



# Resource Guide

For Iowans  
Affected by  
Brain Injury





# How to Use This Guide

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(855) 444-6443

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Brain injury is a complicated diagnosis, and understanding this new world can be confusing and overwhelming after an injury has occurred. For more than 35 years, the Brain Injury Alliance of Iowa has been working to be there for Iowans who find themselves navigating this unanticipated landscape.

We have created this resource guide to assist individuals who have experienced a brain injury, their caregivers, and the professionals who work with them in better understanding brain injury. This guide offers general information about brain injury and may answer some specific questions you have.

If you need further assistance, please feel free to reach out to us here at the Brain Injury Alliance of Iowa. Our core service, called Neuro Resource Facilitation, is a fee-free service offered in the state of Iowa to help individuals navigate medical and general life challenges after a brain injury.

To learn more about our supports available or how we may assist you, please contact us at (855) 444-6443 or [info@biaia.org](mailto:info@biaia.org).

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# **Understanding Brain Injury**



# General Information About Brain Injury

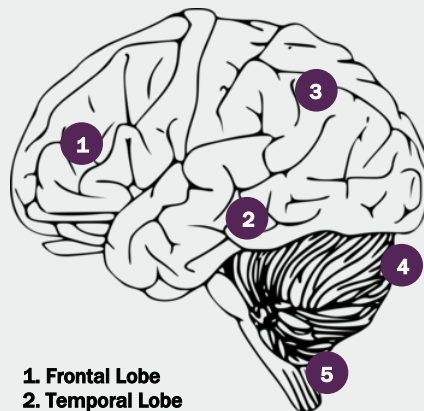


Did you know that the brain is the most important organ in the human body, and it is essential to everything we do? It controls all of the major systems within our bodies, including speech, thoughts, movement, sensations, and much more.

As shown in Figure A, this complicated organ can be broken down into various sections. The main portion of the brain, or cerebral cortex, is broken into two halves known as the right cerebral hemisphere and the left cerebral hemisphere. The right hemisphere controls movement on the left side of the body, and the left hemisphere controls movement on the right side of the body.<sup>1</sup> The two hemispheres can be divided even further into four lobes of the brain.

These four lobes of the brain are called the frontal lobe, temporal lobe, parietal lobe, and occipital lobe. Each of these four lobes must be understood to appreciate the side effects of a brain injury. Figure B shows a summary of the various functions that the different lobes of the brain are responsible for.<sup>2</sup>

**Figure A**



- 1. Frontal Lobe**
- 2. Temporal Lobe**
- 3. Parietal Lobe**
- 4. Occipital Lobe**
- 5. Cerebellum**

## Definitions and Causes

To fully understand brain injury, it is also important to consider all of the definitions surrounding the term “brain injury.” The term “acquired brain injury” (ABI) is an umbrella term used to describe any injury or disease of the brain that results in an alteration of brain function. An ABI is non-congenital, non-

**Figure B**

### Frontal Lobe

- Initiation
- Problem solving
- Judgment
- Inhibition of behavior
- Planning/anticipation
- Self-monitoring
- Motor planning
- Personality/emotions
- Awareness of abilities/limitations
- Organization
- Attention/concentration
- Mental Flexibility
- Speaking (expressive language)

### Temporal Lobe

- Memory
- Hearing
- Understanding language (receptive language)
- Organization and sequencing

### Parietal Lobe

- Sense of touch
- Differentiation: size, shape, color
- Spatial perception
- Visual perception

### Occipital Lobe

- Vision

degenerative, and not hereditary.<sup>3</sup> Examples of an ABI include loss of oxygen, stroke, traumatic brain injury, infections, tumors, and many others.

Another definition to be aware of is “traumatic brain injury (TBI),” which is a more commonly used term when describing brain injury. A TBI is defined as an injury to the brain that is caused by an external force that results in a change to the functioning of the brain.<sup>4</sup> Common causes of TBI include concussions, physical assaults, falls, motor vehicle crashes, or being struck on the head.

It is vital to understand the cause of a brain injury, as it can help provide insight





about an injury. Rehabilitation teams often consider the cause of a brain injury to help guide their rehab efforts for an individual. Additionally, epidemiologists often gather data surrounding the cause of an injury to help guide prevention strategies.<sup>5</sup>

## Support

Support from family members, neighbors, and professionals after a brain injury is incredibly valuable to the long-term recovery process. While some individuals may only take weeks to recover from their injury, others may go through years of rehabilitation as they find a path to a “new normal.” Going at it alone is not necessary on this journey. For more than three decades, the Brain Injury Alliance of Iowa has worked with tens of thousands of Iowans with brain injury, their families, and communities providing help, hope, and healing.

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# Rehabilitation After a Brain Injury



## Rehabilitation

After an injury, rehabilitation can serve as an essential piece of the puzzle as a person works toward recovery or finding their “New Normal.” The fundamental goal of rehabilitation is to help individuals relearn or strengthen existing skills to promote independence, which can allow a person to return to their home or community.

As each person is unique, so is each person’s brain. Thus, the pathway of recovery from a brain injury will be different for each individual. Figure C shows the major areas of care, or a continuum of care, following a brain injury. Some individuals may proceed through this continuum in a linear path, while others may access different types of care off and on over various points in time during their recovery.

There are various systems of care

that may be involved in an individual’s rehabilitation. These various forms of care happen in a variety of settings, which may include acute hospital settings, sub-acute or skilled nursing settings, or an individual’s own home or community. The numerous forms of care also have different goals for each setting, which range from stabilizing a person’s medical condition to focusing on integrating an individual back into a community-based setting. If you have questions about providers or resources related to rehabilitation, please go to [www.biaia.org](http://www.biaia.org) for more information.

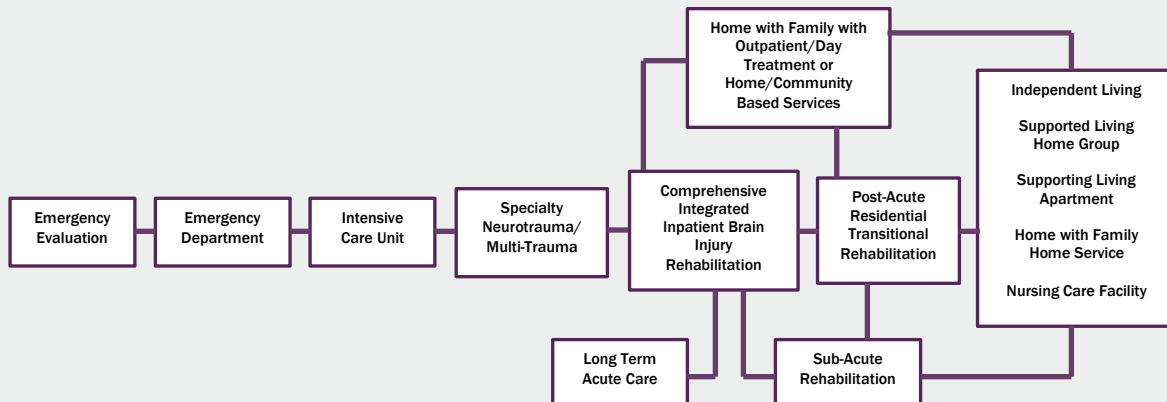
## After a Mild Traumatic Brain Injury or Concussion

Every day, thousands of individuals experience a concussion. Concussions account for nearly 70% of all traumatic brain injuries (TBIs). Some individuals seek medical care from their doctor or an emergency room, and

Figure C

### Traumatic Brain Injury (TBI) Continuum of Care

Adapted from the Rocky Mountain Regional Brain Injury System to depict the continuum of care for individuals with moderate and severe TBI.





## Systems of Care

### Emergency or Critical Care

- Care that occurs at the scene of the injury and in the emergency room with the goal of preventing further injury.

### Acute Rehabilitation

- Care that occurs in a hospital that usually lasts no longer than a few weeks to manage medical conditions until a person is considered to be in stable medical condition.

### Sub-Acute or Skilled Nursing

- Care that occurs in a hospital or a skilled nursing program when both medical needs and brain injury treatment are still needed.

### Post-Acute Rehabilitation

- Care that occurs in a hospital or rehabilitation setting that usually lasts a few months. A person receiving this type of service may undergo intensive therapies on a daily basis lasting 6-8 hours a day to help maximize recovery.

### Community Based Neurobehavioral Services

- Temporary residential or hourly services that are community based, focusing on addressing complex neurobehavioral challenges as a result of a brain injury, usually needed for about 6 months on average.

### Home & Community Based Services/Supported Community Living

- Services that are community-based that focus on addressing complex cognitive and behavioral challenges as a result of a brain injury. These services are considered to be long-term.

### Outpatient Services

- Various types of intermittent therapies that may be accessed through a hospital or clinic. Typically appointments last 1-2 hours, and a person returns home after receiving services.

### Hospice & Palliative Care

- Palliative care is an approach that improves the quality of life of patients and their families facing life-threatening conditions, through the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other problems.

some of these people go on with their daily lives as if nothing happened and just “shake it off.” While some individuals symptoms from this type of mild brain injury resolve rather quickly, some individuals will go on to experience lifelong side effects that can disrupt his or her daily life.

A concussion, or mild traumatic brain injury (TBI), is caused by an external force to the brain that results in a disruption to a person’s normal brain activity. People often think of sporting events when they think of concussions, but concussions can also be caused by motor vehicle accidents, a blow to the head, falling down, and other events. Early symptoms of concussion include dizziness, headache, disorientation, confusion, tiredness, vomiting, and/or nausea. But sometimes these symptoms can persist for weeks, months, and even years after an injury.

Brain injuries are often referred to as a “silent epidemic” because they often lack an

outward appearance and can be easily overlooked. After a concussion, a medical examination may not reveal anything abnormal and a person may be sent home with no arrangements for follow-up care. However, just like a broken arm, sprained ankle, or other injuries, brain injuries and concussions take time to heal. It is important to report a concussion or other mild brain injury to your primary care provider. For additional information about concussions, visit [www.iowaconcussion.org](http://www.iowaconcussion.org).

## Importance of Primary Care

As an individual returns to their home or community after an injury, it is vital to their recovery process to ensure their primary care provider has knowledge and experience serving individuals who have sustained a brain injury. In the general public, “...evidence shows that access to primary care helps people live longer, healthier lives.”<sup>6</sup> Access to a primary care physician is essential to the healthcare system, and it encourages physicians to focus on medical care in a patient-centered approach.

## Neurologists

A neurologist is a medical provider who specializes in the brain and nerves. It is very common to work with a neurology team following a brain injury. A neurologist may work with a patient regarding specific symptoms from a brain injury, which may include posttraumatic headaches and seizures. They may also provide medications to help control various symptoms that are a result of the person’s injury.<sup>7</sup>

## Neuropsychologists

A neuropsychologist is a medical provider who is able to provide an assessment of an individual’s cognitive and emotional functioning following an injury. They may complete a common clinical test, called a neuropsychological assessment, to get feedback about how an injury has affected an individual’s thinking, memory, judgment, behavior, personality, and emotions. This information can be used by the rehabilitation team to help guide treatment following an injury.<sup>8</sup>

A neuropsychological assessment may be completed just once after an injury, but sometimes is repeated multiple times over an individual’s recovery process to provide insight about their recovery. Some individuals may

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even complete these evaluations many years after a brain injury.

After an assessment is completed, the results are compared to a set of standardized norms or estimates of a person's pre-injury abilities. This information can be extremely valuable in getting an idea of what a person may be able to do or not do after their injury.<sup>9</sup>



## Other Common Specialists<sup>10</sup>

**Physical Therapist (PT):** These professionals evaluate and treat a person's physical needs, which may include areas of the body related to strength, flexibility, sitting, standing, balance, and walking. Treatment by a PT includes exercises and training on how to use various types of equipment (walkers, canes, wheelchairs, etc).

**Occupational Therapist (OT):** These therapists provide evaluation and treatment surrounding various types of activities of daily living (ADLs), which may include dressing, bathing, and other activities that may require compensatory strategies, like memory and organization.

**Speech Therapist (ST):** These professionals specialize in the treatment of speech, swallowing, communication, listening, swallowing, and thinking.

**Vision Therapist:** These therapists are able to address side effects related to vision after an injury, which can often be overlooked in initial evaluations following a brain injury. Vision therapists are able to help identify treatment options that allow information to travel, flow, and be processed between the eyes and the brain.<sup>11</sup>

**Psychiatrist:** These medical providers are physicians who specialize in treating issues with behaviors and emotional control, along with other mental health conditions that may arise after an injury (anxiety, depression, PTSD, etc).

**Social Worker:** Social workers may provide support to a patient and family as they adjust emotionally after an injury. They may also help coordinate a discharge plan and work to get individuals connected to various community resources. Social workers may also help answer questions related to insurance.

## Medical Equipment

After an individual has experienced a brain injury, they may need various types of medical equipment to help support their independence. This may include specialized equipment that could be used in an individual's home or vehicle. Examples of medical equipment that may be used include electronic organizers, medication-dispensing devices, communication devices, bath aids, and many others.

## Long-Term Problems

Individuals may experience lasting side effects of a brain injury. Some side effects may be very apparent at first, while others may take years to pinpoint. Change in the function of the brain can have a profound impact on an individual's job, their family, and their community involvement.

**Headaches:** Headaches are one of the most common side effects that linger after a brain injury. These can often make it difficult to carry out daily activities, especially when they are long-lasting. The various types of headaches include migraine headaches, tension-type headaches, and headaches caused by side effects from medication. Treatment varies greatly from person to person, so it is important to discuss headaches with your medical providers. It can also be helpful to track information, such as time, frequency, duration, and intensity of headaches in a journal.<sup>12</sup> Journal entries may help identify triggers or help guide treatment

**Seizures:** Another symptom that may arise after an injury is seizures. Having a seizure can be an unsettling experience, which is why it is important to understand seizures and what to do if one occurs. While only about 1 in 10 individuals who have been hospitalized after a brain injury experience a seizure, those who do can return to most activities.

During a seizure, a sudden and abnormal electrical disturbance occurs in the brain. The disturbance can cause some alarming symptoms, which may include stiffening and shaking of the body,

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unresponsiveness, staring, drooling, loss of bladder control, lip smacking, sudden tiredness, and others. Seizures usually last 1-2 minutes, but can continue last up to 10 minutes. Family members and caregivers should monitor seizures so that they can accurately explain it to medical providers. If a seizure does not stop or breathing is affected, it may be necessary to call 911. <sup>13</sup> For more information about seizures, please go to [www.epilepsyiowa.org](http://www.epilepsyiowa.org).

**Fatigue:** Individuals who have experienced a brain injury often experience fatigue more quickly and frequently than others. Fatigue may cause you to have less energy to care for yourself and do things that you were previously able to do. It can also make some activities, like driving, more dangerous. There are certain things that can be done to decrease fatigue, which may include getting enough sleep, identifying triggers of fatigue, avoiding alcohol and caffeine, and others. If you are experiencing fatigue, it can be important to discuss with your medical provider strategies to address this symptom. <sup>14</sup>

**Vision:** Common types of vision problems after a brain injury may include blurred vision, decreased peripheral vision, double vision, and others, which can affect your day-to-day life. Ask your physician about possible referrals to an ophthalmologist, an optometrist, or a vision therapist to address concerns. These professionals may be able to help identify various types of treatment options that are available to address these symptoms. <sup>15</sup>

**Cognition and Memory:** Cognitive symptoms after a brain injury may affect a person's ability to think, understand, and remember information. Cognition includes attention, concentration, processing information, memory, communication, planning, organization, sequencing, and others. There are a variety of compensatory strategies that can be used by an individual, their caregivers, and professionals working with them to help improve functioning in these areas. <sup>16</sup>

## Assistive Technology

As previously discussed, a brain injury can cause long-term physical, cognitive, and behavioral impairments. These impairments may have a significant impact on an individual's ability to do everyday tasks, like walking, hearing, organizing a plan for the day, remembering details from a phone conversation

earlier in the day, and many more. These impairments can significantly affect a person's ability to live independently.

Assistive technology can help individuals compensate for those long-term side effects and increase their chances of successfully living independently. Some examples of assistive technology include memory aids, medication managers, noise-cancelling headphones, communication tools, and much more. For more information on locating assistive technology, please contact the Brain Injury Alliance of Iowa.



## At Home

There are various types of services that may be available in your home or community that focus on allowing a person to maintain as much independence as possible, while keeping a person safe from harm. Some of these services may be covered by insurance, while others must be paid for privately. Programs may include:

**Day programs:** Organized day programs, or adult care, may be available to individuals after a brain injury. This type of care is usually offered to individuals in a group setting. It can encourage social interaction and provide supervision while caregivers are attending to other tasks.

**Respite:** These are services that are available to caregivers to help provide temporary relief from caregiving duties. A respite provider would provide all of the usual cares offered by the primary caregiver during a specified period of time, which may last a few hours to a few days.

**Home & Vehicle Modifications:** Some equipment that is considered “medically necessary” may be covered by insurance. Other types of equipment that may be deemed as unnecessary may have to be paid for privately. Some examples of home and vehicle modifications may include electronic organizers, medication-dispensing devices, communication devices, bath aids, and many others.

**Transportation:** Transportation is an essential component to an individual’s well-being. Some individuals may need to locate transportation resources to help them get to and from medical appointments, grocery stores, and other necessary locations. There are various types of transportation options available, some that may be covered by insurance.

**Case Management/Service Coordinator:** These professionals may provide direct assistance to an individual and their caregiver(s) to help them locate resources and services.

**Social Capital or Recreation Programs:** Community involvement is what makes up social capital. It is important for a person with brain injury to be part of a community and build social capital. This provides help for people to be healthier and happier.

**Accommodations for Daily Life:** There are many accommodations for daily life that might need to be made, including schedules, commitments, lifestyle changes, relationships, and physical supports.

**Record Keeping:** Getting organized is important. The use of calendars, notebooks, visual aides, and smart phone apps can be helpful in maintaining an accurate record.

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## Funding for Services



After an injury, an individual and their family may be left with a daunting question—how do we pay for all of this? Services that are essential for the continued improvement of quality of life for an individual can be expensive. Here is some information about public and private funding that may be available:

### Private Health Insurance

These are health insurance plans that might be privately purchased or offered by employers or other entities. Some employers offer only one insurance plan, while others offer multiple options. Usually an employer is able to help cover the cost of a health insurance plan, rather than a person paying a monthly premium entirely out of pocket. As with every insurance, there may be limitations to what will be covered. Individuals and their caregivers may need to consider other funding sources if a person has lost their job following an injury and is no longer able to participate in an employer-sponsored health insurance plan.

### State Public Insurance

There are various types of public insurance that are available through the state of Iowa. They include:

**Medicaid:** Medicaid is a health insurance program offered to individuals with low-income or medically needy individuals. It may also cover children, older adults, and/or individuals with disabilities. Eligibility for this program is primarily based on income and need.

**Health Insurance Marketplace:** This is a service that helps people shop for and enroll in affordable health insurance. The federal government operates the marketplace, available at [www.HealthCare.gov](http://www.HealthCare.gov), for most states. Some states run their own marketplaces. The Health Insurance Marketplace provides health plan shopping and enrollment services through websites, call centers, and in-person help.

**County/Region Funding:** Funding for mental health and disabilities services (MHDS) may be available to individuals. Eligibility for this type of funding is based on location, income, and a qualifying diagnosis.

### Federal Public Insurance

There are various types of public insurance that are available at a federal level. They include:

**Medicare:** This type of insurance is a federally funded program that is available for individuals who are age 65 and older, individuals with disabilities, and some others. There are specific parts of Medicare that people can choose to opt in or out of, which include Part A (Hospital Insurance), Part B (Medical Insurance), Part C (Medicare Advantage Plans), and Part D (prescription drug coverage).<sup>17</sup> For more information, please visit [www.medicare.gov](http://www.medicare.gov).

**Social Security Disability Income (SSDI) or Supplemental Security Income (SSI):** The Social Security Administration (SSA) oversees the federal



disability programs—SSDI and SSI. These programs benefit individuals who are considered disabled. Eligibility for both programs is based on income, employment history, disability, and a variety of other factors. These two programs may serve as a source of income in the event that a person may be unable to return to work or return to the same job after an injury. Please visit [www.ssa.gov](http://www.ssa.gov) for more information.

## Private pay

Private pay is the cost of paying for an expense out of pocket. This is usually a last resort for many individuals after all other funding options have been maximized.

## Trusts

Medicaid is a needs-based program that is available to individuals to help pay for health coverage for select groups of people, including individuals with a low income or a disability. To qualify for Medicaid in the state of Iowa (as of 2017) non-exempt assets cannot exceed \$2,000 and income must be at or below \$2,205 or less per month. (Please note that these numbers may change for married couples if one spouse is living in an outside facility or nursing home, and the spouse may qualify for Medicaid even if over the asset and income limits). To ensure access to Medicaid and other state or federal programs, some individuals and families decide to pursue various types of trusts to maintain program eligibility.<sup>18</sup>

**Miller Trusts:** If you meet the asset limit, but you are above the income limit, you may consider a Miller Trust. This type of trust diverts monthly income that is over the state's threshold into a trust account, which can allow a person to continue to remain eligible for Medicaid. Go to [www.iowalegalaid.org](http://www.iowalegalaid.org) for more information about this type of trust.

**Special Needs Trusts:** A Special Needs Trust is a type of trust that is established for an individual who is under the age of 65 and is considered disabled. It specifically helps an individual who may be over the resource limits (potentially due to an inheritance or litigation settlement) maintain eligibility for Medicaid programs. Go to [www.iowalegalaid.org](http://www.iowalegalaid.org) for more information about this type of trust.<sup>19</sup>

**Supplemental Trusts:** This type of trust is a unique set-up that holds assets that assist an individual who is receiving Medicaid benefits. Payments from this type of trust cannot be used for basic needs, like food and shelter. They are intended to be used for other broad expenses, like education, vocation, uncovered medical bills, entertainment, or other expenditures. Go to [www.iowalegalaid.org](http://www.iowalegalaid.org) for more information about this type of trust.<sup>20</sup>

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# Working After a Brain Injury



Returning to a job after a brain injury can be an intimidating, but it is often possible. With the help of various types of supports that are available, individuals with a brain injury can return to employment.

## Iowa Vocational Rehabilitation Services

The mission of Iowa Vocational Rehabilitation Services (IVRS) is to work for and with individuals who have disabilities to achieve their employment goals. They have multiple office locations across the state that work to help individuals locate and sustain employment. You can find additional information about their services at [www.ivrs.iowa.gov](http://www.ivrs.iowa.gov).

## Iowa Workforce Development

Iowa Workforce Development (IWD) is a state agency committed to providing employment services for individual job seekers. Employers and businesses can post jobs, hire veterans, and apply for qualifying federal tax credits. The agency also maintains a statewide delivery system of 15 regional, 4 satellite, and 14 expansion offices to provide services to Iowans in communities demonstrating need. For more information, go to [www.iowaworkforcedevelopment.gov](http://www.iowaworkforcedevelopment.gov).

## Home and Community-Based Services Supported Employment

The Medicaid Home & Community Based Services (HCBS) Waivers can help cover the costs for Supported Employment (SE). The services that may be covered include activities to obtain a job and supports to maintain employment. Please contact the Brain Injury Alliance of Iowa for more information regarding services covered by the brain injury waiver and how to apply.



## Other Employment Resources

**Iowa State Workforce Partners:** Ticket to Work provides employment support to SSDI and SSI beneficiaries between the ages of 18-65. There are seven state agencies that are State Workforce Partners. Ticket to Work is just one of many work incentives offered through Social Security. For more information, go to [www.iowaworkforcedevelopment.gov](http://www.iowaworkforcedevelopment.gov).

**Iowa Work Incentive Network Services (Iowa WINS):** Benefit Specialists at Iowa WINS can help explain how work would affect your benefits from the Social Security Administration as well as incentives that are available for you and/or your employer. More information can be found at [www.iowawins.org](http://www.iowawins.org).

**Job Accommodation Network (JAN):** If you have a question about workplace accommodations or the Americans with Disabilities Act (ADA) and related legislation, JAN can help. For more information, go to [www.askjan.org](http://www.askjan.org).

**Iowa's Work Incentive Planning and Assistance:** is a grant funded program sponsored by the Social Security Administration that provides work incentives planning and assistance services to Social Security beneficiaries who receive Social Security Disability Insurance (SSDI) and/or Supplemental Security Income (SSI) who want to pursue gainful employment/self employment. Disability Rights IOWA (DRI) staff members who provide WIPA services are called Community Work Incentives Coordinators (CWICs). They focus on you, your choices, your future, and especially your work goals. For more information, go to [www.iowawipa.com](http://www.iowawipa.com).

**Understanding Brain Injury:** This useful guide was created by Mayo Clinic for employers provides information about what to expect, what to watch for and how to help employees who have sustained brain injuries adjust to the workplace. This guide can be located at [www.biaia.org/resource-library/employment](http://www.biaia.org/resource-library/employment).

**Iowa Employer's Disability Resource Network:** An Iowa resource for the recruitment and retention of employees with disabilities. Go to [www.edrnetwork.org](http://www.edrnetwork.org) for more information.

**Iowa Department of the Blind:** The Department of the Blind's Vocational Rehabilitation (VR) program helps blind or low-vision Iowans prepare for, obtain, and retain employment in a variety of occupations. For more information, go to [www.blind.iowa.gov/employment](http://www.blind.iowa.gov/employment).

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# Emotional & Behavioral Health



An injury to the brain can cause changes in a person's emotions and personality. These changes can sometimes be labeled as "behaviors." Examples of these behavioral changes include anger, irritability, anxiety, depression, and others. Addressing these emotional changes can be done with the help of a rehabilitation team, medical providers, and caregivers.<sup>21</sup> Your medical providers can help determine what treatment might be best to address the symptoms. It can be helpful to seek out information about specific emotional changes that a person may be experiencing following an injury.

## Depression & Anxiety

Depression and anxiety are very common problems that individuals experience after a brain injury. Up to 60% of individuals who have experienced a brain injury are affected by depression and anxiety in the first few years following an injury.<sup>22</sup> People may experience anxiety and depression not only as an emotional response to their injury, but also due to physical changes in the brain. There are various types of treatment and medications that may be available to help address these side effects. It is very important to work directly with your medical providers to determine what treatment might be best to address the symptoms.<sup>23</sup>

## Counseling

As you discuss depression and/or anxiety symptoms with your medical provider, you may receive a referral to a counselor or therapist. While this may seem like an intimidating prospect to some, it is simply another form of specialized therapy to help address the emotional symptoms

that individuals with a brain injury and their caregivers may be experiencing.

Additionally, you may find it helpful to locate a counselor or therapist that has experience, and knowledge about brain injury. Individuals with brain injuries may experience symptoms that could make traditional counseling approaches ineffective, due to impairments like memory loss, disinhibition of behaviors, planning/anticipation deficits, and more. These providers may be better equipped with effective strategies to help address these challenges.

## Support Groups

Peer support is highly valued by many families affected by brain injury. On a local level, members meet together monthly to share experiences and information on an informal basis. Most groups function as support-giving entities to both individuals with brain injury and to their families. The Brain Injury Alliance of Iowa has support groups active in several communities throughout Iowa. Benefits of participating in a local support group meeting include presentations by specialty speakers, referrals to local resources, and learning from others in similar circumstances. Please go to [www.biaia.org](http://www.biaia.org) to find information about local support groups in your area.

## Medication

A person may benefit from taking some medications after a brain injury. While medications may not be able to "cure" a brain injury, they may be able to help manage various cognitive, behavioral, and physical side effects following a brain injury. It is important for individuals and their caregivers to consider symptoms of



medications, as well as interactions that these medications can have with one another. For more specific information about various types of prescriptions, please speak directly with your medical providers.<sup>24</sup>

## Substance Abuse

Alcohol and substance use are often closely linked to brain injury. In fact, between 30-50% of people with TBI were injured while they were under the influence of alcohol and about one-third were under the influence of other drugs.<sup>25</sup> Most people are able to cut back on alcohol and other drugs after an injury, but some individuals may need additional supports to help reduce the negative consequences of alcohol and substance use.

Here are a few facts about brain injury, alcohol, and drug use:<sup>26</sup>

- If a person begins to use or continues to use alcohol and other drugs, they may significantly slow down or stop their recovery. Recovery after a brain injury can occur for many years after an injury, and avoiding alcohol and drugs is the best way to improve the odds of showing ongoing improvement.
- Drug and alcohol use may put a person at a higher risk for experiencing seizures.
- Individuals with a brain injury face an increased risk of having subsequent brain injuries. However, individuals who use alcohol and drugs are at even more increased risk of additional brain injuries due to lack of balance, impulse control, compromised judgment, and other behavioral changes.

If you or someone you know is interested in identifying ways to reduce or stop alcohol and/or substance use, there are resources available to help. For more information about locating these resources and supports, please contact your medical provider or the Brain Injury Alliance of Iowa.

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## Children & Mild Brain Injury



When a child or teen experiences a brain injury or concussion—from mild to severe—it is often very concerning to parents and families. Symptoms of a brain injury may include headaches, irritability, sleep disturbances, slowed reaction times, and many more. While some brain injury effects may resolve quickly, other effects can continue to impact a child’s experience in the classroom. Even a mild brain injury, such as a concussion, should not be overlooked.

Symptoms may start to resolve better through coordination between the child’s family and the medical, educational, and athletic (if applicable) professionals in the child’s daily life. Special adjustments in the classroom can help compensate for challenges the student may encounter and to help aid in the recovery process.

### Return-to-Learn Strategies

After a child experiences a brain injury or concussion, they should return to their daily activities in a very gradual process. This procedure should involve a delicate balance between giving the brain time to rest and recover, while also engaging in some everyday activities to allow the brain to regain important functions, like reading, writing, engaging with peers, and learning. Brain injury professionals describe the return to the classroom as “Return to Learn.”

A set of “Return to Learn” guidelines is no small matter. A child and their family should seek the guidance and expertise of medical professionals with knowledge about brain injury to help guide this process. It may even be advised that your child utilize special programs that are available within a school to help maximize

the likelihood of a successful return to their everyday lives. Some of these programs include Individualized Education Programs (IEPs), 504 Plans, and other special education programs. Please see additional information about these programs on page 22 of this booklet.

### Return-to-Play Strategies

After a student has fully integrated back into the classroom after a concussion or brain injury, they may then begin the process of returning to sports practices and events under the supervision of their medical team. This process is known as “Return to Play.” As with the “Return to Learn” strategies, “Return to Play” guidelines are completed through a set of graduated steps that increasingly build upon a student-athlete’s symptom-free progression. Medical professionals and/or athletic trainers monitor this progression closely to prevent any new symptoms and help the athlete from pushing themselves too hard.<sup>29</sup> The “Return to Play” process gradually progresses the athlete from light aerobic activity to full-contact (if applicable) competition.

These strategies can have a tremendous positive impact on recovery for a child after a brain injury when used appropriately. While a mild concussion may seem like something that can be easily dismissed, the term “mild” may not fully align with the severity of the impact that the side effects may have on a child’s every day functioning. Consult your child’s medical provider immediately following a concussion or brain injury.

For more information on Return-to-Learn or Return-to-Play, please go to [www.iowaconcussion.org](http://www.iowaconcussion.org).



## Educational Programs

**Individualized Education Programs (IEPs):** An IEP is a written document used by a public school for an eligible child to help provide a set of specialized instruction guidelines to aid professionals in the delivery of education to a child with a disability. A multidisciplinary team within school, along with the parents or guardians, forms an IEP. This team meets annually, at a minimum, to review the child's progress. It can serve as a written guarantee that a child will receive the necessary supports and services that they need that will allow them to continue to receive a valuable education. An IEP contains written and measurable goals that are specific to a child's disability. Goals may be academic, social, or behavioral in nature.<sup>27</sup>

**504 Plans:** A 504 Plan is developed by school professionals to ensure that a child with identified short- or long-term disabilities is able to receive special accommodations within a classroom. These accommodations are used by a public school to ensure academic success in the classroom. The primary difference between a 504 Plan from an IEP is that a 504 Plan does not require specialized instruction. Instead, it focuses on ensuring equal access to public education and services by the use of accommodations within the existing classroom.<sup>28</sup> Examples of a 504 Plan accommodation may include additional time taking a test, modified text or audio books, extended breaks between classes, and preferential seating.

For an extensive list of resources and programs available in the state of Iowa to help children in the classroom, please go to [www.biaia.org](http://www.biaia.org).

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## Aging With a Brain Injury & Falls Prevention



In the state of Iowa, traumatic brain injury (TBI) has had the biggest impact on individuals that are aged 65 or older. Falls are the leading cause of TBI deaths, hospitalizations, and emergency room visits, which have a disproportionate affect on Iowa's continuously aging population.<sup>30</sup> It is estimated that one out of every three adults aged 65 or older falls each year.<sup>31</sup> As the number of older adults affected by brain injury continues to rise each year in Iowa, it is important to take steps to help prevent injuries and find supports to help those who have been impacted by a brain injury.

A variety of resources in the state of Iowa have developed to help prevent falls in this already vulnerable population by agencies including the Iowa Department of Public Health, the Iowa Department on

Aging, the Iowa Falls Prevention Coalition, and the National Council On Aging. These evidence-based programs help older adults address poor vision, decreased strength, medication use, and fall hazards within their home.

### Evidence-Based Falls Prevention Programs<sup>32</sup>

**A Matter of Balance:** This program involves a series of 8 classes that are provided over a 4-8 week period. Leaders who have been trained in the program provide classes that focus on flexibility, balance, and strength to help prevent falls. The program is intended for older adults who have limited physical abilities and who may have sustained a fall in the past.

**Stepping On:** This program is a community-based workshop that is held once a week for seven weeks, led by trained leaders and guest experts. Participants learn about specific skills and information to help prevent falls, as well as balance exercises that can be done at home. Some topics that are covered in the highly interactive classroom environment include home and environment safety, improving balance and strength and medication review.

**Tai Chi for Arthritis:** Tai Chi is a popular ancient Chinese exercise program that consists of slow and relaxed movements. Tai Chi helps reduce pain, and improve balance, strength, and mobility, which all lead to a reduced risk of falling. This program is available to individuals of all fitness levels and can be practiced regularly.



## Six Things You Can Do to Prevent Falls (Iowa Department of Public Health)

Many falls can be prevented. By making some changes, you can lower your chances of falling. Here are six things that you can do to prevent falls:

### **1. Regularly review your medications**

Have your doctor or pharmacist review all the medicines you take, even over-the-counter medicines. As you get older, the way medicines work in your body can change. Some medicines, or combinations of medicines, can make you sleepy or dizzy and can cause you to fall.

### **2. Talk to your health care provider**

Ask for an assessment of your risk of falling. Share your history of recent falls.

### **3. Have your vision checked**

Have your eyes checked by an eye doctor at least once a year and update your eyeglasses. You may be wearing the wrong glasses or have a condition like glaucoma or cataracts that limits your vision. Poor vision can increase your chance of falling.

### **4. Talk to your family members**

Enlist their support in taking simple steps to stay safe. Falls are not just seniors' issues.

### **5. Exercise to improve your balance and strength**

Exercises that improve balance and make your legs strong, reduce your chance of falling and can help you feel better and more confident. An example of this kind of exercise is Tai Chi. Lack of exercise leads to weakness and increases your chances of falling. Ask a doctor or health care provider about the best type of exercise program for you. Contact your local community or senior center for information on exercise, fall prevention programs, and options for improving home safety.

### **6. Make your home safer**

About half of falls happen at home. To make your home safer:

- Remove things you can trip over (like papers, books, clothes, and shoes) from stairs and places where you walk.
- Remove small throw rugs or use double-sided tape to keep the rugs from slipping.
- Keep items you use often in cabinets you can easily reach without using a step stool.
- Have grab bars securely installed next to and inside the tub and next to the toilet.
- Use non-slip mats in the bathtub and on shower floors.
- Improve the lighting in your home. As you get older, you need brighter lights to see well. Hang light-weight curtains or shades to reduce glare.
- Have handrails and lights installed in all staircases.
- Wear shoes both inside and outside the house. Avoid going barefoot or wearing slippers.

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## Family & Caregivers



Recovery following a brain injury is a unique experience for each survivor. For many, it is the beginning of a lifelong journey through understanding and acceptance of change. Family members and spouses, who serve as caregivers and assume supportive roles, embark on a similar journey—and few are prepared to take on such a role. They find themselves suddenly thrown into the caregiving role, while also experiencing loss and grief at the same time.

### Ambiguous Loss and Grief

Grief is a common, and often essential, reaction after a loss. Many people do not anticipate the ambiguous loss that occurs when someone does not experience a physical death, but instead a non-physical death. This non-physical loss may be a result of injury, the changing of a relationship, or other life-altering events.

Family members, friends, and other loved ones of an individual who has experienced a brain injury may find themselves dealing with grief. Brain injuries can cause life-altering physical changes, financial strain, changes in relationships, and emotional distress, just to name a few. An individual who has experienced a brain injury may look the same as they did before, which can make it hard to accept that this person thinks and acts differently than he/she used to. This grief can be ambiguous, because we are uncertain of the future that lies ahead.

The grieving process is how individuals heal and move forward in their lives after an injury, but it does not happen overnight. Common emotions that one

might experience during the grieving process include denial, anger, guilt, sadness, and many other emotions.

Grieving is a necessary process in our journey to move forward. It may take months or years, and is often unpredictable. Grieving a loss does not happen in a certain sequence of steps. Instead, individuals may feel happy and strong one day, and are overwhelmed by disbelief and confusion the next.<sup>33</sup>

During the grieving process, it is important to surround yourself with a positive support system and to talk with friends, families, and/or professionals about the difficult emotions that you are experiencing.

### Guardianship, Power of Attorney and Supported Decision Making

Guardianship, Power of Attorney, and other types of substitute decision-making are legally binding arrangements that have been established through the court system to give a person or group of people the right to make decisions on behalf of another person (called a ward). A ward may be deemed unable to care for his or her personal safety due to side effects from a brain injury. As shown in Figure D on page 26, there are various types of legal arrangements that can be made on behalf of a ward, which are arranged from top to bottom as least restrictive to most restrictive.

In the United States, we are considered adults and legally capable of making decisions for ourselves at the age of 18. Even when others may not agree with our decisions, we are still free to think and behave



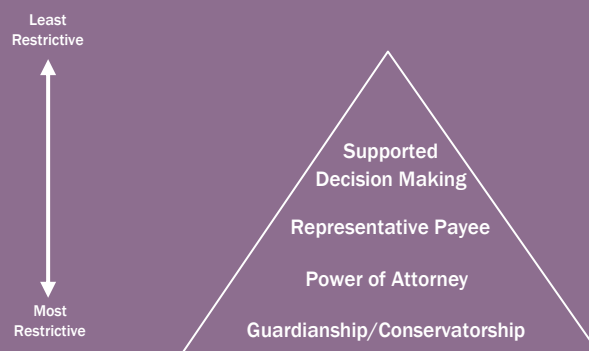
in certain ways without legal interference, so long as we are doing so without breaking any laws. Therefore, a court would need to be presented with a substantial amount of evidence that supports removing this basic right from an individual.<sup>34</sup>

An individual who is petitioning the court for guardianship, conservatorship, or some other alternative to guardianship would need to provide substantial evidence to a court. This evidence would need to provide significant proof that a ward is considered harmful to themselves or others. For more information about this and other related matters, please go to

[www.iowalegalaid.org](http://www.iowalegalaid.org) or

[www.iowaaging.gov](http://www.iowaaging.gov).

Figure D



#### Guardianship or Conservatorship

- This is a type of legal authorization that allows a guardian or conservator the right to make financial, legal, and health decisions on behalf of a ward. It involves the greatest loss of freedom; therefore, a court may only consider this after less restrictive options have been attempted and found unsuccessful.<sup>35</sup>

#### Power of Attorney

- This is a type of document that gives a specific person or group of people legal authority to act on your behalf in the event that you become debilitated from making decisions for yourself.<sup>36</sup>

#### Representative Payee

- This is a person or an organization that has been appointed by the court to help manage an individual's money. They typically assist an individual in paying bills, creating a budget, and managing other financial obligations.

#### Supported Decision Making

- This is considered the least restrictive least restrictive. This is an alternative to guardianship that encourages an individual to make their own decisions with the support of their caregiver and/or other team members.

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# Brain Injury Prevention



An estimated 17,000 traumatic brain injuries (TBIs) occur in Iowa annually, according to the Iowa Department of Public Health. For many, brain injury rehabilitation is a long process that is measured in years rather than months. Many people with severe brain injuries face a wide range of lifelong problems. These problems, in turn, can dramatically affect an individual's ability to live independently, care for a family, and work.

Numbers alone cannot convey the true extent of brain injury. Lives, hopes, dreams, families, and friendships are often altered in the wake of a brain injury. Research, rehabilitation, public awareness, and advocacy can help prevent brain injury, which reduces the occurrence of brain injuries and minimizes the negative impact on our society. The only way to truly cure brain injury is to prevent it.

## Falls Prevention

Falls are the leading cause of brain injury in Iowa and nationally. Prevention efforts are very important.

Additional information about falls prevention can be found at [www.idph.iowa.gov/falls-prevention](http://www.idph.iowa.gov/falls-prevention).

## Bike Safety

Bicycle-related injuries are a major cause of brain injuries in the United States every year. In fact, it is estimated that up to 1,000 people are killed every year from bicycle-related accidents, half of which are children. With only about half of children ages 5 to 14 estimated to wear their helmets, it is a public health concern that we need to be aware of.<sup>37</sup> Wearing a helmet to help prevent injuries is one of the best

ways to keep children safe.


## Helmet Safety

Motorcycle crashes are both deadly and costly, but deaths can be reduced or prevented with increased helmet use. One of the single most-effective ways for states to both save lives and save money would be to implement a universal helmet law. In 2015, it was estimated that wearing helmets saved 1,772 lives in America. An additional 740 additional lives could have been saved if all motorcyclists had been wearing their helmets. Helmets reduce the risk of death by 37% and the risk of head injury by 69%.<sup>39</sup>

### Bike Safety Tips<sup>38</sup>

1. Wear a helmet!
2. Obey traffic signs on the road, just as if you were driving your car.
3. Stop at all crossways, stop signs, and red lights.
4. Ride your bike on the right side of the road to go with the flow of traffic.
5. If permissible by law, use sidewalks and bike paths whenever possible.
6. Be sure to wear reflective clothing and use lights on bikes, especially when it is dark outside.





# **Brain Injury Alliance of Iowa Overview**



# Brain Injury Alliance of Iowa Overview



## History & Mission

The mission of the Brain Injury Alliance of Iowa is to create a better future through brain injury prevention, advocacy, education, research, and support. Founded in 1980, the Brain Injury Alliance of Iowa (BIAIA) was the second charter chapter of the Brain Injury Association, Inc. Our members include people with brain injuries, their family members, their friends, and professionals who work with people who have had brain and head injuries. BIAIA is now a member of the United States Brain Injury Alliance (USBIA). You can locate more information about USBIA at [www.usbia.org](http://www.usbia.org).

We support, assist, and advocate for persons with acquired brain injury and their families. We respond to challenges and represent concerns voiced by the people we serve through legislative efforts and active support of programs created for the needs of those impacted by brain injuries. We serve the brain injury community securing and developing community-based services, encouraging research, establishing support groups, and providing access to pertinent information and resources. We educate the public and increase statewide awareness of brain injury as a serious disability with lifelong consequences, through the development and distribution of informational materials, conferences, webinars, symposia, and other meetings.

## Statistics

Currently, more than 3.1 million children and adults in the U.S. live with a lifelong disability as a result of a traumatic brain injury (TBI)<sup>40</sup> and 6.4 million have a disability due to a stroke.<sup>41</sup> Based on data provided by the Iowa Department of Public Health, this translates into more than 95,000 Iowans living with a disability from an acquired brain injury. That is more than the populations of Sioux City, Waterloo, Council Bluffs, Ames or Iowa City.

According to the Iowa Department of Public Health, "For the first time in the history of TBI surveillance in Iowa, the numbers and rates of TBI deaths are decreasing. Although deaths are decreasing, hospitalizations and emergency department (ED) visits resulting from TBI are steadily increasing:"

- From 2008 to 2010, there were, on average, 334 (compared to 545 in 2006-2008) TBI-related deaths per year.
- For every death from TBI in Iowa, there were three Iowans hospitalized and 32 who sought services in an emergency department.
- During the reporting period, on average, 33% of Iowans who lost their lives to injury (1,672), 10% of those hospitalized (16,289) or 7% of those who visited the emergency department visits (258,660) because of injury, did so because of TBI.<sup>42</sup>



# Services of Brain Injury Alliance of Iowa



## Neuro Resource Facilitation

Neuro Resource Facilitation (NRF) is a fee-free service offered by the Brain Injury Alliance of Iowa to help people with brain injury and their families, caregivers, and community navigate medical and general life challenges after a brain injury. We offer support in living with brain injury and transitioning back to work and the community. It is our goal to help connect individuals and families with the services and supports they may need.

Support is provided in a variety of forms, including:

- Providing brain-injury-specific information and resources
- Enhancing natural supports and providing linkage to appropriate supports, services, and community resources
- Providing training to service providers to increase Iowa's system capacity to provide appropriate services
- Accessing, securing, and maximizing funding, both private and public
- Sharing the Iowa Brain Injury Resource Network Tote Bag, which contains important information on various types of services and supports for individuals and families experiencing brain injury.

## Iowa Brain Injury Resource Network

The Brain Injury Alliance of Iowa has engaged a statewide network of agencies and professionals, called the Iowa Brain Injury Resource Network (IBIRN), to provide coordinated and comprehensive care for Iowans and their families experiencing brain injury. We strive to

continually expand Iowa's capacity to serve individuals and families experiencing brain injury, and to increase the number of access points where people can get consistent, reliable information and referrals to get the assistance or care they need. IBIRN member sites receive monthly communication about BIAIA services and supports, updated resources, training opportunities, and the ability to participate in our Brain Injury Tote Bag program.

Additionally, IBIRN supports Iowa's service providers and community organizations, offering training and technical assistance on supporting individuals and families experiencing brain injury. Providers may request case-specific consultations, a variety of brain injury educational resources for professionals, and public awareness presentations.

## Support Groups

On a local level, members meet together to share experiences and information on an informal basis. Most groups function as support-giving entities to both individuals with brain injury and to their families. We have support groups active in several communities throughout Iowa. Benefits of participating in a local support group meeting include presentations by specialty speakers, referrals to local resources, and learning from others in similar circumstances.

## Iowa Concussion Consortium

Over the past few years, the Brain Injury Alliance of Iowa has spearheaded the Iowa Concussion Consortium (ICC) group in response to the increased need for consistent and reliable information on concussions and other brain injuries to Iowa's health care professionals, school staff, students, parents,

and guardians. The Iowa Concussion Consortium and the Brain Injury Alliance of Iowa have identified evidence-based concussion management protocols in response to this need. Please go to [www.iowaconcussion.org](http://www.iowaconcussion.org) for additional information.

## Events and Training

The Brain Injury Alliance of Iowa offers a range of brain-injury-specific training for professional organizations. This includes community seminars and symposia, online webinars, and annual conferences and events. Please contact us directly to find out more about training opportunities available, or to request a specific kind of educational event for your community or group.

## Advocacy & Legislative Action

Starting as an all-volunteer organization in the 1980s, BIAIA has worked for decades as an advocacy hub for statewide legislative and policy change. As a result, the Governor's Advisory Council on Brain Injuries was established in 1989 as part of the Department of Public Health. Since then, it has been a powerful partner for governmental and systemic changes in Iowa.

BIAIA has become increasingly active in legislation and policy impacting not only Iowans with brain injuries, but also other Iowans with disabilities. We take very seriously our role as advocates and as a source of information and encouragement for those who wish to become advocates for themselves.

Our Neuro Resource Facilitation staff are available Monday-Friday, 8:00 am – 4:30 pm, to answer questions from Iowans affected by brain injury about legislative and other issues. Please call us at 855-444-6443 or email [info@biaia.org](mailto:info@biaia.org).

## Self-Advocacy

Navigating the complicated medical, social, financial, and legal systems—all while considering individual lifestyles, relationships, and preferences—can be a tremendous challenge after brain injury. The fast pace of society often doesn't allow for others to take time to evaluate what questions we might have. Learning how to advocate for yourself or someone else is a skill that takes practice.

There is an art to building relationships and partnerships, as opposed to making demands. To understand what

advocacy is, you must identify what your needs are, communicate needs effectively with others, and then find the resources to meet those needs. The Brain Injury Alliance of Iowa can be a key partner in making those connections.

## Membership

The Brain Injury Alliance of Iowa (BIAIA) is a not-for-profit, statewide membership organization whose endeavors are funded by special events, memberships, contributions, and grants. You can join BIAIA and work toward a richer, brighter future for all survivors. By working together to promote a better system of care, we all benefit greatly. BIAIA has both individual and corporate membership options available.

## Share your Story

Interested in sharing your story of survival or caregiving after a brain injury? Want to help spread stories of hope and inspiration? Get in touch with us!

### **Russell K., Iowa City**

“The Brain Injury Alliance of Iowa was key in helping my wife understand what had happened to me after my fall from a ladder. I spent many days in a coma in the intensive care unit on the edge. After I got out of intensive care, BIAIA staff helped us understand our insurance and our options for post-acute rehabilitation. We believe this was a critical service in my recovery and return to work.”

### **Elizabeth B., Bettendorf**

“My 35-year-old daughter was in a car crash 10 years ago. She had recovered enough to live in her own apartment with the support of “home and community based services” via the Medicaid program. After nine years of services we were notified that her annual review indicated she no longer qualified for services and supports. We knew that there had been no changes in her abilities but she did have a new case manager. BIAIA was able to help us use a brain injury specific assessment as part of an appeal to the Department of Human Services for continued services, which was granted! Without this support our daughter would be living with us, or in a nursing home.”

### **Robert W., Des Moines**

“My mother knew of the Brain Injury Alliance of Iowa and suggested I contact them when my wife was being discharged from the hospital after a long neurological illness. The hospital social worker had sent me to look at nursing homes for her to move to. My wife is 35 and I was heartbroken at the idea of sending her to a nursing home. BIAIA helped me understand how to advocate with the hospital, and my insurance company for intensive brain injury rehabilitation. My wife came directly home after 4 weeks in that program and was able to re-enter life! She is again the primary caregiver for our children and I am back to work. BIAIA was a lifesaver for our family.”

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