- Sleep on a regular schedule, and rest when you are tired.
- Limit your use of alcohol and certain drugs, because they can slow your recovery and put you at risk of further injury.
- Make sure your doctor knows about all the drugs/medications or nutritional supplements you are taking.
- Seek out occupational, speech, or physical therapy if you feel you need it.
- Avoid strenuous physical activity or risk-taking that might lead to another brain injury.

### Get on with your social life:

- As you are able, return to your regular activities, but do not try to do everything at once.
- If you are easily distracted, work on one thing at a time. Try to reduce outside stimuli and work in a quiet environment.
- Keep in contact with friends and family. Talk to them about important decisions.
- Ask your doctor about driving, bicycling, or operating equipment, because your injury may have affected vision, balance, or reaction time.
- Seek individual counseling or support groups. A counselor can help you deal with your feelings about brain injury and ways it has changed you. NDBIN can link you to support groups.
- If memory is a problem, carry a notebook to write things down. Investigate the use of calendars, computer programs, personal data assistants, and other memory aids.

#### Get back to school or work:

- If your child has had a concussion or a brain injury, get an assessment by a neuropsychologist (or the school psychologist) to measure the injury and how it is likely to affect the child. This can be the basis for an individual education plan (IEP).
- For adults, the neuropsychological assessment may help your employer understand your needs and may help you get benefits. If you wish to share this information with your employer, give your consent to your doctor.
- Learn how your injury may affect you on the job and discuss any needed accommodations with your supervisor.
- For support or assistance with returning back to school or work contact NDBIN for support with that process.

# Medical Care, Hospital Care, and Rehabilitation

The medical and rehabilitation care needed after a brain injury, is a process, not a single event. The brain is complex and there is not a guaranteed straight path from injury to recovery. It is impossible to predict with any certainty what impact a brain injury will have on a person—both immediately following the brain injury and in the long term.

It is also important to recognize that the severity of the injury largely determines the duration and level of medical care, hospital care, and brain injury rehabilitation that is needed. Other factors that influence a person's recovery from brain injury include:

- Emergency response to the injury,
- Age of the person,
- Health of the person prior to the injury,
- Education, experience, and personality of the person prior to the injury,
- Family support,
- Financial resources and insurance coverage, and
- Timing and access to medical and rehabilitation services.

#### The Process of Medical Care

Many persons need medical care and evaluation after discharge from the hospital. For example, persons with brain injury may struggle with problems related to memory, cognitive skills, learning new skills, emotional changes, vision, and many other aspects of physical and mental health that may not be apparent until after hospital discharge.

The hospital works to create stability in a person's medical condition. After a person is stabilized, they often are discharged. Medical problems are not always identified until sometime after an injury occurs. As a result, the responsibility of accessing quality, comprehensive medical care is shifted to the patient. Be sure to stay in communication with your primary care doctor. Many persons with brain injury experience significant changes as they go through the rehabilitation process.

All children and teens with brain injury should have periodic follow-up medical care with their pediatrician, and neuropsychological examinations should occur approximately every three to five years. Brain injuries in children and teens are unique because a child's brain is still developing. As a result, the impact of a brain injury may not be fully understood until the affected part of the brain develops.

### Acute vs. Sub-Acute Rehabilitation

Acute rehabilitation addresses skills related to physical health, personal care, cognitive processing, language and communication, movement and mobility, behavior and environmental awareness and responsiveness. Usually, acute rehabilitation happens first. Sub-acute rehabilitation addresses skills relating to community living, employment, school, behavior, recreation, and independent living. Occasionally, a person with brain injury may need to enter acute rehabilitation after medical or behavioral issues are resolved.

# Living with Brain Injury

After you or a loved one has sustained a brain injury, your life and the lives of those around you may be impacted in various ways. The way you see yourself and others may change. The following information will help describe some of the changes you or a loved one may experience after a brain injury and how to adjust to these changes.

### **Changes in Identity**

Identity is defined as the characteristics that make a person who they are and is typically formed from childhood through adolescence and into adulthood. Brain injury can impact people during any of these phases of life, altering the perception of themselves and how others may see them. People may view themselves differently after a brain injury. This change can be a result of not being able to do things they once did. You and your loved ones may need additional reassurance and support during the recovery process.

After brain injury, some people feel lonely despite being surrounded by loved ones. This sense of isolation may arise from a variety of factors, such as difficulty with:

- Communicating with others.
- Understanding what others are saying.
- Expressing thoughts and feelings.
- Relating to others.
- Feeling understood.

With many physical injuries – a broken leg, a routine surgery – there is a predictable amount of recovery time, and successful rehabilitation can be attributed to how hard an individual works and their own strengths, abilities, and personal motivation. Recovery after brain injury isn't always predictable. People on similar recovery journeys may heal at vastly different rates – so, it's important to maintain hope during this lengthy process.

### **Changes in Communication**

Communication is complex and involves speaking, listening, writing, reading, and gestures. After experiencing a brain injury, you or your loved one may have difficulty expressing yourself, paying attention, understanding others, or learning new information.

Communication is fundamental in order to maintain relationships. Following are a few suggestions of ways loved ones can help with communication:

- Speak slowly and clearly.
- Have difficult conversations when your loved one is rested.
- Use simple words or short sentences.
- Talk about familiar subjects.
- Introduce new information slowly.
- Use pictures, gestures, facial expressions, and written words to help explain information.
- Reduce distractions and outside noise.
- Check to make sure your loved one has understood what you've said.

#### **Grief and Loss**

After brain injury, people may struggle with grief and loss. You and your loved ones may feel as though the person you were is lost. It may be helpful to open up to loved ones, acknowledge changes, and recognize feelings of grief and loss as a result of the changes.

Grief is a common emotion associated with loss. People with brain injury and their loved ones may feel this emotion with the realization that life may never be as it was before; your dreams for the future may no longer be possible. Grief is a process, not an event. There is no set time and each individual may react or behave differently while grieving. Some people find it helpful to journal, writing their thoughts and feelings. It can be helpful to connect with support groups or seek professional counselors for guidance.

#### **Aging with Brain Injury**

Aging is a natural part of life, but people who have sustained brain injuries may experience the effects of the aging process sooner and/or more severely. Activities of daily living, mobility, energy levels, and physical function may become more difficult. Brain injury should be viewed as a chronic condition, not a single event; conditions and disorders may continue to develop long after the injury.

#### **Support Groups**

NDBIN can help link individuals with brain injury and their loved ones to self-directed, voluntary support groups. Support groups can provide a number of benefits:

- Emotional healing comes when people interact with other people.
- Sharing of similar experiences helps individuals feel less alone and more ready to deal with dayto-day issues.
- Encouragement from learning about how others have conquered situations similar to theirs.
- Contribution helps support group members feel valued.
- Education results from the exposure to information and personal experiences in a group.
- Socialization occurs when connections with people are made, and confidence in social skills develops when appropriate interaction occurs in support groups.
- Self-expression, as emotions are experienced and released, creates a greater understanding of oneself.
- Confidence building results as members take responsibility for the work of the group and see progress with the plans they made.
- Safety, in the environment of a confidential, supportive, non-judgmental group, allows for honest disclosure and sharing of common difficulties.
- A sense of growth occurs as long-term members see new participants and reminisce about where they began and how far they have come in their personal journeys.

Because support group locations and times change, please contact NDBIN for current information at 1(855) 866-1884 or online at www.ndbin.org. Groups are self-help, self-supporting, and independent from NDBIN. If you would like assistance with starting a support group in your area or resources/ speakers for your group, please contact NDBIN.

# The Impact of Brain Injury on Families

Increasing understanding and knowledge of brain injury can help families and caregivers adjust and navigate the recovery process. NDBIN can help with explaining brain injury to loved ones and we have a variety of resources available in our lending library to assist with the understanding of brain injury.

When a loved one sustains a brain injury, it can be difficult to navigate the recovery process and anticipate what changes are likely to occur post-injury. The impact of brain injury and familial relationships can be profound. While every brain injury is different, knowing and understanding some of the commonalities and things to expect can assist in easing stress and anxiety.

It can be challenging for the entire family when a loved one has a brain injury; new roles arise due to unexpected traumatic changes. Even after the individual's medical condition has stabilized, their medical appointments and rehabilitation will continue to require additional time, resources, and attention. Sometimes, parents or other caretakers will need to take leave from work or change dynamics in their spousal/co-parenting relationship because the demands within the family have greatly increased.

### **Changes in Roles and Relationships**

During the recovery process, individuals with a brain injury may need additional support and reassurance from their loved ones and support network. The roles you and your loved ones play may be different following an injury. Changes that occur as a result of a brain injury may impact your ability to be the same type of friend or partner that you were before your injury. After a brain injury, you may need to give up home or work responsibilities in order to focus on recovery. You may be less independent and have to adjust to others doing for you what you used to do for yourself. Your spouse, children, or

parents may take over roles you previously held. This can be a difficult time for the individual, family, and friends because the future may be unknown. Your loved ones may have new or increased responsibilities, such as managing healthcare, handling finances, and caring for you.



### Caregiving

Caregivers are responsible for making sure a person's needs are met. This may include tasks such as bathing and personal care, preparing meals, providing transportation, managing money, preparing medications, and scheduling appointments. Since each brain injury is unique and recovery varies for each person, the amount of support or assistance you may need from a caregiver also varies. Some people need assistance for a short amount of time after a brain injury, while others require support from a caregiver throughout their life.

Since brain injuries occur unexpectedly, people often become caregivers for a loved one with no warning or time to prepare. Abrupt changes such as this can be difficult for both individuals involved in the relationship. The role of caregiving can be overwhelming, exhausting, and stressful. Caregivers have mentioned feeling confused, alone, helpless, angry, and sad, but caregiving can also be rewarding and satisfying.

### **Caregiver Support**

As a caregiver, it is extremely important to take care of yourself. Your well-being is important and can be easily overlooked when caring for someone else. In order to maintain health as a caregiver, it can be helpful to maintain a healthy diet and lifestyle and visit a doctor regularly. It can also be helpful to engage in hobbies and activities that are important to you and your physical and emotional well-being. If caregiving becomes a long-term commitment, there may be state or federal funding available for respite care for temporary relief. Respite care is professional help to care for your loved one for a short period of time so you can take time for yourself. This service may be provided in a variety of settings such as your home, adult day centers, or respite centers; however, there is sometimes a wait list for securing respite care.

### **Brain Injuries and Children and Teenagers**

When a child sustains a brain injury, it can be difficult to know what to expect and how the injury will affect the child. As children are still developing, they may have a difficult time adjusting because they do not have as vast of a cognitive, emotional, or physical foundation to fall back on. A significant change in relationships or academic performance can be expected, and it may take longer for the child to learn new skills or reach developmental milestones. Children may exhibit new and worsening behaviors and may appear to regress following injury. It is important that people remain patient when working with children with brain injuries. It is critical to discuss with the child's primary care provider what to expect and what options there are to assist the family and child through the process. It is also important to know that relationships may change when a child sustains a brain injury, making it that much more critical to understand the injury and watch for changing behaviors.

When a teenager sustains a brain injury, it is important to have ongoing assistance so that the teen feels supported. Teenagers are experiencing a multitude of changes physically, socially, and emotionally, and sustaining a brain injury can derail or disrupt the development process in any or all of these areas. Depending on the severity of the injury, a teenager may need accommodations or additional services to assist them in school and to help ease the transition post-injury. Although the impact of a brain injury on education can be profound, the impact on other areas of life can be equally affected. Teenagers may exhibit emotional and behavioral changes after injury, with the most common impairments being attention, concentration, memory, and information processing. Executive functioning can also be impacted by a brain injury. Executive functions include planning, reasoning, organization, and problem-solving. When a teenager sustains a brain injury, they may exhibit frustration or irritability when

performing executive tasks, such as using a planner, or organizing materials at school, and may benefit from extra supports when completing these tasks. It is important to be aware of where the teenagers' level of executive functioning is to avoid frustrations. NDBIN can help you determine what that level is.

#### **Supporting Children**

Children, like adults, can be deeply affected when a close relative, especially a parent or sibling, sustains a brain injury. The needs of young people are often forgotten as families struggle to rebuild their lives after a brain injury. At a time of trauma and uncertainty, children may feel upset, confused and excluded from the information loop. When a brain injury happens, adults may instinctively want to protect children by not talking about what has happened. However, research suggests that children cope much better if they are told the truth and kept informed at a level that makes sense to them. This is especially important in the early days when a loved one is first admitted into the hospital, as the child will wonder what has happened and will probably experience a disruption in their normal routine. They will also likely continue to need support when the individual comes back home, although how much will depend on the effects of the injury and the adjustment to the new way of life following the brain injury. NDBIN has a variety of resources to help explain things in an age appropriate way. Our staff can also assist you with determining the right way to frame this information, please contact us for more information on this. Role changes within the family can also have an impact on children. Even very young children may be required to assume additional household duties to try to support the parent without an injury who is caring for a spouse or a child with an injury. Older children may be given extra responsibility, perhaps being asked to look after younger children in the family. They may be asked to 'keep an eye' on the person with an injury and this can gradually reverse roles, where children become almost parentlike towards a parent with an injury or take on a parenting role of a sibling. Children may experience conflict over the reversal of roles between parent and child. Others will find it helpful for them to play a supportive role. Make sure any tasks that a child takes on to help around the house or with caregiving activities are suitable for their age. Assure that they are given the chance to regularly talk about how they are feeling with someone they trust, and are encouraged to seek support if they are struggling with their new role.

Siblings often share a unique bond and relationship that differs from the bond experienced between themselves and their parent(s). It can be common for a sibling to experience feelings of unfairness, whether they are angry the injury occurred or even angry that their sibling appears to be getting special treatment, and confusion as a result of the changes that occur after injury. Siblings, especially young children, may not be able to understand why their sibling is receiving more attention, and they can feel left out, neglected, or uncared for. Siblings can also feel overprotective of the injured sibling, which can cause secondary anxiety and depression. Another possibility is experiencing post-traumatic stress or survivor's guilt after the injury, especially if they were involved and did not experience a brain injury themselves.

There are many ways to cope with the common feelings that occur when a loved one sustains a brain injury. When encouraging healthy coping, it is important to encourage communication and take cues on how much information should be given so you can reduce harm or stress. Be sure to communicate with children that they are not to blame for the brain injury - many children will assume they somehow contributed to the injury and will carry some sense of responsibility for it. Encourage children to talk about their own feelings, provide them with information on brain injuries, and allow them time for themselves or their own activities they enjoy. Having time for themselves, whether it is time for a hobby or an activity, or just time by themselves is especially important because they may feel more overwhelmed than they did prior to the injury.

### **Brain Injuries and Spouse/Partner Relationships**

A brain injury can significantly impact a relationship between partners/spouses. Couples may find themselves faced with dramatic changes in their relationship and lifestyle. The most common changes that occur after injury are changes in responsibilities, role changes, and issues or difficulty communicating.

Brain injury survivors often have new or changed personality traits, challenges, fears, and emotional or physical limitations. Survivors are often surprised at how these changes also alter the way they feel and behave in their relationships. These changes have led many spouses to say they feel as if they are married to a stranger. Intimate partners may have concerns or fears regarding behavior and emotional changes that resulted from the injury; they may even experience uncertainty, which can increase stress, anxiety, and depression.

After an injury, the individual must focus their energy on rehabilitation and learning new skills in order to adapt to changes that have occurred. As a result of this shift in focus, responsibilities in the home may change. Partners may be expected to perform duties not typically completed by them, such as various household tasks, shopping, driving, management of finances, and planning and coordinating for the entire family unit.

Roles can also change and take various forms. Early on after the injury, it may appear to the couple that the change(s) in roles and dynamics are temporary. However, some may find that the role reversal is permanent, and with the more role changes that occur within the relationship, more strain can occur and adjusting can be much more difficult. One of the best ways to cope and reduce the negative impacts of an injury is to support each other with the role changes and be mindful and patient with each other while adjusting to the new roles and responsibilities.



#### **Changes in Intimacy**

Sex can enhance the quality of life for people. When people feel good about themselves, it can be easier to engage in a healthy sex life. However, after a brain injury, some people may experience changes in sexuality and sexual functioning. During times of transition and strife, people may begin doubting themselves and may not feel confident about how they look or move. This can impact a person's desire to engage in sex.

Since a brain injury can impair reasoning, judgment, and inhibition, some people may notice inappropriate sexual behaviors after a brain injury.

Sex after a brain injury may also be more physically difficult. A person who has experienced a brain injury should be cleared by a doctor before participating in sexual activities. If sex has become painful or difficult due to physical changes, it is important to speak to your primary doctor or rehabilitation team. If you or a loved one has questions or concerns regarding this topic, please contact a healthcare professional with whom you feel comfortable talking. Some people find it difficult to talk openly about sexual issues. Begin by gaining the support of one trusted professional on your team who can start this conversation. It is important to problem-solve any medical, emotional, or behavioral changes that have made participating in sex difficult.



# **Cognitive Strategies**

After a brain injury, it is common for people to have problems with cognition, which includes the ability to choose, understand, remember, and use information. Cognition includes:

- Attention and concentration.
- Processing and understanding information.
- Memory.
- Communication.
- Planning, organizing, and assembling.
- Reasoning, problem-solving, decision-making, and judgment.
- Controlling impulses and desires and being patient.

# How does a brain injury affect cognition, and what can be done about it?

## **Discuss Your Concerns with Your Provider**

You should discuss any questions or concerns you have with a physiatrist (rehabilitation specialist) or your rehabilitation team. It is important to mention new problems as they develop. New problems could be the result of medication or require further evaluation.

## **Attention and Concentration**

A person with a brain injury may be unable to focus, pay attention, or attend to more than one thing at a time. This may result in:

- Restlessness and being easily distracted.
- Difficulty finishing a project or working on more than one task at a time.
- Problems carrying on long conversations or sitting still for long periods of time.

Since attention skills are considered a "building block" of higher level skills (such as memory and reasoning), people with attention or concentration problems often show signs of other cognitive problems as well.

#### Management Strategies:

- Decrease the distractions. For example, work in a quiet room.
- Focus on one task at a time.
- Begin practicing attention skills on simple, yet practical activities (such as reading a paragraph or adding numbers) in a quiet room. Gradually make the tasks harder (read a short story or balance a checkbook) or work in a noisier environment.
- Take breaks when you get tired.

### **Problems with Processing and Understanding Information**

After a brain injury, a person's ability to process and understand information often slows down, resulting in the following problems:

- Taking longer to grasp what others are saying.
- Taking more time to understand and follow directions.
- Having trouble following television shows, movies, etc.
- Taking longer to read and understand written information including books, newspapers, or magazines.

- Being slower to react. This is especially important for driving, which may become unsafe if the person cannot react fast enough to stop signs, traffic lights, or other warning signs. Individuals with a brain injury should not drive until their visual skills and reaction time have been tested by a specialist.
- Being slower to carry out physical tasks, including routine activities such as getting dressed or cooking.

#### **Management Strategies:**

- Place your full attention on what you are trying to understand. Decrease distractions.
- Allow more time to think about the information before moving on.
- Re-read information as needed. Take notes and summarize in your own words.
- If needed, ask people to repeat themselves, to say something in a different way, or to speak slower. Repeat what you just heard to make sure you understood it correctly.

#### **Cognitive Outcome/Recovery and Rehabilitation**

Since there are many factors that can affect how someone will improve cognitively, it is difficult to predict how much someone will recover. With practice, cognitive problems usually improve to some degree.

Cognitive rehabilitation is therapy to improve cognitive skills and has two main approaches, remediation and compensation:

- Remediation focuses on improving skills that have been lost or impaired.
- Compensation helps you learn to use different ways to achieve a goal.

#### Language and Communication Problems

Communication problems can cause people with brain injuries to have difficulty understanding and expressing information in some of the following ways:

- Difficulty thinking of the right word.
- Trouble starting or following conversations or understanding what others say.
- Rambling or getting off topic easily.
- Difficulty with more complex language skills, such as expressing thoughts in an organized manner.
- Trouble communicating thoughts and feelings using facial expressions, tone of voice, and body language (nonverbal communication).
- Having problems reading others' emotions and not responding appropriately to another person's feelings or to the social situation.
- Misunderstanding jokes or sarcasm.

#### **Management Strategies:**

Work with a speech-language pathologist to identify areas that need work. Communication problems can keep improving for a long time after the injury.

#### How family members can help:

- Use kind words and a gentle tone of voice. Be careful not to "talk down" to the person.
- By checking in to determine understanding if there seems to be any confusion.

- Do not speak too fast or say too much at once.
- Develop a signal (like raising a finger) that will let the injured person know when they have gotten off topic. Practice this ahead of time. If signals don't work, try saying "We were talking about..."
- Limit conversations to one person at a time.

### **Problems Learning and Remembering New Information**

- People with brain injuries may have trouble learning and remembering new information and events.
- They may have difficulty remembering events that happened several weeks or months before the injury (although this often comes back over time). Persons with brain injuries are usually able to remember events that happened long ago.
- They may have problems remembering entire events or conversations. Therefore, the mind tries to "fill in the gaps" of missing information and recalls things that did not actually happen. Sometimes bits and pieces from several situations are remembered as one event. These false memories are not lies.

#### **Management Strategies:**

- Put together a structured routine of daily tasks and activities.
- Be organized and have a set location for keeping things.
- Learn to use memory aids such as memory notebooks, calendars, daily schedules, daily task lists, computer reminder programs, and cue cards.
- Devote time and attention to review, and practice new information often.
- Be well rested, and try to reduce anxiety as much as possible.
- Speak with your doctor about how medications may affect your memory.

### **Planning and Organization Problems**

- People with brain injuries may have difficulty planning their day and scheduling appointments.
- They may have trouble with tasks that require multiple steps done in a particular order, such as laundry or cooking.

#### **Management Strategies:**

- Make a list of things that need to be done and when. List them in order of what should be done first.
- Break down activities into smaller steps.
- When figuring out what steps you need to do first to complete an activity, think of the end goal and work backward.

#### **Problems with Reasoning, Problem Solving, and Judgment**

- Individuals with brain injuries may have difficulty recognizing when there is a problem, which is the first step in problem-solving.
- They may have trouble analyzing information or changing the way they are thinking (being flexible).
- When solving problems, they may have difficulty deciding the best solution or get stuck on one solution and not consider other, better options.
- They may make quick decisions without thinking about the consequences or not use the best judgment.

#### **Management Strategies:**

- A speech-language pathologist or psychologist experienced in cognitive rehabilitation can teach an organized approach for daily problem-solving.
- Work through a step-by-step problem-solving strategy in writing: define the problem; brainstorm possible solutions; list the pros and cons of each solution; pick a solution to try; evaluate the success of the solution; and try another solution if the first one doesn't work.

### Inappropriate, Embarrassing, or Impulsive Behavior

Individuals with brain injuries may lack self-control and self-awareness, and as a result, they may behave inappropriately or impulsively (without thinking it through) in social situations.

- They may deny they have cognitive problems, even if these are obvious to others.
- They may say hurtful or insensitive things, act out of place, or behave in inconsiderate ways.
- They may lack awareness of social boundaries and others' feelings, such as being too personal with people they don't know well or not realizing when they have made someone uncomfortable.

#### What causes it?

- Impulsive and socially inappropriate behavior results from decreased reasoning abilities and lack of control. The injured person may not reason that, "If I say or do this, something bad is going to happen."
- Self-awareness requires complex thinking skills that are often weakened after a brain injury.

#### Things family members can do:

- Think ahead about situations that might bring about poor judgment.
- Give realistic, supportive feedback as you observe inappropriate behavior.
- Provide clear expectations for desirable behavior before events.
- Plan and rehearse social interactions so they will be predictable and consistent.
- Establish verbal and nonverbal cues to signal the person to "stop and think." For example, you could hold up your hand to signal "stop," shake your head "no," or say a special word you have both agreed on. Practice this ahead of time.
- If undesired behavior occurs, stop whatever activity you are doing. For example, if you are at the mall, return home immediately.

# **Financial Supports**

After a brain injury, many people face financial struggles and challenges that may be overwhelming. This section provides a background of financial planning and discusses various government financial resources and options for a person with a brain injury.

### **Financial Planning**

A brain injury can greatly affect the financial situation of the person with the brain injury and their family members/dependents. There may be a change in earning potential and the projected income from salary/wages. Change in expenses, such as housing, transportation, and personal care, may also affect finances. Income from government benefits, legal settlements, and other sources may become necessary.

Although it can seem like a lower priority when the brain injury has occurred, it is imperative to take time to develop a comprehensive plan for meeting current and future financial needs. This information needs to be revisited frequently because it is an important step in making sure you are able to continue to live in the community while having your needs met. A social worker in the hospital or county employee in the financial services setting can help you make plans for this and discuss some future financial plans for you, as well as assist in finding the additional financial resources you may require.

In addition, check with your employer to determine if you have short-term and long-term disability benefits, regardless of whether the injury happened at work.

## Special Needs Trusts (SNT)

To maintain eligibility for benefits and leave assets to an individual with a brain injury, it may be necessary to set up a SNT. SNTs are designed specifically to supplement, not replace, benefits to ensure expenses are covered. Some of these expenses include, but are not limited to: out-of-pocket medical expenses, insurance, hobby materials, entertainment, personal care, or essential dietary needs.

Money from the SNT cannot be distributed to the person with the disability; it must be distributed directly to a third party. Trust assets are not held in the name of the person with the disability. Family members can become the beneficiary of the trust assets. The laws governing a trust are complex, it is important to seek the advice of a qualified attorney.

### **ABLE Accounts**

An Achieving a Better Life Experience Act (ABLE) savings account is for individuals with disabilities and their families. It is similar to a 529 college savings plan. Earnings grow tax free when saved for a variety of qualified expenses. An individual with significant disabilities that meets established criteria is eligible for one ABLE account. The account may be opened at any age but the disability must have an age of onset before the age of 26 and the disability must still exist at the time the ABLE account is opened.

#### **Government Financial Resources**

There are public benefits available to people with disabilities. Some of these resources place limits on income and certain types of assets, but in order to find out more about how to qualify, it is always good to reach out to your county human services department and ask questions to see if these resources are available to you. All government financial programs also have an appeals process for individuals who have been denied benefits. If you believe that you should be eligible, you have the right to appeal the decision.

### **Social Security Disability Insurance**

Apply for SSDI benefits as soon as possible because there is a six-month waiting period. If a person has qualified for SSDI, benefits begin on the sixth full month after the application is accepted. It is important to understand how complex the application process for SSDI can be. A disability attorney can help you apply for SSDI or appeal an initial denial. The Social Security office reports denial rates for first-time applicants for disability are as high as 65%. The appeal process is part of the application process and is your right. Disability attorneys generally complete a complimentary consult on your case and only collect payment after you have been awarded disability benefits. To apply, call your local Social Security Administration (SSA) office found in the resource section of this book.

### **Supplemental Security Income**

Supplemental Security Income (SSI) is a strictly need-based federal financial assistance program for persons with disabilities who have limited resources. The program is intended to guarantee a minimum monthly income to a person with disabilities who has little or no income and resources.

People with disabilities can be eligible for SSI even if they have never worked. Age is not a factor. If a person is eligible for SSI, they are automatically eligible for Medicaid. People receiving SSI must meet certain income and resource/asset limitations to be eligible. Insurance policy payments, court settlements, worker's compensation, and other financial resources may limit your eligibility for SSI.

#### **Medicare**

Medicare is a federal health insurance plan that provides for people with disabilities who are determined to be eligible for SSDI due to disability. People will qualify for Medicare two years after being awarded SSDI benefits. Medicare is not based on income. Medicare has four components: hospital insurance (Part A), medical insurance (Part B), Medicare Advantage Plan (Part C), and Prescription Coverage (Part D). Local SSA officers process applications and provide information about the program.

### **Medical Assistance (Medicaid)**

Some people will be eligible for Medical Assistance (MA), known in other states and by the federal government as Medicaid. MA can pay for eyeglasses, dental care, mental health services, family planning, hospice care, lab and x-ray, health centers, medical equipment, home healthcare, inpatient and outpatient hospital rehabilitation services, nursing home services, some prescribed medications, and transportation to and from medical appointments.

### **Department of Veterans Affairs Benefits**

The Department of Veterans Affairs (VA) is a federal program that provides benefits to eligible veterans and their dependents. An honorable or general discharge will qualify a veteran for benefits. Veterans in prison or on parole may be entitled to certain VA benefits. The VA has a system that prioritizes who can receive services and at what time. Since there are a limited number of beds available in VA facilities, there are often waiting lists for services. For more information, please contact your local VA for services available to you or your family member. You may also contact a veteran advocate through your county.

### **Workers' Compensation**

The Workers' Compensation Program is an insurance program provided by many employers at no cost to the employee. If an employee is hurt on the job or develops a disease due to the conditions on the job, Workers' Compensation may pay all reasonable and necessary medical care related to the injury or illness.

If a brain injury happens on the job, a person or their family should immediately inform the employer that an injury has occurred. Many employers require that an employee report their injury within 24 hours of the injury occurring.

# **Advocacy and Legal Rights**

#### What Is Advocacy?

Put simply, "advocacy" means fighting for a cause. In this case, the cause is your health, your happiness, and your future. Since you understand your situation better than anyone else, you are your best advocate.

#### Self-Advocacy

People with brain injuries and their loved ones have the right to advocate for themselves. NDBIN, vocational rehabilitation counselors, resource facilitators, case managers, discharge planners, educational specialists, and other professionals can help you understand your options. You are the authority on what is best for your situation. Always remember that you are your own best advocate. Do not be afraid to ask questions or campaign assertively to access available services.

Understanding is important for successful self-advocacy, so ask questions until you fully understand your situation.

#### **Your Legal Protections**

Depending on your circumstances, you may have certain legal rights.

#### These include the right to:

- Receive notice about decisions that affect your care and treatment.
- Direct and actively participate in planning for your care and treatment.
- Appeal decisions that affect your care and treatment.
- Have your privacy protected.
- Have access to your medical records.
- Be free from abuse.
- Live, work, learn, etc. in the most integrated setting.
- Be free from discrimination in employment, housing, transportation, education, etc.,
- Have obstacles removed that limit your access to locations or services.
- Obtain reasonable accommodations to help you work or learn successfully.

#### These rights may arise out of a number of rules and laws from a variety of entities, such as:

- Federal government
  - The Americans with Disabilities Act (ADA) protects basic civil rights and prohibits discrimination against people with disabilities. The ADA guarantees people with disabilities the same opportunities as other Americans in areas such as employment, state and local government programs and services, transportation, telephone services, and public accommodations.
  - » *The Fair Housing Act (FHA)* prohibits discrimination in the sale or rental of housing against people who are handicapped.
  - » *Individuals with Disabilities in Education Act (IDEA)* provides special education to children with specific learning disabilities.

- » *The Rehabilitation Act* prohibits organizations that receive federal funding from discriminating against individuals with disabilities in programs and activities because of their disability. The Rehabilitation Act requires employers and educational institutions to provide reasonable accommodations.
- State government
  - » *The Olmstead Commission* supports people with disabilities living, learning, working, and enjoying life in the most integrated setting.
- Local government, such as city or county ordinances regarding housing, transportation, etc.
- Private organizations, such as privacy policies and Patients' Bill of Rights.

### **Alternative Decision-Making**

Guardianships and conservatorships are one of the most restrictive measures and generally only happen if you become so incapacitated that you cannot make financial or personal decisions and you do not have the capacity to delegate these duties to another person. A court may grant a full or limited guardianship or conservatorship, but in any event, the guardian or conservator should act only in your best interest and should not overly restrict your rights.

For more information about advocacy and legal rights, contact the North Dakota Protection & Advocacy Project. The mission of Protection & Advocacy is to preserve, protect, and advocate for the rights of persons with disabilities.

North Dakota Protection & Advocacy Project 400 E. Broadway, Suite 409 Bismarck, ND 58501-4071 (701) 328-2950 • Phone (701) 328-3934 • Fax (800) 472-2670 • Toll Free 711 • TDD Relay panda@nd.gov



# Housing

After a brain injury, many individuals experience difficulty with judgment, behavioral symptoms, memory, attention span, or confusion that may lead to unsafe living situations. Individuals and families may need to create an environment that encourages safe practices regarding cooking, the use of electrical equipment, answering the door and telephone, and any other activity that could pose a safety risk. The following housing options are organized from least restrictive to highest level of care.

## **Possible Living Options After a Brain Injury**

#### 1. Returning Home and Home Modifications

#### Home and Community-Based Services

North Dakota provides home and community-based services (HCBS) through several programs that each serve different needs. The goal of these services is to allow an individual to live in the community with the services available instead of living in a nursing home or an institution. Available options can range from intensive such as receiving 24-hour services in an adult foster home to minimal such as chore services. Each program offers a specific set of services, and each program has varying functional and financial eligibility criteria. Contact NDBIN for more information on HCBS services and assistance in accessing services.

#### Respite

The purpose of respite care is to provide short-term care for individuals with disabilities and a brain injury while giving a temporary break to their regular caregivers. Some funding sources may cover respite services, but unfortunately, respite opportunities are limited in North Dakota. Speak to local social services about being able to utilize this service for you or your loved one.

#### Centers for Independent Living Services

These centers assist with independent living, advocacy, social, and attitudinal barriers. Outreach services and support group/social and recreational services are also available. North Dakota has four Centers for Independent Living (CILs) that provide independent living services to individuals of all ages with disabilities.

#### All CILs provide the following core services:

- Independent living skills training,
- Peer support,
- Individual and systems advocacy, and
- Information and referral.

# CILs also provide additional services as determined by consumer-identified needs in their service area. The services may include:

- Personal assistance services,
- Housing assistance,
- Transportation assistance,
- Social and recreational activities,
- Community awareness and education, and
- Technical assistance to businesses and local governments.

#### 2. Basic Care Facility

Basic care facilities provide long-term basic nursing care and assistance for people who need help with everyday activities, such as dressing or bathing. This is residential care for people who can't live in the community.

North Dakota has two basic care facilities specifically for a brain injury, Dakota Point in Mandan and HI Soaring Eagle Ranch in Valley City.

#### 3. Skilled Nursing Facility

A skilled nursing facility (SNF) provides rehabilitation care and skilled nursing services for patients who:

- Are not well enough to be discharged home and cannot tolerate the more intensive amount of therapy provided by an inpatient rehabilitation facility.
- Can benefit from having a registered nurse on-site for a minimum of eight hours per day (on a physician's plan).
- Need nursing and/or rehabilitation.
- Don't need daily supervision by a physician, although the care provided must still be based on a physician's plan.

A SNF can be a stand-alone facility, but when it is in a nursing home or hospital, it must be a separately licensed unit, wing, or building.

Medicare will generally cover up to 100 days in an SNF. You will pay nothing for the first 20 days. There will be a co-pay for days 21-100. Some Medicare supplemental ("Medigap") insurance policies will cover part or all of your co-pay, so check your insurance coverage. Private insurance coverage for care at an SNF varies. North Dakota has one skilled nursing facility for brain injuries, Dakota Alpha, in Mandan.

# Have you checked out NDBIN's Virtual Resource Directory?

Go to www.ndbin.org/resource-directory for a comprehensive, searchable by location or service, directory of North Dakota's offerings for brain injury survivors, providers and family members

# **Returning to Work**

### Returning to Work and Continuing or Starting Post-Secondary Education

After your brain injury, you may have to decide if and when you can return to work or continue/start post-secondary education. This section addresses options for continuing employment or education and describes employment training and education programs available in North Dakota for people with disabilities, including brain injury.

No matter where you are at in the return-to-work process, NDBIN will help you explore your options and provide support. We can assist by answering questions, locating support programs, and identify possible workplace accommodations.

#### **Returning to Work**

Depending on the nature and severity of your brain injury, you may or may not be able to return to the same job you had before your brain injury. Before returning to work, you should take extra care in assessing your job skills and abilities, as well as any changes you may have experienced. It is also helpful to get professional feedback from your doctor, rehabilitation therapists, or a vocational rehabilitation counselor.

### **Working with Your Current Employer**

If the nature of your brain injury allows you to return to work at your current job, you will want to discuss the timing of your return to work with your doctor and rehabilitation team. Sometimes, people with brain injuries return to work full time sooner than they should, which can negatively impact rehabilitation and successful return to work. Follow your doctor's instructions and take the time you need to heal before returning to work.

It is very possible that your current employer does not have the knowledge about brain injury that is needed to assist you in returning to work. Provide information in writing to your supervisor and human resources representative so that he/she can better understand how your brain injury has affected you and how he/she can help you return to work successfully. NDBIN can answer questions, provide training for employers, or provide you with educational materials to share.

When returning to work, under the Americans with Disabilities Act (ADA), you must still be able to perform the essential functions of your job with or without reasonable accommodations. Reasonable accommodations to help you perform your job might include:

- Making work areas accessible.
- Allowing flexible work schedules.
- Reassigning some tasks to others.
- Using a job coach.

Some people rely on accommodations to do their job; others use organizational tools on their own. To request workplace accommodations, you will need to disclose your disability as a result of your brain injury. Disclosing your disability is a very personal decision, but choosing to disclose gives you legal protection under the law. You will want to connect with professionals who are well versed in the ADA and job accommodations, such as vocational rehabilitation counselors, or an employment support agency such as Community Options, etc., to consider all your options. See NDBIN's Resource Directory

for a list of employment support agencies and a sample letter to get guidance on how to request job accommodations.

If you are unable to return to your previous job, you have several options. You could prepare for and seek new work, volunteer, or go back to school to learn and/or relearn skills.

## **Looking for New Employment**

When looking for a new job, seeking and finding work that best meets your interests, needs and ambitions while using your skills can be challenging. A brain injury can change a person's abilities, greatly influencing work life. You want to be reasonable and realistic in your self-assessment and expectations. Some people with brain injuries have trouble with organization, distractibility, decision-making, impulsivity, fatigue, stamina, learning difficulties, and relationships with co-workers. For some individuals with changes due to brain injury, applying for Vocational Rehabilitation Services (referred to as Voc Rehab or VR) may be helpful. You may also seek services through Community Options to help with seeking employment or finding new employment goals.

### Vocational Rehabilitation (VR)

VR can help analyze your skills and interests by providing vocational counseling and guidance. VR works with people who have disabilities to establish an employment goal, find and keep meaningful employment, and – when appropriate – identify assistive technology that can help maximize job performance.

#### When you call VR, you will go through an application and intake process.

- Explain to the person who answers the phone that you have sustained a brain injury and would like to apply for services.
- Always keep track of the name of the person you spoke with and the date and time you called, each time you contact VR.
- Ask how the application process works.
- Find out when the next orientation is for VR services for people with disabilities.
- During the application process, you will receive information on what to do if you are not satisfied with VR services. It is called the "Client Assistance Program."

#### Eligibility - You are eligible for VR services if:

- You have a physical or mental impairment;
- You have a substantial impediment to employment; and
- You require vocational rehabilitation services to become employed.

#### Services available through VR include:

- Vocational Rehabilitation Services counselors can work with you and your employer to help everyone understand brain injury and how the workplace may be adjusted to make accommodations to assist you being successful on your career path.
- Placement Services are available to eligible individuals who would like assistance establishing vocational goals, preparing for work, practicing interview skills, finding a job, or making appropriate accommodations at your workplace. Placement specialists are trained to understand the current economy and employment needs. These specialists bring to the job search their expertise in disability services and knowledge of employers looking for qualified employees.

- Supported employment job coaches provide on-the-job training and support for a limited time, once you secure employment. A job coach works side-by-side with you in the workplace to help you learn job responsibilities and adjust to the environment. The job coach can be supportive while you learn to understand boundaries and expectations of the work place.
- Assistive technology devices and services can help people with disabilities be independent and successful in the workplace. A person can use assistive technology to help him or her with communication, moving around, sitting/standing at a desk, working with computers, taking notes, and many other job responsibilities.

After you have been placed successfully at a job, VR will close your case. If you have trouble after case closure, call VR to discuss your options.

If you need assistance navigating any part of the VR process, please contact the North Dakota Brain Injury Network.

### Volunteering

One excellent way to restore stamina and endurance, explore job skills, interests, and work habits is through volunteering. Volunteer work can provide valuable experience and be extremely rewarding. Volunteering can build your resume and help you feel more connected to people while you make a significant contribution to the world around you. Many faith-based institutions, schools, and human service organizations also rely on a large pool of valuable volunteers. It is recommended you look into one of the hundreds of nonprofit organizations in North Dakota that suits your interests and abilities.

### Returning to College or Participating in Adult and Community Education Services

If you are returning to college or plan to attend for the first time, call the main telephone number of the institution and ask for the office or person in charge of working with students with disabilities, often called the Disability Services Office. These offices have support staff that coordinate services and accommodations for people with disabilities.

Under the ADA, post-secondary institutions are required by law to provide reasonable accommodations or modifications necessary for students with disabilities to have equal access to educational opportunities and services as those of non-disabled students. Examples of available accommodations may include extended time for testing, note taking, testing in a quiet location, priority registration, or accessible housing. You will need to provide recent medical documentation of your disability in order to request reasonable accommodations. Students should expect to self-advocate for their needs with individual instructors.

# **Education Supports and Rights**

When children and teens are hospitalized after a brain injury, a care conference may be held before they are discharged back into their parents'/guardians' care. These meetings include many members of the child's medical care team, the child's parents/guardians, and potentially a school representative. It is recommended that you reach out to the school your child attends and invite them to attend this meeting. This meeting is to plan a smooth transition and to ensure that communication paths are established with the school and medical team.

Determining appropriate accommodations often depends upon the severity of injury, how the injury impacts the student's functioning, and the length of time the student is symptomatic. School interventions can vary from general accommodations in the classroom to more extensive modifications that may require customized education services such as a 504 Plan or the development of an Individualized Education Plan (IEP). Educational needs and accommodations can change quickly in the first weeks and months following a brain injury, especially a mild injury. This may require checking frequently with the student to assure the general classroom accommodations are sufficient or if they need to be changed. This will ensure that the plans are reflective of current educational needs.

### **Available School Supports and Services**

**General Accommodations** - Symptoms resulting from most mild brain injuries/concussions are temporary and resolve within a few days or weeks. General accommodations are short term and may include a shortened school day schedule, minimal/no homework, rest breaks, quiet environment, extended transitions between classes, and preferential seating.

**Section 504 Plan** - For students with more long-term issues, a 504 Plan might be implemented. Parents can request that their child be evaluated for 504 accommodations. Once eligibility has been determined, the school district has a legal responsibility to prepare and implement a 504 Plan, in accordance with applicable regulations, including the identification of accommodations to the environment, curriculum, materials, and instructions in the least restrictive environment. 504 Plans are also available for post-secondary learning and work environments, contact NDBIN for assistance with when and how to ask for a 504 Plan.

**Special Education Services** - If the student's educational needs resulting from a brain injury are chronic and/or severe, a parent or education staff can request a special education evaluation. Determination of eligibility for special education services must be established before those services can be provided. An IEP will be written and annually reviewed by the educational team, of which parents are a vital part.

NDBIN will help you through this process. We can provide individual supports to you or your family member. We can aide the school in training teachers and para educators on brain injury. We have sample IEPs that can be used to generate ideas for goals for students who have experienced brain injuries. We also can provide access to our lending library.

# Transportation

After a brain injury, some people drive with restrictions or need vehicle modifications, while others find they need (or want) public transportation. This section describes some of the options that persons with disabilities can use to get around.

### Driving

People use many skills when driving, including attention, visual processing, reaction time, judgment, spatial orientation, and motor skills. A brain injury may greatly impact many of these abilities. People with brain injuries should use caution when deciding whether to continue driving after a brain injury and listen to recommendations given by medical professionals.

Some service providers offer detailed driver assessment programs in which program staff work on and off the road to determine a person's ability to drive. Other programs offer individuals the opportunity to relearn driving skills. Your primary care physician can also advise you in regard to your ability to relearn how to drive safely.

### **Public Transportation**

The North Dakota Department of Transportation (NDDOT) offers a fixed route for public transportation; transportation providers vary by county and/or city. NDDOT offers a free map by request, by calling their toll-free number at 1 (855) 637-6237 or visit their website.

### **Medical Rides**

Medical rides are offered to assist with transportation from rural areas to medical facilities. Medical rides are regularly scheduled and, depending on the location, may be formally structured or provided as needed. All counties in North Dakota offer transportation services three to five days a week, depending on the location. To find out more about medical rides in your area, call NDDOT's toll-free number, 1 (855) 637-6237.



# **Assistive Technology**

Assistive technology (AT) is the term used to describe devices, technology and aides that allow a person to be more independent. These can range from low tech, for example-post-it notes, to high tech, for example-iPads. When choosing the device, the task to be completed, your strengths and preferences, and setting where the task will be done need to be considered. Consider starting small with one type of support as to not get overwhelmed with too many options to start out with. In some cases you may be able to select AT independently, or follow up with your provider for suggestions.

#### ND Assistive

3240 15th Street S, Suite B Fargo, ND 58104 (701) 365-4728 or toll free 1 (800) 895-4728

4501 Coleman Street, Suite 107 Bismarck, ND 58503 (701) 258-4728 or toll free 1 (800) 895-4728 Email: info@ndassistive.org



# **Neuropsychological Services**

Neuropsychology is a sub-specialty of psychology that specializes in the assessment and treatment of patients with cognitive related conditions such as a brain injury. What distinguishes a clinical neuropsychologist from other clinical psychologists is knowledge of the brain, including an understanding of areas such as neuroanatomy and neurological disease.

### **Neuropsychological Evaluation**

A neuropsychological evaluation may be beneficial following a brain injury to assist in treatment and rehabilitation.

An evaluation can provide information related to cognitive limitations, strengths, weaknesses, and valuable information related to return to work options.

### What is a Neuropsychological Evaluation?

A neuropsychological evaluation often includes at least three components:

- 1. Review of medical and other records.
- 2. An interview with the individual and often, another person who knows them well (a family member, close friend, or caregiver).
- 3. Administration of tests that measure abilities and mood.

Using these three sources of information, the neuropsychologist will provide a comprehensive report that summarizes relevant medical history, evaluation results, areas where cognitive or emotional functioning has changed, and recommendations for work, home, and family.

### How long will the testing process take?

The length of testing time depends on unique factors in each situation but is usually completed in six to eight hours. Testing may be broken up over a couple of appointments or may be completed in one day.

### What to provide before the evaluation?

Provide the neuropsychologist with:

- Any available pre-injury, injury, and post-injury data that would be useful.
- Information related to the individual's current functioning: changes in personality and skills; level of independence; and current problems experienced by the individual and family.
- Information related to plans for the future and expectations of the individual with brain injury and expectations of family members.
- The purpose of obtaining the evaluation.

# How often should an evaluation be done?

During the first two or three years after a brain injury, repeat evaluations may be helpful to identify emerging strengths, persistent deficits, and changing needs. After an evaluation, ask for a recommendation about if and when the evaluation should be done again.

# **Common Measures**

The Glasgow Coma Scale and Rancho Los Amigos Scale are two scales commonly used to determine the functional level of your injury. Your provider may use these periodically throughout your rehabilitation to measure your progress.

#### GLASGOW COMA SCORE (GCS)

The Glasgow Coma Scale (GCS) is scored between 3 and 15. It is composed of three parameters: best eye response, best verbal response and best motor response.

#### Best Eye Response (4)

- 1. No eye opening
- 2. Eye opening to pain
- 3. Eye opening to verbal command
- 4. Eyes open spontaneously

#### Best Verbal Response (5)

- 1. No verbal response
- 2. Incomprehensible sounds
- 3. Inappropriate words
- 4. Confused
- 5. Orientated

#### Best Motor Response (6)

- 1. No motor response
- 2. Extension to pain
- 3. Flexion to pain
- 4. Withdrawal from pain
- 5. Localizing pain
- 6. Obeys commands

You should always look at a GCS broken down by components not just the total. A Coma Score of 13 or higher correlates with a mild brain injury, 9 to 12 is a moderate injury, and 8 or less, a severe brain injury.

#### THE RANCHO LOS AMIGOS SCALE

The Rancho Los Amigos scale was developed at the Rancho Los Amigos Hospital in California and is often used by doctors and therapists to explain the behavioral, cognitive and emotional changes that take place during healing.

**Level 1**—*No Response:* Patient appears to be in a deep sleep and does not respond to voices, sounds, light or touch.

**Level 2** – *Generalized Response:* Patient reacts inconsistently and nonpurposefully to stimuli; first reaction may be to deep pain; may open eyes but will not seem to focus on anything in particular.

**Level 3** — *Localized Response:* Patient responses are purposeful but inconsistent, and are directly related to the type of stimulus presented, such as turning head toward a sound or focusing on a presented object; may follow simple commands in an inconsistent and delayed manner.

**Level 4** — *Confused, Agitated:* Patient is in a heightened state of activity; severely confused, disoriented and unaware of present events. Reacts to own inner confusion, fear or disorientation. Behavior is frequently bizarre and inappropriate to the immediate environment. Excitable behavior may be abusive or aggressive.

**Level 5** — *Confused, Inappropriate, Non-Agitated:* Patient appears alert; responds to simple commands. Follows tasks for two to three minutes but easily distracted by environment; frustrated; verbally inappropriate; does not learn new information.

**Level 6** — *Confused-Appropriate:* Patient follows simple directions consistently; needs cueing; can relearn old skills such as activities of daily living, but memory problems interfere with new learning; some awareness of self and others.

**Level 7** — *Automatic-Appropriate:* If physically able, patient goes through daily routine automatically, but may have robot-like behavior and minimal confusion; shallow recall of activities; poor insight into condition; initiates tasks but needs structure; poor judgment, problem-solving and planning skills.

**Level 8** — *Purposeful-Appropriate:* Patient is alert, oriented; recalls and integrates past and recent events; learns new activities and can continue without supervision; independent in home and living skills; capable of driving; deficits in stress tolerance, judgment; abstract reasoning persists; may function at reduced social level.

**Level 9** — Patient independently shifts back and forth between tasks and completes them accurately for at least two consecutive hours; aware of and acknowledges impairments when they interfere with task completion; requires standby assistance to anticipate a problem before it occurs; depression may continue; patient may be easily irritable and have a low frustration tolerance.

**Level 10** — Patient is able to handle multiple tasks simultaneously in all environments but may require periodic breaks. Irritability and low frustration tolerance may persist when feeling sick, fatigued and/or under emotional distress.

# Training

NDBIN has numerous available education and training opportunities to meet your needs. We can also provide customized educational trainings of your choosing on a variety of topics related to brain injury. Contact us today to learn more about scheduling a customized training for your group!

# The North Dakota Brain Injury Network offers the following training opportunities:

#### Webinar Wednesdays

A webinar series designed to meet your needs whether you are a brain injury/stroke survivor, caregiver, or provider. Past webinars are archived on the NDBIN website for viewing and requesting CEUs. Visit **www.ndbin.org/events/webinars** 

#### **Brain Injury Basics**

Interactive training provides a general knowledge of brain injury and what it means for the individuals they serve and care for.

#### Certified Brain Injury Specialist Training (CBIS)

Becoming CBIS certified is an intense training endeavor. The CBIS certification delves into the essential aspects of brain injury treatment needed to effectively care for patients. A variety of disciplines have already become certified in North Dakota – from speech-language pathologists to optometrists.

#### Mind Matters Conference

This two-day annual conference features nationally renowned speakers and highlights new research, trends, practice strategies, and collaborative models of care.

#### **Concussion Symposium**

This event features the latest research, methodology and information related to concussion.

#### Online Brain Injury Courses

NDBIN offers 5 video module format FREE courses, see page 45 for additional details.



# **Common Definitions**

Acquired Brain Injury (ABI) - An injury to the brain that is not hereditary, present at birth, or degenerative. Causes include heart attack, carbon monoxide poisoning, seizure disorders, and toxic exposure.

Activities of Daily Living (ADLs) - An individual's self-care routine, including feeding, toileting, dressing, bathing, and grooming.

Acute care - A hospital-based program with skilled service delivery that optimizes the individual's medical condition. The individual may or may not receive therapies.

Acute rehabilitation - A hospital-based, highly intensive skilled service delivery to optimize the person's medical condition and functional status. Focus on development of bowel and bladder control, communication, mobility, basic hygiene, orientation, and learning. Usually the individual receives three hours or more of therapy per day. Average length of stay is three to five weeks.

Agitation - Uncontrolled restlessness, upset, or excitement in response to internal or external factors.

Amnesia - Loss or impairment of memory function secondary to brain dysfunction.

Aneurysm - A localized, abnormal dilation of a blood vessel due to a defect or weakness in the vessel wall.

Anomia - Difficulty naming things.

Anoxia - A lack of oxygen to the brain. Brain cells need oxygen to stay alive. When blood flow to the brain is reduced or oxygen in the blood is too low, brain cells are damaged. Can occur from trauma as well as "non-traumatic events" including heart failure, near drowning, electrocution, and other events which can alter oxygen flow to the brain.

Aphasia - A loss of previously acquired language function due to damage to the brain; typically includes impaired comprehension, reading, spelling and writing, as well as verbal expression.

**Apraxia** - An inability to perform skilled motor acts not attributable to impaired motor strength or coordination, sensation, or comprehension; patients may be able to perform an activity spontaneously that they cannot perform on command.

Arousal - The change from a state of sleep to one of being awake.

Arteriovenous Malformation (AVM) - A malformation of the arteries and veins in the brain. These blood vessels are thin and fragile and may cause bleeding in the brain.

Aspiration - Food or liquid going in to the lungs instead of the stomach.

Ataxia - Impaired balance of the body or impaired coordination of an arm or leg.

Attention - The ability to focus on a given activity.

Awareness - Understanding the problems resulting from a brain injury.

**Behavior management program** - Specific plans of care developed by the treatment team to assist patients in appropriate social skills and interactions with others.

**Behavior modification** - A specific clinical management strategy that rewards/reinforces desirable behavior and discourages/inhibits undesirable ones. Uses the principles of learning to change behavior. There are specific rewards and consequences designated for specific behaviors exhibited by the individual. The ultimate goal is the individual will learn to control their own behavior without positive or negative consequences being imposed from outside.

**Brain swelling/cerebral edema** - The brain swells after severe injury. Severe swelling can cause compression of the brain stem and death. It can also lead to neuron damage from compression of the cells or from anoxia caused by a disruption of the blood flow and oxygen to the brain.

Cognition - Thinking or mental activity.

**Cognitive therapy** - A means by which the brain relearns some of the skills it has lost as a result of brain injury.

**Concussion** - A temporary altered mental status or loss of consciousness from traumatic brain injury.

**Confabulation** - Making something up that is not true (although the individual with a brain injury may believe it is true).

**Contusion** - A bruise to a part of the brain.

**Decubitus** - An opening of the skin, obtained in bed, which requires special topical treatment and body positioning to heal. Also called a pressure ulcer or pressure sore.

**Diffuse axonal injury** - Widespread microscopic injury to nerve connections (axons) along with injury to specific brain structures, including the upper brain stem.

Diplopia - Double vision.

**Distractibility** - Inability to hold attention on an activity.

**Dysarthria** - Weakness, slowness, decreased range, and/or uncoordinated muscles of the mouth, throat, and lungs resulting in problems with clarity of speech.

Dysphagia - Difficulty with chewing or swallowing food or liquid.

**Encephalitis** - An infection of the brain, most often due to a virus.

**Encephalopathy** - A general category that may include damage to the brain caused by infections (meningitis, encephalitis), tumors, or metabolic disorders (chemical changes to the brain).

Fluid restriction - Sometimes drinking fluid may cause the brain to swell, because the brain absorbs the fluid. Make sure to talk to the primary nurse before giving fluids to an individual.

**Glasgow Coma Scale** - A scale used to measure coma based on numerical scores for eye opening, speech, and limb movements or postures.

Hemianopia/Hemianopsia - Partial blindness in which the left or right visual field is "blacked out" in both eyes.

**Hematoma** - If the blood vessels in the brain are damaged by the impact inside the skull, they may bleed to create a pool of blood or hematoma. It can cause brain injury by damaging the neurons it comes in contact with or by squeezing neurons increased pressure in the brain. Typically, it is treated with a surgical drain.

Hemiparesis - A weakness on one side of the body.

Hemiplegia - A paralysis or complete inability to move one side of the body as a result of injury or damage to the brain.

Hemorrhage - Internal or external bleeding.

**Hydroceaphalus** - The flow of cerebrospinal fluid in the ventricles of the brain can sometimes be blocked or disrupted after a brain injury. Fluid can constantly be made in the ventricles causing increased pressure. This is called hydrocephalus, and it can be a serious secondary effect of a brain injury. Inserting a needle and drawing the fluid off the brain and into the abdominal cavity can be used to treat this. This procedure is called a ventriculoperitoneal shunt and reduces pressure inside the brain.

**Impulsiveness** - Doing or saying something too quickly, often leading to errors and difficulties.

**Incontinence** - The inability, due to physical and / or cognitive reasons, to control urination or bowel movements.

**Increased Intracranial Pressure (ICP)** - Occurs because of buildup of pressure within the skull. The brain, membranes, and cerebrospinal fluid are encased within the bones of the skull. The fluid formed from the swelling or bleeding builds up and causes increased pressure inside the brain, and the increased pressure causes further damage to the brain tissue.

**Initiation** - The ability to begin an activity.

**Intracerebral Hemorrhage (ICH)** - Bleeding inside the brain, caused when a diseased blood vessel bursts and floods surrounding brain tissue with blood.

Judgment - The ability to know the dangers of certain activities and to make correct decisions.

Loss of Consciousness (LOC) - A partial or complete loss of consciousness with interruption of awareness of oneself and ones surroundings.

**Memory** - Remembering and learning new things, including what you do, what others say, and what you see or read.

**Neurologist** - A medical specialist in disorders of the nervous system. May be involved in the initial diagnosis of brain injury and may continue to monitor recovery.

**Neuropsychologist** - A psychologist who specializes in brain-behavior relationships. Administers a series of tests to evaluate a person's cognitive, emotional, intellectual, and academic/vocational skills.

**Neurosurgeon** - The medical specialist who performs surgery on the brain and has expertise in structural diseases of the central nervous system.

**Occupational therapist** - Person who helps the individual regain the physical, perceptual, and cognitive skills required to perform Activities of Daily Living (ADLs).

**Organization** - The ability to arrange thoughts and make them sound sensible and orderly.

**Orientation** - A sense of what is going on around you. Knowing the day, date, month, and year; things about yourself, where you are and how to get around; and knowing what happened to you.

**Perseveration** - Inability to turn the attention from one thought to another.

**Physiatrist** - A physician specializing in physical medicine and rehabilitation. In hospitals and rehabilitation settings, the doctor often leads the rehabilitation team and coordinates the goals into a unified approach.

Physical therapist - Person who focuses on individual's motor functioning and mobility.

**Post-traumatic amnesia** - The period of time after a head injury when a person does not reliably recall ongoing day-to-day events.

**Pragmatics** - Behaviors related to communication such as eye contact, gestures, and facial expressions.

**Primary injury** - The injury that occurs at the time of the traumatic injury.

**Psychiatrist** - A medical specialist who concentrates on behaviors, personality change, mood changes, memory change, and sleep/wake cycles. The doctor may diagnose, monitor, and prescribe medications.

Rancho Scale - A scale of stages of recovery after traumatic brain injury.

**Secondary injury** - The injury that occurs after the traumatic injury.

**Seizure disorders** - A secondary effect of brain injury can be a seizure disorder, caused by a specific injury that leads to a disruption in the electrical activity of the brain. Seizure disorders can occur at any point after a brain injury. Usually they are treated with anticonvulsant drugs.

**Shearing injury** - Damage to the brain caused by areas of brain tissue moving in the same direction at different speeds, resulting in diffuse brain damage.

**Social worker/case manager** - Role varies in different settings. Acts as a link between the individual, the family, and the team members. Many provide education, resources, emotional support, and discharge options. May negotiate between facility and financial source.

**Spasticity** - Exaggerated response of muscles causing stiff and awkward movements and abnormally increased muscle tone; can be caused by an injury to the brain.

**Speech-language pathologist** - Speech-language pathologists (SLPs) work to prevent, assess, diagnose, and treat speech, language, social communication, cognitive-communication, and swallowing disorders in children and adults.

**Stroke or Cerebral Vascular Accident (CVA)** - A stroke occurs when a blood vessel that carries oxygen and nutrients to the brain is either blocked by a clot or bursts (or ruptures). When that happens, part of the brain cannot get the blood (and oxygen) it needs, so it and brain cells die. Stroke can be caused either by a clot obstructing the flow of blood to the brain (called an ischemic stroke) or by a blood vessel rupturing and preventing blood flow to the brain (called a hemorrhagic stroke). A TIA (transient ischemic attack), or "mini stroke", is caused by a temporary clot.

**Sub-acute rehabilitation** - A hospital or skilled nursing facility-based services with focus on medical stability and/or complex nursing needs in addition to receiving rehabilitation similar to acute rehabilitation. Usually the individual receives one to three hours per day during the week. Average length of stay is two to three months.

Subdural hematoma - A blood collection that forms between the dura and the skull; blood fills the space under the skull and exerts pressure on the brain.

**Toxic or metabolic injury** - Occurs after exposure to unsafe substances such as lead or a harmful buildup of the body's own chemicals, as seen in kidney failure.

Tracking - Visual following of an object or sound with the eyes.

**Traumatic Brain Injury (TBI)** - With or without skull fracture is an insult to the brain caused by an external physical force that may produce a diminished or altered state of consciousness. Mostly common causes include vehicle crashes, falls, sports injuries, and violence.

**Vocational rehabilitation counselor** - Evaluates the individual's past vocational or educational performance and current vocational skills. The goal is to help an individual resume appropriate and realistic employment.



# Unmasking braininjury The Mission







# **PROMOTE** awareness of the prevalence of brain injury

**GIVE** survivors a voice and the means to educate others of what it's like to live with a brain injury

**SHOW** others that persons living with a disability due to their brain injury are like anyone else, deserving of dignity, respect, compassion, and the opportunity to prove their value as citizens in their respective communities

# Join the Movement!

VISIT www.ndbin.org/unmasking

**MAKE** your own mask and add it (and your own voice!) to the collection.

**SCHEDULE** a mask making event.

HOST a traveling display of masks in your location!

For more information contact NDBIN at (855) 866-1884 or www.ndbin.org. Unmasking Brain Injury is a project of the North Dakota Brain Injury Network in partnership with the North Dakota Department of Human Services.







Online Brain Injury Courses offered by the North Dakota Brain Injury Network. We want to help you meet your training needs. These five separate courses can help professionals, survivors, and family members learn more about brain injury.

- Introduction to Brain Injury\*
- Cognitive and Behavioral Consequences of TBI in Adults\*
- Primary Care and TBI
- Pediatric TBI
- Substance Use and TBI

\*Courses required by Department of Health and Human Services. for all direct service providers working with individuals with brain injury. Print and submit a copy of your certificate of completion upon provider enrollment with Medicaid.

#### Additionally these courses offer CEU credit for the following disciplines:

- Occupational Therapy
- Nursing
- Social Work
- Counselor Examiners
- Addiction Counseling
- Speech Language Pathology/Audiology
- Psychology
- Emergency Medical Services LCCR/Distributive
- Certified Brain Injury Specialist

NDBIN offers additional educational opportunities and customized on-site training to meet all your needs.

*Each course is \$25. Sign up for five courses and receive one for free. North Dakota residents will receive a promo code discounting their courses 100%. Email <u>Carly Endres</u> (carly.endres@und.edu) for the promo code.* 







#### What is NDBIN?

The North Dakota Brain Injury Network provides information and support to individuals with brain injury, their family members and various service providers and agencies. Our resource facilitator assists with navigating the service system and provides technical assistance in finding the right resources for each individual. We offer outreach and education to increase public awareness of brain injury, as well as peer support by connecting people with others who have experienced a brain injury. We can provide onsite training to facilities and organizations as well. All of our services are FREE.

#### **Support for Educators**

#### Technical assistance such as

- · juvenile brain injury screenings
- juvenile symptom inventory administration
- troubleshooting behavior
- connecting with relevant services
- observation of student and formal recommendations.

Trainings for families, para educators, and staff

Development of 504s and IEP goals

As long as the student has a brain injury (Concussion, TBI, stroke, tumor, etc) and is a resident of North Dakota we can offer our services at no cost!







How every family, school and medical professional can implement a Community-Based Concussion Management Program

# REAP<sup>®</sup> The Benefits of Good Concussion Management

# **REAP**<sup>®</sup>

Remove/Reduce Educate Adjust/Accommodate Pace



Authored by Karen McAvoy, PsyD © 2018 KAREN MCAVOY, PSyD. ALL RIGHTS RESERVED Third Edites 2018

The REAP Project, which stands for **Reduce • Educate • Accommodate • Pace**, is a community-based model for concussion management that was developed in Colorado. The early origins of REAP stem from the dedication of one typical high school and it's surrounding community. After the devastating loss of a student to "Second Impact Syndrome," the administrators, teachers, certified athletic trainer, school nurse, school psychologist and counselors all banded together to create a wider safety net for all students in that school. The net became stronger when parents and community medical professionals also worked together to coordinate care and recovery from concussion. The lessons learned from this tragic event are that a "Multi-Disciplinary Team" approach is the foundation of good Concussion Management.

To download the REAP manual go to **www.ndbin.org/brain-info/concussions** 





Many survivors will tell you life after a brain injury can be scary, but it doesn't have to be. This journey can be challenging but with support of a fellow survivor and NDBIN's staff, you will find the road to recovery is much brighter!

**Survivor Connections** – Connects an experienced brain injury survivor with a new survivor through a monthly phone call facilitated by NDBIN's staff.

#### How to Connect

- 1. Survivors can sign up through the NDBIN referral form or contact NDBIN for more information. https://www.ndbin.org/client-referral
- 2. An experienced survivor and a resource facilitator, will make monthly calls to the new survivor.
- 3. The new survivor receives support, resources, and education to aid in their successful recovery.



#### **Sources Cited**

msktc.org/tbi/factsheets/Alcohol-Use-After-Traumatic-Brain-Injury

ohiovalley.org/informationeducation/substanceuse/

www.research.va.gov/topics/tbi.cfm

www.nd.gov/dpi/uploads/63/AGuideToPostSecondaryEducationInNorthDakota.pdf

www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/support-groups/art-20044655

msktc.org/tbi/factsheets/Cognitive-Problems-After-Traumatic-Brain-Injury

dpi.wi.gov/sites/default/files/imce/sped/pdf/tbi-memoryguide.pdf

# NDBIN staff will attempt to keep information as accurate and current as possible.



# **Brain Injury Playing Cards**

# Entertaining way to spread awareness

North Dakota Brain Injury Network playing cards are intended to help families, providers, and survivors learn new facts, open dialogue and aide in the recovery of individuals with brain injury.

- Family and friends better support their loved ones when they know more about brain injury
- Education about brain injury is important for everyone
- Learning about brain injury assists survivors to understand their own recovery

# Games work on skills in a fun, interactive way

Card games may sound like child's play, but they are helpful tools in recovery and rehabilitation. Research shows that playing games like cards, puzzles, or board games are good ways to practice skills and exercise the mind.

- Playing games can trigger forgotten skills and make practice fun
- Cards are a simple and inexpensive way to take recovery anywhere
- Multiplayer games help with communication and social skills

# For more information about brain injury or to order cards contact us!



1 (855) 866-1884 • www.ndbin.org • info@ndbin.org



# Each card includes a fact about brain injury

#### **Game Suggestions**

**Card Sorting** works on motor skills, concentration, sequencing and attention Cards can be sorted many ways! By suit, odd/even numbers, black/red, every other even/odd, etc.

**Solitaire Games** helps with sequencing, math skills, concentration and visual memory.

**Memory/Matching Games** develop recognition, recall, spatial memory, attention, and concentration. Start simple with limited number of matches and work up to more complex variations.

**War** helps with focus, attention, speed, recognition, categorization and reaction time.

**Golf** works on social skills, math skills, visual memory, recall, recognition, and short-term memory.

Kings in the Corner develops socialization, sequencing, recognition, visual memory, attention and focus.

**Gin Rummy** helps with reading social cues, sequencing, recognition, visual memory, attention and focus.

**Hearts** enhances socialization, attention span, concentration, memory and logical reasoning.



# **Importance of Brain Injury Screening**

At the doctor's office, coma is often the marker of a Traumatic Brain Injury or TBI, but many people with mild brain injuries do not lose consciousness. In particular, youth do not lose consciousness like an adult does. It is a common myth that children are more resilient than adults, when in fact it just takes longer for their symptoms to develop because they are developing skills, rather than maintaining skills like an adult would.

#### Some behaviors noted with brain injury, although some individuals may have more subtle symptoms:

- poor judgement
- problems reasoning
- severe memory difficulties

- hyperactivity unresponsive to treatment
- new learning problems
- problems making decisions

explosive temper

• extreme impulsivity

# When an individual has sustained multiple mild injuries, it has a compounding effect!

Not everyone realizes they have a brain injury, even when the symptoms are chronic and impact their daily lives. Individuals may never connect that the problems they are dealing with may be due to a blow to the head—even one that occurred years earlier.

Studies have demonstrated that hidden brain injury is a contributor to increases in **homelessness**, **involvement with the criminal justice system**, **substance use and mental health disorders**.

When brain injuries are not identified, symptoms may be inappropriately attributed to other health or behavioral conditions. When this occurs, **appropriate treatment and symptom management is being missed**.

Establishing brain injury screening can help in seeking appropriate services and supports for individuals. This can also help prevent unnecessary hardships for those who are struggling with loss of ability and growing frustrations that can lead to further health problems.

Contact NDBIN today to schedule your screening training!



# Brain Injury Services Roadmap

Who is eligible for NDBIN services? North Dakota residents that identify as having a brain injury.

<sup>st</sup> Stop: Referrals-can be made online at: https://www.ndbin.org/client-referral or by calling: 1 (855) 866-1884 **2<sup>nd</sup> Stop:** NDBIN (or trained support agency) will implement our brain injury screening Stop: If positive screen- continue on with our symptom inventory to help determine symptoms impacting survivor the most **A**th Stop: Sign appropriate Releases of Information (ROI) related to needs from symptom inventory 5<sup>th</sup> Stop: Continue to receive support services from NDBIN **6**<sup>th</sup> Stop: Talk to your primary provider about a referral for a neuropsychological battery

# Should I Pursue a Formal Brain Injury Diagnosis?

#### Why would I need to?

With milder brain injuries, symptoms can be less noticeable. Further assessment is often needed to get a brain injury diagnosis.

Injury severity (mild, moderate, severe) is different than a formal diagnosis.

With severe injuries there was usually a loss of consciousness and neuroimaging that showed brain injury. But with a mild injury, that is not always the case and then a neuropsychological assessment is required.

#### What is a neuropsychological assessment?

A neuropsychological assessment consists of a **variety of tests** designed to measure the damage caused by brain injury. It provides more information about your cognitive capabilities, or in other words your ability to **learn, think, reason, remember, solve problems, make decisions, and pay attention**.

#### What does a neuropsychologist do?

A neuropsychologist, who is a psychologist with a Ph.D. or Psy.D. credential and specialized training in brainbehavior relationships, conducts the evaluation.

#### What else should I expect during a neuropsychological assessment?

In addition to administering the assessment, the neuropsychologist will likely interview you, the survivor with the brain injury and your family members, study available hospital records, and review any other information that provides insight into what you were like before your injury.

#### What can I do with my results?

When you are given the results, they can help your rehab or hospital team guide their care. It can help give your family members an idea of the impact your injury had on you. Many times, the information they give can help with return to work and what to expect about your brain on a day-to-day basis. These results can also be utilized when applying for support such as Social Security Disability.

#### How can I get a neuropsychological assessment?

To receive a neuropsychological assessment, you will need a referral from your primary care provider. Prior to your appointment with your primary physician, schedule your Brain Injury Screening and Symptom Inventory with us by calling: (855) 866-1884 or emailing: <u>info@ndbin.org</u>.

#### To learn more about neuropsychologists in North Dakota, visit NDBIN's resource directory.

**Sources cited** Neuropsychological assessments. Brain Injury Association of America. (2022b, August 8). <u>https://www.biausa.org</u>



# North Dakota Brain Injury NETWORK NEUROIMAGING

Following a brain injury, clinicians may use imaging tests to see inside the brain. Imaging tests can show abnormalities, such as blood clots or brain bleeds, as well as show the individual's actual brain function. It is important to note that NOT all brain injuries show up on neuroimaging; many milder injuries are cellular and cannot be detected with this type of technology.

There are several types of imaging available. These are the most commonly utilized:

#### Computed Axial Tomography (CAT or CT)



Scans produce crosssectional pictures to create 3-D brain images that will

show the brain's density and any abnormalities, such as swelling, bleeds (called hematomas), and skull fractures. Though not as sensitive as MRI scans, CT scans take less time to perform and are typically the first scans taken in the hospital.

#### Computed Tomography Angiography (CTA)



Provides the treatment team with images of blood vessels in the brain and throughout the body to show blockages or abnormalities.

#### Electroencephalogram (EEG)

A test that measures the electrical activity in a person's brain. This test is usually done to determine the amount of brain activity and to detect any suspected seizure activity.

#### Magnetic Resonance Imaging (MRI)

Produces detailed images of the brain using radio waves and a strong magnetic field.



MRI scans typically take longer to obtain than CT scans, but they are more sensitive and provide more detail. They are not typically done in the immediate care (Emergency Department or Intensive Care Unit) or during the initial treatment after a brain injury.

#### X-ray

Allows the treatment team to locate any skull fractures or other broken bones as a result of the injury.



#### Functional Neuroimaging

Are tests to create pictures of the brain's activity during various tasks. These studies may include SPECT (single photon emission computerized tomography) and PET (position emission



# Consult your physician for more information on neuroimaging and whether or it not can be beneficial for you.

Sources cited: Neuroimaging. Brain Injury Association of America. (2022, August 8). https://www.biausa.org

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

## You can now fill out a <u>referral form</u> online.

<b>Referral Form</b> The North Dakota Brain Injury Network (NDBIN) is intended to provide information about brain injury and assist in accessing services. This is a FREE follow-up service, and can be discontinued at any time.				
I would like NDBIN to contact:	Individual Person	al Representative		
Individual Information				
Individual's Name:		Date of	birth:	
Address:	City:	State:	Zip:	
Telephone:Date of In	jury:Ca	use of Injury:		
Housing situation:living alone	living with family	living with other caregive	rother	
Personal Representative Information				
Representative's Name:		Date:		
Address:	City:	State:	Zip:	
Telephone:	Relationship to in	ndividual:		
Services interested in (please check all that apply) Community Resources-Provide information regarding access to community based resources and assistance in accessing services.				
Brain Injury Information-Access to brain injury specific information, education and materials for individuals, family, and providers.				
Support Groups-Offer information regarding regional and virtual supports groups.				
Survivor Connections-Structured program providing telephone based connection between individuals with lived experience and those new to brain injury.				
Case Consultation-Individualized technical assistance for professionals to increase success supporting individuals and families experiencing brain injury.				
Other:				
I give permission for my clinic/provider to forward this form on my behalf to the North Dakota Brain Injury Network. After the provider sends this referral form, a representative from NDBIN will contact me about resources, support and educational opportunities that are available to my family and I.				
Signature of individual or authorized re- Submit completed form via Fax (701) 77	presentative: 7-1431 or email <mark>info@nd</mark>	bin.org.	Date:	
To be completed by forwarding provider Organization Making Referral:				
If applicable please provide Provider's Name:	Phone:	Email:		

# NORTH DAKOTA BRAIN INJURY NETWORK

The North Dakota Brain Injury Network provides information and support to individuals with brain injury, their family member and various service providers and agencies. Our resource facilitator assists with navigating the service system and provides technical assistance in finding the right resources for each individual. We offer outreach and education to increase public awareness of brain injury, as well as peer support by connecting people with others who have experienced a brain injury. We can provide on-site training to facilities and organizations as well. *All of our services are FREE.* 

Visit NDBIN's website: www.ndbin.org

View NDBIN's online courses: www.ndbin.org/training

View NDBIN's upcoming events, such as our annual Mind Matters conference: www.ndbin.org/events/upcoming

> Information on hosting an Unmasking Brain Injury event: www.ndbin.org/brain-info/unmasking-brain-injury

> Sign up for email updates here: www.ndbin.org/subscribe

Request your free deck of playing cards here: www.ndbin.org/contact/card-request