The Road to Rehabilitation, Part 4: Navigating the Curves: Behavior Changes & Brain Injury
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Introduction

Individuals who have sustained a brain injury can face many difficult challenges. Some people have physical disabilities, such as paralysis or loss of a limb. Many individuals have emotional problems, such as depression or mood swings. Most persons must overcome cognitive problems, such as memory loss, difficulty with problem-solving and/or decision-making. Often, behavior problems can be a difficult hurdle—for individuals—as well as their families and friends.

Behavior challenges can appear in many forms. Problems with social skills and interactions with other people account for the most frequent behavior problems. Unfortunately, other more severe behavior problems also can appear following brain injury. Aggression toward others, self-injury, property destruction, tantrums, yelling, cursing and noncompliance can cause serious concerns for families, friends, teachers, co-workers and others.

At the very least, these behaviors can be annoying and troubling. At worst, such behaviors can cause serious injury or property damage. Perhaps most importantly, behavior problems can interfere with rehabilitation. They also can be an obstacle to community reintegration. The following material will offer advice on ways to identify behavior problems and to deal with them effectively, helping you and your family move toward recovery. Behavior problems are the least understood of all problems faced by individuals recovering from brain injury. Unlike the fields of medicine, physical therapy and other forms of treatment, the approach to treating behavior problems is not always based on agreed upon principles.

Professionals from many disciplines in the field of brain injury rehabilitation attempt to understand and treat behavior problems. These professionals include behavior analysts, cognitive therapists, neurologists, neuropsychologists, nurses, occupational therapists, psychiatrists, psychologists, recreation therapists, rehabilitation counselors and speech pathologists. Each works to assess the individual’s strengths and the ways in which behavior problems interfere with independent functioning. Likewise, each is involved in attempting to decrease maladaptive behaviors and teach more adaptive skills.

Approaches can vary greatly because professionals in contrasting disciplines receive different types of training. Even the field of psychology...
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contains many different schools of thought, many with differing theories. Treatment approaches based on one theory can vary in fundamental ways from treatment approaches based on a different theory.

Some psychologists believe that changing the way people feel about themselves and their behavior will result in behavior problems not occurring. Others recommend giving individuals an opportunity to discuss their problems and how they might relate to childhood experiences. Still other professionals feel that the best method of treating behavior problems is to place the individual in a positive and supportive environment.

There are no simple universal solutions to treating behavior problems. Every person with behavior problems is an individual whose situation is unique. Still, certain approaches to treatment have proven effective and should be included in most treatment approaches.

This booklet will help you better understand behavior problems and find effective treatment.

Defining Behavior Problems

Basically, behavior problems are acts that either are dangerous or have a negative effect on an individual’s rehabilitation or community reintegration. But, it is not easy to sum up what constitutes a behavior problem. Behavior problems are determined by the community and the specific situation in which the behavior occurs. Many behaviors are acceptable in some situations, but not in others. For example, fighting is encouraged in defense of one’s country and in the boxing ring. However, fighting becomes a problem when it occurs in the home or the workplace. Yelling is acceptable at sporting events, but not when interacting with family members. Property destruction is expected when someone is hired to tear down a house, but presents a problem in a rehabilitation facility or someone’s home.

Many individuals have occasional inappropriate behaviors that are not dangerous and do not impede their rehabilitation or their ability to function. The best way to identify a behavior problem is to consider an action’s severity and how often it occurs.

Severity

Severity of a behavior is determined by its impact on other individuals in the immediate vicinity. For instance, mild aggression, in the form of hitting, may not be considered a behavior problem by family or rehabilitation professionals. But more severe aggression, such as hard punching, biting or tearing clothes, is unacceptable in most situations. Likewise, a mild temper tantrum might be acceptable, whereas a serious outburst with loud yelling
and major property destruction cannot be tolerated in most situations. In cases of severe problems, the behaviors must be treated so that the individual can make maximum progress toward rehabilitation goals.

**Frequency**

Some actions can constitute behavior problems because of their extreme frequency. Making inappropriate statements to others may be acceptable if it does not occur too often. However, if such comments are made repeatedly—possibly hundreds of times per day—they may interfere with rehabilitation or community reintegration. Similarly, mild aggression or self-injury might be acceptable on a once-a-week basis. But, if it occurs repeatedly every day, it is easy to see how such behavior might interfere with rehabilitation or community reintegration. As with more severe behaviors, problems that occur frequently must be treated for an individual to realize progress in his/her rehabilitation goals.

**Causes of Behavior Problems**

Human behavior is very complex. What people do, why they do it and how they do it has been the object of scientific study for centuries. In this brochure, what is known about behavior as it relates to individuals who are recovering from brain injury will be discussed.

There are two factors that determine our behavior: the brain and the environment. When either is affected, a person’s behavior can change. Unfortunately, some changes in the brain and the environment have the unwanted effect of producing inappropriate behaviors.

**Neurologic Causes**

The brain controls our thought processes and all bodily functions. In short, it controls behavior. When the brain is injured, behavior often is affected. Unfortunately, many changes in behavior following brain injury are not adaptive or acceptable to other people. Such behavior can take many forms, as illustrated by the examples below.

Many people experience increased agitation for a period of days, weeks or months following brain injury. This agitated state is a natural result of the damage to the brain and the disruptive effect that it has on a person’s general functioning. In many cases, the agitation goes away as the brain learns to function in its newly acquired injured condition. But in some cases, agitation can be a lifelong condition that results in significant behavior problems if not treated.
Damage to the frontal lobe, common in motor vehicle crashes and assaults, can cause specific behavior problems. The frontal lobe controls decision-making, judgment and other executive functions. Often when the frontal lobe is damaged, an individual has great difficulty tolerating frustration or overstimulation. This can lead to feelings of agitation and, sometimes, to yelling, cursing, aggression, property destruction and/or other such behaviors.

In many types of brain injury, a person has difficulty with concentration and judgment, as well as problem-solving, making decisions and understanding subtle environmental cues. In turn, the person may become confused, make a bad decision or act impulsively, leading to acting out behaviors such as aggression or property destruction.

In many cases, behavior problems are the result of impaired ability to process information or understand situations accurately. Behavior problems also can occur because individuals often become fatigued easily following a brain injury. Brain injury can affect memory, vision, hearing and communication in ways that increase the probability of behavior problems. Another source of unwanted behaviors can be emotional responses related to damage to the limbic system.

Thus, it is easy to see how damage to one’s brain can lead to behavior problems. These problems can be traced to the neurologic damage and the impaired interactions that follow, and are in no way the fault of the individual.

**Environmental Causes**

An individual’s environment consists of everyone with whom he/she comes in contact with and everything that happens to him/her. The environment’s responses to behaviors profoundly affect how people act. There are four primary ways in which the environment affects how we behave:

**Responding to Cues:** Everyone behaves by responding to cues from the environment. Questions from others, instructions and written signs all exert control over behavior. Successful people learn to make appropriate decisions and responses to cues from the environment. For example, a stop sign or a red traffic light provides cues that it is appropriate to brake a moving vehicle. Instructions to complete a certain task provide cues about what is expected by someone else.

**Positive Reinforcement:** When good things happen to a person following some behavior on his/her part, the individual is more likely to repeat that behavior in the future. For example, if people are thankful and smile when someone holds the door for them, the person will be more likely to hold...
doors for other people. However, if a person never received positive feedback for holding a door, they eventually would stop holding doors for other people.

**Negative Reinforcement:** When behavior gets a person out of unpleasant situations, or if it removes the threat of one, that behavior becomes strengthened. Again, it is more likely to occur in the future. For example, suppose a young child asks his/her parent for candy while at the grocery store. The parent tells the child that it almost is time for dinner. The child begins to cry and scream. This causes everyone in the store to look at them, which makes the parent very uncomfortable. So, the parent gives in to the child and buys the candy. This causes the temper tantrum to stop, and everyone stops looking at them. The parent’s action of giving in to escape from the unwanted attention has just been strengthened, and will be more likely to occur again in similar situations. It has been reinforced negatively by removal of the unpleasant situation.

**Punishment:** When an individual’s behavior leads to a negative consequence, they are less likely to exhibit that behavior again. For instance, if people frowned and hushed a person for talking in a movie theater, that person probably would stop talking. If this happened several times, the individual probably would think twice before talking in a theater again.

In these four ways, our environment influences the development of acceptable behaviors as well as inappropriate behaviors. These factors can be used in therapy to help individuals change their behavior and learn appropriate, adaptive behaviors.

Additionally, the environment can contribute to the development and persistence of behavior problems in a number of ways related to the four environmental factors discussed above:

**Responding to Cues:** Following damage to the brain, a person no longer may be able to respond to customary cues as he/she once did because he/she does not notice understand or process cues quickly enough. What previously had been a cue to do a simple chore may be misunderstood as a hostile or demeaning threat. Or, an individual may have trouble keeping up with family or friends in terms of responding to social cues from others, and may express his/her frustration with aggression or withdrawal.

**Positive Reinforcement:** It has been documented scientifically that behavior problems sometimes are maintained because they result in attention from other people, such as family, friends, staff or other clients.
Consider someone who experiences cognitive difficulties that lead to depression, confusion and self-doubt about the future. In addition, this person occasionally has episodes of aggression accompanied by property destruction. During the outbursts, he becomes the center of attention for therapists and other staff who are present. Following the outbursts, he has individual meetings with a therapist, a counselor, a neuropsychologist and the residential director to discuss what happened. The attention from other people is comforting, and lets this person know that others care about him. Plus, the fact he gets to meet with staff on a one-on-one basis is helpful and reassuring. This type of positive attention strengthens the inappropriate behavior that preceded it.

Likewise, people learn that an inappropriate behavior, such as a tantrum, can result in access to preferred activities, such as watching a favorite TV show, staying up late or gaining access to snacks or other preferred items.

In many cases, the response to inappropriate behavior can include an element of reprimanding. Still, research has shown that even severe behavior problems such as aggression and life-threatening self-injury can be maintained by the positive reinforcement of another person’s response.

Negative Reinforcement: Despite the best intentions of skilled and caring rehabilitation professionals, the recovery process can be very unpleasant for individuals who have sustained a brain injury. Physical activities can be painful. Seemingly simple cognitive activities can be confusing and difficult to perform. Speech problems may make it difficult to speak, or to be understood. Many activities may seem childlike and become demeaning or embarrassing.

It is easy to see that individuals undergoing rehabilitation or attempting community reintegration often are confronted with situations that are unpleasant for any number of reasons. Sometimes, individuals learn that they can use inappropriate behavior to avoid unpleasant situations.

Consider someone who finds physical therapy painful and frustrating. The individual may learn that attacking his/her physical therapist or the orderly transporting him/her to physical therapy results in the person being rescheduled for some easier therapy or being allowed to do nothing. When this happens, the inappropriate behavior is strengthened by avoidance of the unpleasant situation.

Similarly, a person may not like occupational therapy because he/she cannot complete the cognitive exercises and feels like a failure. Or, the individual may not like the therapist or other group members. In some cases, this person will learn that if he/she has an outburst that disrupts the session or scares others, he/she may be excused from therapy. In this case,
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the outburst will be reinforced by the escape from therapy, making it more likely to occur in the future.

**Punishment:** Behaviors that are followed by unpleasant consequences are less likely to occur in the future. Unfortunately, this can complicate the rehabilitation process, where necessary measures result in unpleasant consequences such as pain, confusion, embarrassment or failure. A person’s efforts to participate in rehabilitation can be discouraged in this way. For example, when a person unsuccessfully attempts to master a previously known skill such as walking or talking, failure and the associated frustration and embarrassment can be discouraging to future attempts.

Most people have learned that they do some things well and have trouble with other things. The same is true for the person undergoing rehabilitation or community reintegration. When the skills that are most important to a person’s recovery are followed by some type of punishment, those behaviors are weakened. Then, a person’s ability to obtain positive reinforcement is limited. As a result, the individual is prone to find other behaviors that are effective, even if those behaviors sometimes are inappropriate. Other individuals may withdraw into depression and social isolation as they experience more and more failure.

It should be stressed here that as with neurologic causes, behavior problems caused by environmental factors are not the fault of the individual who has sustained brain injury. The fault lies in the environment accidentally strengthening inappropriate behaviors instead of appropriate responses. Unfortunately, the rehabilitation environment itself often is responsible for reinforcing behavior problems. This can happen when cues are confusing or unclear, or when consequences for behavior problems accidentally reward the individual. It is very likely that the individual is not aware of the reasons for the occurrence of behavior problems and probably wishes he/she could behave more acceptably. Thus, the focus of treatment needs to be on changing the environment, not changing the person.

**Combination of Causes**

For most people with brain injury, behavior problems result from a combination of neurologic and environmental causes. In most cases, the initial occurrence of behavior problems following brain injury largely is due to neurologic damage. Individuals who did not have behavior problems previously become aggressive, disruptive and difficult to get along with. Clearly, the brain injury caused these behavior problems.

However, as discussed above, the environment plays a part in determining the future likelihood of behavior. Even in cases where brain injury causes a
behavior problem, the reaction of an individual in one’s environment can have an effect on how often the behavior will occur in the future.

As was noted, an individual with frontal lobe damage becomes frustrated easily, leading to agitation and aggression. This aggression can be strengthened if it results in positive reinforcement in the form of attention, or negative reinforcement in the form of escape from unpleasant tasks. In this case, the origin of the behavior was neurologic, but the behavior continues to occur in part because of environmental influences.

Alternately, if the same individual becomes aggressive as a result of frustration and agitation but the behavior does not result in reinforcement, the behavior would be less likely to reoccur. The behavior would be even less likely if the individual has been taught adaptive strategies to obtain attention or escape unpleasant situations.

It can be difficult to evaluate behavior problems that occur as a result of neurologic and environmental factors. Again, it is important to distinguish between the individual and the behavior. While it is possible to change an individual in the sense of teaching new skills, the treatment of behavior problems must focus on changing the environment.

Neuropsychologists can be helpful in this area. They administer tests that identify problems with functioning related to damage in specific areas of the brain. These tests have been designed to identify a person’s strengths and weaknesses in performing mental tasks. They also can be helpful in understanding a person’s behavior problems, and which strategies may be most effective in addressing them.

**Treatment Options**

Unfortunately, some individuals with brain injury and behavior problems find themselves being treated in facilities that are not appropriate for their problems. Historically, many persons with behavior problems were not able to be managed in rehabilitation facilities and ended up being placed in psychiatric facilities, where treatment staff were unaware of the complex issues related to brain injury and behavior problems. The result was ineffective treatment. A person with behavior problems and a brain injury has the right to effective treatment in an appropriate brain injury rehabilitation program.

Fortunately, there are now a number of different treatment options that can help individuals with behavior problems. The specific types of treatment depend on two factors. One is the individual. Each person is unique, with behavior problems that result from a particular combination of factors. Each behavior treatment plan must be tailored individually to the needs of the particular person.
The second factor is the degree of seriousness of the problem. Problems that are relatively minor—as measured by severity or frequency—often can be treated in community settings or outpatient clinics. More severe problems most likely will require treatment in an inpatient setting by trained staff. Finally, while behavioral therapy alone often is quite effective, the prudent use of medications in combination with the behavioral interventions outlined in this brochure also is appropriate in maximizing the individual’s ability to recover.

Minor Behavior Problems

With all behavior problems, the treatment of choice depends, in large part, on the specific behavior, how often it occurs and in what situations. However, any effective treatment program should include the components mentioned below:

The individual with behavior problems should be included in the identification and design of the treatment plan whenever possible.

Any treatment plan being considered should be discussed with the individual, in terms of what the problem is, why it is a problem and what will be done to address it. Not only is this fair from an ethical point of view, but it also usually increases the chances for positive outcomes because the individual is involved in the process.

The plan should be as positive as possible.

Families, and even some professionals, sometimes assume that the only effective means of decreasing inappropriate behavior is through the use of punishment or loss of privileges. While mild forms of punishment may sometimes be necessary for troublesome behaviors, many behavior problems can be eliminated through strictly positive means. Even if punishment techniques are necessary, they only should be used in conjunction with positive procedures.

The plan should teach a person adaptive behaviors to take the place of the inappropriate behaviors.

If someone aggresses to escape from household chores, part of the treatment is to prevent such an escape. However, it is just as important to teach the person acceptable ways of having more control over the requirement that they do chores, as well as acceptable ways to express frustration or anger. For example, you might provide the option of choosing what time chores will be done, the order of chores or what the consequence will be for doing, or not doing, the chores. And you might teach an
acceptable means of requesting a short break, or asking for assistance or clarification.

The plan’s design should make it very likely that the individual will succeed, especially in the early stages.

Take the example of the person who refuses to do his/her daily chores and avoids doing so by aggressing. Besides the considerations discussed above, you would want to make your initial expectations as reasonable as possible. No plan would be effective if the person was required to go from doing one chore a day to doing ten chores in order to earn reinforcement. Instead, the person might be more likely to comply if they must complete only two or three chores to earn reinforcement. Then, additional chores could be added gradually.

The plan should be easy for the individual to understand.

Complicated plans that attempt to do too much at one time can be confusing and make it less likely the individual will comply with requests.

The plan must be implemented consistently.

Everyone who implements the plan—whether family or staff—must have the same expectations and be consistent in their interactions with the individual.

Likewise, anyone who implements a plan must do it the same way every time. Abrupt changes in a plan can send mixed messages and could reinforce inappropriate behavior.

The plan must be flexible enough to adapt to changes in the individual.

Although spur-of-the-moment changes are not good, there is nothing wrong with thoughtful changes that are made on the basis of progress or lack of progress. It is best to make changes at times not associated with the behavior problems. For instance, sit down and discuss possible changes to the chore routine at night, not during the chore or in the middle of a temper tantrum.

Although the requirement that plans be positive already has been stated, this aspect cannot be stressed enough.

Praise individuals for appropriate behavior that represents progress away from problem behavior. For example, persons who get agitated in certain situations should receive acknowledgment and praise anytime they successfully control themselves in that situation.
When staff, parents or significant others talk about an individual in their presence, they only should discuss the person’s successes. It is very helpful if a person overhears two people talking about something good he/she did, no matter how minor. Conversely, overhearing two people discuss some shortcoming or behavioral outburst can have very negative effects.

People with behavior problems need a lot of encouragement to learn that they can control their behavior more effectively. Make sure they know that you are noticing their efforts and the results.

**Severe Behavior Problems**

Unfortunately, many severe behavior problems cannot be treated effectively in most home, school or community settings. The design, implementation and monitoring that are necessary must be done in highly structured settings by trained and experienced staff. (See the following section)

**Treatment Programs**

The following section is included to help families and professionals evaluate potential programs for the treatment of severe behavior problems. The available programs vary greatly in terms of their ability to offer effective programs for treating behavior problems. The information below can be used in determining how different programs compare in the services they offer.

**Staff Experience**

Are all staff who will be working with an individual trained in brain injury?

Are there behavioral treatment staff who are trained and experienced in dealing with severe behavior problems?

In programs to treat severe behavioral difficulties, the clinical team should include doctoral level behavior analysts and neuropsychologists who have experience with behavior problems.

Are the clinical staff (i.e., occupational therapists, physical therapists, speech pathologists, teachers, vocational specialists) trained in dealing with severe behavior problems?

Behavioral treatment is most effective when all staff are involved, understand the plan and are comfortable implementing it.

Are the direct care staff trained in safe crisis management techniques?
Are they closely supervised in their implementation of behavioral treatment programs?

Setting

Is the setting as homelike as possible or does it more closely resemble a psychiatric facility?

The more natural the treatment setting, the more likely that treatment gains will carry over to life in the community after the person is discharged.

Is the setting safe for someone who might be engaging in self-injury or major property destruction?

Is the setting secure? Is there any chance that a confused and agitated individual could leave the facility and be at risk from traffic or dangerous individuals?

Are there opportunities for functional and realistic activities?

This means vocational opportunities for adults and educational activities for children.

Are the activities realistic for the individual’s age and functioning level?

Do they bear any relevance to what the individual will be doing after discharge from the facility?

Are there opportunities for appropriate recreational activities?

People with behavior problems need leisure time. They also need opportunities to learn appropriate behavior in leisure situations.

Treatment Context

Is behavioral treatment carried out in all therapeutic contexts?

Are behavioral treatment programs implemented in occupational, physical and speech therapy, as well as the presence of behavioral staff?

Behavior problems do not occur in a vacuum. They occur in therapy rooms, the dining room, the residence, the grocery store and many other places. Effective assessment and treatment demands that they be treated in all situations in which they occur.
Are there opportunities for community outings?

When behavior is manageable in community settings, individuals should be given opportunities to leave the facility and experience the outside world.

Is treatment provided that is relevant to the important aspects of a person’s overall rehabilitation?

Is consideration given to the individual’s life situations, culture and planned discharge setting?

General Treatment Issues

Are staff pleasant and positive in their interactions with clients?

When individuals are not in behavioral crisis, staff should interact with them in a manner that shows respect, caring and positive concern for the person’s well-being.

When staff encounter clients in the facility do they greet them by name and ask how they are doing?

Do staff demonstrate an honest interest in individuals, for example, by commenting on some topic of interest to the individual?

Do behavioral treatment plans incorporate a strong emphasis on positive programming?

Are there many more rewards for appropriate behavior than there are loss of privileges or other punishments for inappropriate behavior?

Do behavioral treatment plans actually exist?

Some well-meaning rehabilitation professionals think the best way to treat behavior problems is to avoid their occurrence. So, if a person became aggressive when asked to help prepare dinner, the plan would be not to ask the person to prepare dinner. This is not helpful because it does not teach the person appropriate behaviors. An effective behavior plan would be based on an analysis of why aggression was part of meal preparation. The plan would be implemented actively to reinforce appropriate participation and teach more acceptable ways of communicating than by aggression.

Do behavioral plans incorporate each of the treatment components discussed above for minor behavior problems?
Do program staff utilize data to evaluate the success of treatment programs?

Staff should not rely on subjective clinical impressions or their recollections over the past 30-day period to evaluate treatment programs. The treatment of behavior problems is difficult and complex and only should be evaluated on the basis of objective data that reflect an individual’s performance. There should be evidence of data collection sheets and graphs that summarize an individual’s progress.

Discharge Planning

Is treatment planning conducted with the individual’s discharge site in mind?

For instance, a behavioral treatment program for a person scheduled to transfer to a group home might be different than one designed for a person going to a long-term residential facility.

Are treatment plans developed that realistically can be expected to be implemented upon discharge by family, teachers, group home staff or others who will be responsible?

Initial treatment plans for severe behavior problems often must be very complicated and sophisticated. They only can be implemented correctly by highly trained staff. However, good treatment plans evolve to become more natural and able to be implemented by family, teachers and others who will be involved after discharge.

Are family or staff who will be expected to implement a program after discharge trained in the program?

Are they given opportunities to practice implementing the program under controlled conditions prior to discharge?

Outpatient Programs

Many individuals with behavior problems can be treated on an outpatient basis. The main factors affecting whether inpatient or outpatient care is necessary are the frequency and severity of the individual’s behavior problems, as discussed previously.

It sometimes is possible to locate potential outpatient programs through referrals from hospital staff or professionals who provide discharge planning at rehabilitation facilities. If these sources do not prove helpful, contact either the Brain Injury Association national office or your chartered
state affiliate. Either of these organizations will provide a list of possible programs.

Summary

Clearly, individuals with brain injury and their families face difficult challenges. However, with a combination of support from loved ones and the right professional help, people with brain injury can maximize their level of independence and lead happy, productive and fulfilling lives.

It never is pleasant to be around someone who is displaying behavior problems. However, sometimes it is helpful to remember why the behavior problems are occurring. Behavior problems are not the fault of the individual. Rather, behavior problems occur as a result of neurological factors and the influence of the environment.

The good news is that problems can be understood and managed. Individuals respond favorably to positive changes in their environment. Today, there are thousands of individuals who have overcome behavior problems—even severe ones—and are leading productive lives.

Unfortunately, treatment often is not effective immediately. Sometimes weeks, months or even years are required to achieve control over behavior problems. During and after the treatment process, the person with behavior problems needs love, understanding and patience from family and friends.

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For the individual with brain injury and his/her circle of support (i.e., family members, significant others, friends and co-workers) brain injury is a complex and often tumultuous journey. Although there are broad issues affecting ALL individuals with brain injury, both the road to rehabilitation and the outcome experienced by each individual are unique. In this series of brochures, BIA seeks to educate individuals and organizations about rehabilitation after brain injury. Some individuals with brain injury may face challenges in all of these areas, while others may experience problems with just a few of them. Regardless, the information in these brochures is crucial to provide those affected by brain injury, as well as the individuals and organizations treating them, with a basic understanding of the complex challenges following brain injury.