

# 3. Living with a Brain Injury

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## 3-A. The Injury

Each brain injury is unique and the outcomes for each vary according to the influence of a multitude of factors. However, individuals with brain injury typically share many common experiences from the time of the injury through the recovery process. In addition, several common strategies can be helpful for family members and friends as they assist the injured person during the many stages of recovery. Although rates of recovery vary with each stage of the process, the approach used should be consistently centered on the individual's strengths, abilities, and interests. As one person with brain injury so aptly put it, **"It's not about what was lost; it's about how you use what you still have left!"**

### — *The Crisis*

In stage one the injury has just occurred. As word of the injury spreads, people gather at the hospital. Shock is usually the initial reaction. Because the person with the brain injury may or may not be conscious to experience this stage, it is hard to know what to do for them.

This new situation may make everyone feel as if they have no control. Family and friends ask for specific information from the medical staff. They want to know what the final outcome will be. Concrete answers are rarely available during this first stage. Emotional responses vary. During stage one, all should be allowed to react and let their feelings happen and pass. Remembering that everyone is different and allowing him or her to feel whatever is appropriate is critical.

Common reactions during stage one often include panic, anger, denial, guilt and numbness. The more the family (including children), friends and caregivers discuss the situation, the more everyone will be able to give support to each other. Everyone should concentrate on the present, not the future or past. Comfort can often be found in one's own religious belief. One's clergy or the hospital chaplain may help. Hospital social workers are usually available 24-hours a day and can help make arrangements for therapeutic and/or religious support.

### — *Interaction with Medical Professionals*

In the early days following an injury, one remarkably consistent situation is that doctors and families disagree on what the outcome will be. Doctors are very cautious with their prognosis and are careful about raising false hope based on the limited information they have during this crisis stage. Recovery depends on the severity and location of the brain injury. It is impossible for healthcare professionals to predict exact outcomes. They cannot know if the individual will eventually be able to care for him or herself independently or will ever be able to take care of everyday affairs. Family members want to believe their loved one will return to the state they were before and don't want to hear anything less. When they are informed otherwise they feel they are not receiving satisfactory answers from the medical professionals.

Family and friends should be included in the hospital treatment team and be given an active role in the recovery process. For the family, involvement can be an empowering yet

daunting experience. Given the stress and shock of the unplanned circumstances during this stage, it is difficult for them to organize thoughts or ask all good questions. Yet it is very important for them to know that they are making contributions at this stage.

### ***Good questions to ask medical professionals***

- What part(s) of the brain has been damaged or affected?
- What do these parts of the brain do?
- How will thinking and functioning be affected?
- Where are some good rehabilitation hospitals?
- Is he or she going to be transferred to another hospital or rehabilitation hospital?
- Is there a medical case manager or social worker at the hospital to help?
- Who will pay for his or her care?
- If there is no insurance, will someone at the hospital apply for Medicaid for him or her?
- What can we do to help him or her recover?

### **— Legal Issues**

It is advisable to start and keep a detailed written record of everything that happened from the day of the injury forward. A precise account may be critical if there is a subsequent lawsuit or other legal action taken later. This record should include the facts regarding the injury, the accident and sequence of events, witness names and what they had to say, medical records and all other pertinent information about the cause and treatment of the brain injury.

If the injury involved significant legal issues, an attorney who specializes in disability cases should be contacted as soon as possible.

A guardian (someone else, usually a family member) may be needed to act on behalf of the person with a brain injury if they cannot take care of their everyday affairs and needs independently. Becoming one's guardian usually requires legal action. A hospital's legal department or social worker can provide guardianship information.

Additionally, hospitals are required to provide everyone with a patient's bill of rights. It is important to become familiar with what it says in case the rights of the person with brain injury are violated.

### **— Strategies for Family and Caregivers**

A family member or other caregiver may find the following strategies helpful in reorienting the person with brain injury back into the world. These strategies can be helpful during the acute hospital stage and continue to be effective during the rehabilitation and ongoing recovery phases.

### ***A few things to remember***

- People, places and activities that were tolerated pre-injury can be overwhelming, and cause over-stimulation after the injury.
- Make no assumptions about what the person needs.

### ***Strategies for positive interactions with the person with brain injury***

- Talk to them about people, names, places, interests and experiences from their past.
- Show them photos of family members, friends, and familiar places.
- Do not be upset if they do not recognize family members, places, times, and events.
- Talk to them about what is happening at home and at work.
- Take him or her out of the hospital room and outdoors when possible.
- Have friends and family members visit in small groups regularly.
- Consult with a nurse, doctor or rehabilitation professional before allowing the person to watch television or listen to music. The noise may be difficult for him or her to tolerate all at one time.
- Make sure he or she has a calendar and clock. Help him or her reorient to their use.
- Meet with the hospital discharge planner or social worker to discuss community short-term and long-term brain injury resources that will be needed after discharge.
- Avoid too many people talking at once. This type of over-stimulating frustration can make it difficult for him or her to think clearly.
- If the individual senses are overloaded he or she may shut down, explode, cry or become combative. If this happens, let them rest in a quiet place. Have some of the people leave for a while and come back later.

### ***Suggestions for conversations***

- Keep conversations simple.
- Present only one idea at a time.
- Talk in short, simple sentences. It may take longer for him or her to process what is being said and decide how to respond.
- Try to ask questions that require a yes or no reply.
- Ask simple questions; *Where is \_\_\_\_\_? Point to \_\_\_\_\_.* *Show me \_\_\_\_\_.*
- Use repetitive words and actions.
- Try to include the person in every conversation. Never talk down to them or talk about them in their presence as if they are not there.
- Ask the person to say the names of items in the room. This will help them with identification and recall.
- Be prepared for bizarre, inaccurate language or swearing.
- Realize that the person may not be able to understand or may misinterpret what others say.
- Do not act like you know what he or she is saying if you don't. Ask them to repeat if you don't understand.
- Do not use sarcasm or tell abstract jokes. He or she may not understand and take you literally.
- Do not agree with their fantasies or repetitions by saying you also see or hear things that the person is imagining.

## **General Tips for Family and Caregivers**

- Do not overwhelm the individual with false optimism or empty phrases like, "You will be back to your old self in no time."
- Do not compare the person's speech, language or physical abilities to what it was like before the injury. Help them look ahead, not back.
- Do not become alarmed if they are not able to control their laughing or crying. Redirect them or suggest they do something else to calm down.
- Do not scold or tease if they can't do the things they did before.
- Do not make them feel guilty about making mistakes.
- Do not treat them like a baby.
- Do not argue with them. Arguing can be exhausting and will probably cause anger or resentment.
- Be calm, speak slowly and clearly, move slowly and wait calmly for the person to respond and complete tasks.
- Be patient.
- **ACCEPT THE PERSON THEY HAVE BECOME.** It is up to the family and other caregivers to help them maintain dignity and self-respect because of and/or in spite of the changes.

## **3-B. Rehabilitation**

After a person with a brain injury is medically stable, the hospital may transfer the individual to a rehabilitation facility. Rehabilitation goals usually involve helping the person become independent so they can take care of their daily activities. Rehabilitation also educates the person and his or her family about the support systems they will need.

A team will create a written treatment plan that outlines the rehabilitation strategies that will be followed. The plan outlines the services and supports that the person will need in place before going home. The team usually includes the individual with the brain injury, family member(s), caregivers, social workers, doctors, therapists and other medical personnel. Input from the person with the brain injury and his or her family is essential because without their participation and direction the rehabilitative process may be compromised.

### **— Physical Rehabilitation**

There are many healthcare providers that may be involved in caring for a person with a traumatic brain injury. The following lists some of the facilities and services that may be used during the rehabilitation process:

#### **Acute Care Hospitals**

Acute care is given immediately following brain injury in a hospital that has facilities to treat trauma, such as an emergency room, operating room, and intensive care unit. Goals for treating severe brain injury include minimizing infection, or relieving brain swelling or pressure. Once a person with brain injury is stabilized, other therapies to

restore function and recovery are initiated. After treatment in an acute care hospital, a person with a brain injury may be discharged home, referred to an in-patient or out-patient rehabilitation program, or referred to a home health service.

### ***Rehabilitation Facilities***

Rehabilitation is an interdisciplinary approach consisting of physicians, nurses, and rehabilitation therapists, and provides the facilities and structure that the person with brain injury needs for support, retraining, and successful community reentry. To help the person with a brain injury achieve his/her potential, rehabilitation focuses on therapies to improve independence in self-care, cognitive, and social skills so that the individual can either return home or to a less intense treatment setting.

#### *Evaluating Rehabilitation Facilities*

Not all rehabilitation programs are the same. Rehabilitation programs may be located either in an acute care hospital or in a freestanding rehabilitation hospital. In the same way that you are encouraged to seek a second opinion before making any major decision, it is recommended that you assess rehabilitation facilities by visiting any prospective facility.

*The following questions may help you evaluate prospective rehabilitation programs.*

- How frequently and in what format does the rehabilitation team communicate with the family to explain treatment, terminology, or prognosis? For example, are there regular family conferences? Does the family receive written progress reports?
- How many individuals with brain injuries has the program treated?
- Is the rehabilitation program accredited in the specialization of brain injury by CARF (Commission on Accreditation of Rehabilitation Facilities)? CARF confers accreditation in general rehabilitation and in the specialization of brain injury. JCAHO (Joint Commission on the Accreditation of Healthcare Organizations) provides a more general accreditation for acute care and rehabilitation facilities.
- What is the average length of a stay? Who determines it?
- What is the visitation policy?
- What activities are available during the evening or on the weekends?
- When is a home evaluation performed? Is information from this evaluation incorporated in therapies or in planning activities for return to home, school, work, etc.?
- How often is comprehensive reevaluation done?
- What is the program's philosophy on using medication?
- What post discharge follow-up is conducted? For example, will the staff contact you or the family to see how you are doing? Is program staff available to consult for any difficulties encountered? What type of support is available and for how long?
- What are the typical costs involved in rehabilitation and will your insurance cover these services? What payment arrangements can be made with the program?

## ***Outpatient Services vs. Outpatient Rehabilitation Program***

After being discharged from an inpatient rehabilitation program, a person with a brain injury may be referred to continue in:

- Specific recommended outpatient services, or
- An outpatient day rehabilitation program.

### *Outpatient services*

While receiving outpatient services, the individual with brain injury lives at home. The person with brain injury may only need to return for physical therapy or perhaps to see the neuropsychologist once a week. If continued therapy is recommended, the individual may return for separate outpatient appointments.

### *Outpatient rehabilitation program*

In an outpatient day rehabilitation program, the person lives at home but comes to the rehabilitation center daily for a four to eight-hour structured therapy program. The person may continue with several therapies, such as physical therapy, speech, occupational therapy, aquatic exercise, and neuropsychological interventions for cognitive or behavioral issues. Usually, clearly defined vocational, social, and community reentry components are included in addition to therapies.

Outpatient rehabilitation services are often an option for people who have had a brain injury for longer periods of time, for people with mild brain injury who recently have been evaluated and diagnosed, or for those who rehabilitation was not previously available.

## ***Physical Therapy***

Physical therapy is the provision of services for people to develop, maintain and restore maximum movement and functional ability throughout the lifespan. It includes the provision of services in circumstances where movement and function are threatened by the process of aging or that of injury or disease. The method of physical therapy considers full and functional movement as the heart of what it means to be healthy.

Physical therapy involves the interaction between clients, families and care givers, in a process of assessing movement potential and in establishing agreed upon goals and objectives using knowledge and skills unique to physical therapists.

## ***Physiatrist***

A physiatrist is a physician who specializes in the diagnosis, treatment, and rehabilitation of disorders that produce pain, impairment, and disability. Physiatrists are trained to direct a rehabilitation plan that includes the usual tools of medicine in addition to other rehabilitation professionals.

## ***Occupational Therapy***

Occupational therapy refers to the use of meaningful occupation to assist people who have difficulty in achieving healthy and balanced lives; and to enable an inclusive society so that all people can participate to their potential in daily occupations of life.

Occupational therapists work with a variety of individuals who have difficulty accessing or performing meaningful occupations. Most commonly, occupational therapists work with people with disabilities to enable them to maximize their skills and abilities. Occupational therapy gives people the "skills for the job of living." Services typically include customized treatment programs to improve one's ability to perform daily activities, comprehensive home and job site evaluations with adaptation recommendations, performance skills assessments and treatment, adaptive equipment recommendations and usage training, and guidance to family members and caregivers.

## ***Speech Therapy***

Speech-language pathology includes prevention, diagnosis, habilitation, and rehabilitation of communication, swallowing, or other upper aerodigestive disorders; elective modification of communication behaviors; and enhancement of communication. Speech-language pathology is the study of disorders that affect a person's speech, language, cognition, voice disorders and swallowing disorders.

## ***Home & Community Based Services***

Many people with disabilities wish to continue living independently in their homes and communities. For some, this is possible with the aid of supportive services available to Kansans. Home and community-based services, available through the State's TBI Medicaid Waiver Program, are designed to meet the needs of individuals who would have to be in a care home or institution without these services. It provides alternatives to care homes and institutions.

People who would like to stay in their home and community with the assistance of supportive services may be eligible for Medicaid Waiver Home and Community-Based Services if certain requirements are met. The services available in Kansas are funded through Medicaid, so the individual must be Medicaid eligible. Information about other eligibility criteria and available services can be found in Section 4-A.

## ***— Emotional Rehabilitation***

During rehabilitation, the individual with a traumatic brain injury and his or her family members might experience the natural stages of mourning that occur following any major loss. They often feel denial, anger, grief and finally acceptance. This is an emotional time for everyone. If the person or family is having a difficult time understanding their feelings, one may want to seek counseling from a licensed therapist, the clergy, or other professionals. They can help with the grieving and the transition.

Family and friends often notice significant changes in the person with a brain injury. These changes can affect their relationships and need to be addressed. A person's personality, behaviors, mannerisms and other identifying characteristics are frequently dramatically different. Family and friends must focus on the rehabilitative successes of the person and learn to appreciate the endearing qualities and strengths that they can demonstrate. A peaceful acceptance of the person with a brain injury can happen over time. With work, all can eventually develop modified valuable relationships.

### ***Neuropsychologist***

A neuropsychologist assesses and evaluates brain function as reflected in behavior and emotions. The neuropsychologist may conduct testing during the evaluation phase of treatment. Another role of the neuropsychologist is to provide strategies to assist individuals with brain injuries and the family with adjustment in home, work and school settings.

### ***Rehabilitation Psychologist***

A rehabilitation psychologist assesses and evaluates adjustment to the physical, emotional and mental changes brought about by injury. They may act as consultants to educate and assist family members, other professionals, employers, and/or teachers about the needs, capabilities and challenges of an individual with brain injury. During the hospital/ rehabilitation stay, staff may also develop and implement behavioral management strategies to assist the individual at home, work or school.

### ***Psychiatrist***

A psychiatrist is a physician who specializes in mental health during his/her medical training. The psychiatrist evaluates problem behaviors and can prescribe medication, including antidepressants or anti-anxiety drugs.

### ***Social Worker***

A social worker, often referred to as the case manager, provides a link between the individual/family and other care providers. Social workers assist with financial concerns and other priorities related to transitioning back into the community.

### ***General Tips for Family and Caregivers***

- When teaching re-learned skills or information recall use repetition. Repeat skills as many times as it takes. Allow ample opportunity for practice.
- Minimize distractions when working on new tasks. Keep things simple. Work one-on-one. Focus on one task at a time and break tasks into simple steps.
- When he or she responds with anger or disagreement, redirect the person rather than confront them. Look for activities that do not challenge and trigger unwanted behavior. For example, don't ask, "Why are you doing that?" Instead say: "How about trying this."

- Go with the flow, respect the person's routine and energy levels and take frequent breaks. Work with current and past interests and the abilities they have now. Give up things that don't work and move on to something else.
- Talk to each other about your feelings. Feeling frustrated is normal.
- Accept the loss of certain abilities. Acceptance will help everyone focus on strengthening the things that can be done.
- Realize that rehabilitation does not end. Some weak areas may continue to improve with time.
- Realize that even though some areas remain weak, other areas often compensate for losses in those areas.

### 3-C. The Return Home

As the time in the rehabilitation facility ends, the individual, medical staff and the family usually work as a team to develop a discharge plan. The plan ordinarily includes medication regimes, schedules for outpatient or in-home therapy, a schedule of doctor appointments, and other service and support recommendations that will assist the person after they move home. It is important to get copies of all medical records from each facility before discharge. Records may be needed when applying for future services. Assessments will be made in preparation for the return home. Home modifications should be planned and completed in advance so that the person's safety and needs can be met. Wheelchair ramps, widened doorways or installation of grab bars in the bathroom may need to be considered. An occupational therapist should evaluate what will be needed at home.

#### *Ongoing Rehabilitation and Resources*

Transition into the home can be unsettling. At home the primary responsibility for care is transferred from hospital medical staff to a family member or other caregiver. Often a family member must take on a new caregiving role that they have not experienced before. As caregiver, they may take on the added responsibilities of coordinating therapy, medical appointments, driving the person to the doctor, filling prescriptions, while resuming the responsibilities in their own lives. Caregivers can, however, develop an orderly routine by keeping a planning calendar as they go about doing whatever it takes to establish stability during this transition time. After the chaotic disorder that everyone experienced in the days or months right after the injury, order can be very calming.

Return to activities that a person with a TBI previously participated in is often a significant issue following an injury. The individual might not recognize if they have limitations that inhibit their ability to perform certain activities, such as school and work-related activities and driving, as they did pre-injury. Formal evaluation by a vocational or school counselor or other trained professional might be necessary to assess the individual's abilities and determine what supports might be necessary.

There are a number of services and resources available to assist individuals with TBI and their families after they return home. Case management, funding sources such as Social

Security or Medicaid Waiver programs, and life skills trainers may be available to provide assistance. Refer to the resource section of this manual for descriptions of services offered throughout Kansas. Keep in mind that the application and eligibility approval process can be lengthy. Application should be made as soon as possible following the injury. Even if it is discovered that the services are not needed, it is better to apply right away so that the services will be available later if they are needed.

The costs of medical care, therapies, hospitalization, rehabilitation and after-care services can be extremely expensive. Carefully review applicable insurance policies for information about long-term disability coverage. Investigate private insurance, and the cost, coverage and limitations of COBRA benefits. If there is no private insurance, public health assistance should be sought immediately. (For more information on financial assistance, see Section 5.)

## **Compensatory Strategies**

Compensatory strategies are adaptive-equipment devices and strategies that compensate for lost cognitive or physical abilities. Compensatory strategies are used to strengthen skills and to develop new skills that the person can use to be as independent as possible.

Some people find it difficult to start using compensatory strategies. However once they are incorporated into daily use they can reduce the feeling of being overwhelmed with their disability. After a person becomes accustomed to using them and they become more confident, they fall into a daily routine of performing their activities as a matter of routine. The following strategies have helped others with brain injury:

### ***Organizer or Day Planner***

A day planner, memory book, organizer or appointment calendar are excellent memory tools for persons with brain injury. An individual can write down doctor appointments and other appointments, medication lists, important dates, times and information about meaningful activities and identify information about themselves and others. Organizers allow the person to review past and scheduled events as often as they like and ultimately they eliminate the unnecessary worry of forgetting meaningful subjects. Pictures of medical providers, family, friends and caregivers can also be included in memory books to serve as visual reminders. A memory book can create a written history of the person's past and present life that they can reflect on over and over.

### ***Filing System***

A filing system can also be used to help the person with a brain injury get and stay organized. It may consist of a filing cabinet, file folders and a tickler file where medical, legal, financial records and insurance information is kept in order. By keeping files updated and organized, a person can access needed records more easily. Assistance in setting up and using filing systems may be needed.

## ***Check Lists***

It can be helpful for the individual to develop meaningful checklists. Posting a list of personal hygiene routines in the bathroom, a safety checklist placed by the door to be reviewed before leaving the house, or lists with sequential instruction for various housecleaning and other tasks all can be very helpful.

## ***Names and Phone Numbers***

A list of family members, friends, doctors, service providers and emergency contacts should be posted near the phone and included in the person's day planner, wallet, briefcase, purse and/or backpack.

## ***Other General Strategies***

- **A clock or timer** can be used to help the person time how long they have spent or need to spend on an activity such as cooking or showering.
- **A voice recorder** may be used to recall appointments and other important meetings.
- **Wallet information cards** that list a person's name, address, emergency-contact information, doctors, medications, allergies and all significant medical conditions are helpful prompts.
- **Reminder calls** from the offices where they have scheduled appointments can be very useful. The call will prompt them to keep the appointment on the right day and arrive on time.
- **Pictures** of family members, friends and service providers like therapists they see help them recognize people the next time they meet with them.
- **A list of favorite foods** can be used to develop menus and shopping lists.
- Membership in **a peer support group** will help the person identify with others, and make them a part of a support system where they can discuss issues, ideas and strategies that others with traumatic brain injury are using.

Not every strategy will work for everyone. Speech and occupational therapists specialize in developing unique compensatory strategies tailored to meet the individual's specific needs.

## **Avoid minimizing memory loss of the individual with a traumatic brain injury.**

Memory loss that is the result of brain injury should not be confused as normal forgetfulness. Individuals who have had a brain injury need to be reminded that they are not the only ones with memory loss caused by a TBI. There are thousands that have the same type of memory loss that they live with every day.

## — **Medical Professionals**

Family members and individuals with traumatic brain injury often have difficulties understanding what medical professionals tell them. They may often appear to be too busy to answer questions, may respond with vague answers and use medical terminology that is unfamiliar. On the surface, they may appear insensitive and uncaring about the condition of the person with a brain injury and his or her family. This is rarely true, but it helps to have some strategies to use when talking to them.

### ***Strategies to consider when interacting with medical personnel:***

- Be patient; try to talk to them during scheduled appointments rather than catching them in a hallway. During an appointment they can give their undivided attention and time to review records and talk without being interrupted.
- Write down questions and concerns to take to their appointments. Being prepared will ensure that all questions are asked and concerns addressed in an organized way.
- Don't hesitate to ask professionals to explain anything that is not understood.
- Keep a special notebook. Write down medical information that can be referred to later and clarified if necessary.
- Understand that medical personnel are very busy and that they often work under a lot of pressure. Treat them like you value their time.
- Recognize that medicine and rehabilitation are not exact sciences. Medical personnel, therapist or other professionals cannot predict the final outcome.
- Discuss problems with the staff that you feel is not being responsive before making a formal complaint to a supervisor.
- If problems continue, or if staff members are violating the rights of the person with a brain injury or his/her family, do not hesitate to contact the patient advocate or hospital administrator.

## — **Family Members as Part of the Care Team**

### ***Children***

Young children are often excluded from direct involvement and conversations about their injured siblings or other members of their family. Because they don't understand what has happened, they may develop feelings of resentment toward the person with the brain injury because he or she is receiving so much attention.

### ***To ensure that younger family members are not ignored:***

- Be honest. Let the children know that no one knows what the outcome of the injury will be.
- Give children literature they can understand and have open discussions with them.
- Allow them to visit the hospital if they want to.

- Include them in the rehabilitation process when possible.
- Have them write stories of or draw pictures about how they are feeling.
- Allow the child to have their own reactions to the injury and reassure them that their feelings are okay. Children that are not willing to accept the injury at first, often end up playing an active role in the injured person's recovery.
- Have children meet with a therapist or other appropriate professionals so they can talk openly about their own feelings.

### ***Adolescents***

Following the brain injury of a sibling, older children and adolescents may seem self-absorbed and more concerned with what is going on in their own world. Despite their apparent disinterest, they usually have intense feelings that need to be addressed. They may worry that they will have to spend a lot of their time caring for the injured family member. Or they may avoid the whole situation that usually causes emotional barriers between them and their injured sibling. Conversely, they may insist on actively participating in their family member's recovery process.

*An older child can contribute in the following ways:*

- Give teenagers material on brain injury.
- Let them go to see the person at the hospital.
- Ask them if they would like to join the rehabilitation team.
- Encourage them to take an active part in the activities of the person with brain injury after they return home, and while out with them in the community. Do not pressure them to participate. Forcing them may cause resentment and anger toward the individual and other family members.

All the family's children should continue to be included in family activities. The focus should not be on the person with a brain injury all the time.

*To be sure other children get the support they need:*

- Have others care for the person with a brain injury during family activities some of the time.
- Be sure that no unusual expectations are demanded of other children or that their privileges are not unnecessarily taken away. Doing so may create resentment toward parents or the individual with brain injury.
- Get counseling for them if necessary. Counseling will help them adjust to the changes in the family dynamics. Counseling is available through the schools or from a professional referred by the healthcare professionals.

### ***All Family Members as Caregivers***

Family members can become overwhelmed with the crisis, the changes in behavior as well as physical and cognitive abilities of the individual with a brain injury. It is important to remember, there is no single, correct way of dealing with the person's changes following

an injury. Family members go through different feelings and reactions throughout recovery right along with the injured person.

*Some of the strategies for family caregivers are:*

- Be patient. Keep in mind, the individual may be disoriented and confused for some time. He or she will begin to compensate for some of their deficits in time.
- Accept the situation. Family members must come to accept that the individual will most likely never be the same person they were before. Family members must learn to appreciate the individual for who they are, and for what they can do.
- Help the person become independent. Family members must provide the individual freedom to increase their independence. Provide opportunities for them to do things for themselves even if it's questionable that they can succeed. Doing so will allow them to rebuild their confidence and help them get back their sense of self-reliance.
- Give them support. Use a buddy system when trying a new activity. Offer support, and adjust the level of support to accommodate the person's current abilities and skills.
- Get counseling for family members. Individual family members or the entire family can benefit from counseling services. Counseling may help alleviate a variety of built-up emotions, feelings and thoughts. Ultimately counseling should help everyone's acceptance of the new situation.

*Encourage the family to be flexible.*

When the brain injury occurs, family members and friends are all in crisis. The injury happens without warning. Family dynamics are tested and issues arise that are unfamiliar. Young children are often left with neighbors or other family members, older children are told to stay in school or at their jobs and extended family may be told to wait to come to the hospital until more information is available. All involved experience an emotional roller coaster as they wait for news about their loved one's condition. Feelings of isolation are common, questions don't have immediate answers, and stability and routines become utterly disrupted.

*Share available information.*

Keep everyone informed regularly about the extent of injury, give them progress or status updates and let them know other pertinent information as things happen. Explain things to young children in a way that they can understand. Encourage participation by all interested family members, including extended family, in the acute, rehabilitation, and discharge phases of recovery. Gauge the level of involvement to suit the age and wishes of each person. Keeping family and friends informed of changes will help them feel like active participants. Invite them to spend time with other family members, assist with the care of the person with the brain injury or provide respite for parents or other caregivers. Be sure to include everyone in ways that are meaningful and comfortable for them.

*Take care of yourself first.*

An individual cannot offer effective assistance to the person with a brain injury if they are not taking care of themselves. Many family caregivers tend to spend all their time caring for the person with the injury and don't take care of themselves. The individual with an injury is often the focal point for days, weeks, months and years following the injury. Caregivers deserve and need their personal time too. Recreational and social activities can relieve some of their stress. Other family members should encourage caregivers to find ways to meet their mental and physical needs.

## — **Emergency Care Planning**

### **Advance Health Care Directives**

Advance health care directives or advance directives are instructions given by an individual specifying what should be done for his or her health in case he or she is no longer able to make decisions. A living will is one type of advance directive. It is often accompanied by a specific type of power of attorney or health care proxy. These are legal instruments that are usually witnessed or notarized.

- A **living will** is a written document instructing your physician or health care provider on the type of medical care you want or do not want or, in particular, in some cases forbidding treatment and sometimes also food and water, if you should become unable to make these decisions for yourself.

The "Living Will" must be witnessed by two adults who are not related to you, not entitled to any part of your estate by will or otherwise, and not financially responsible for your medical care.

- A **durable power of attorney for healthcare decisions** is a written document that designates another person to serve as your agent for purposes of making health care decisions when you are unable to do so. The document must contain language expressing that this power is to remain in force even if you are incapacitated.

For this document to be valid, it must be dated and signed in the presence of at least two witnesses who are at least 18 years of age. Neither witness can be your agent if they are related to you by blood, marriage or adoptions, entitled to any of your estate, or directly financially responsible for your health care. As an alternative, the Durable Power of Attorney for Health Care Decisions may be acknowledged before a notary public. This document must be given to the attending physician.

As the name suggests, the term "will to live", as opposed to the other terms, tends to emphasize the wish to live as long as possible rather than refusing treatment in the case of serious conditions. In the United States, most states recognize living wills or the designation of a health care proxy. Surveys show that one-third of Americans say they've had to make decisions about end-of-life care for a loved one.

If you die without a valid will, which is called dying intestate, all of your property, other than what is held jointly, will be distributed among your surviving relatives according to Kansas laws. Your estate will be divided into various portions depending on whether a spouse, child(ren), parent(s) or other categories of relatives survive.

### ***Guardianship***

A **legal guardian** is a person who has the legal authority (and the corresponding duty) to care for the personal and property interests of another person, called a ward. Usually, a person has the status of guardian because the ward is incapable of caring for his or her own interests due to infancy, incapacity, or disability. Most countries and states have laws that provide that the parents of a minor child are the legal guardians of that child, and that the parents can designate who shall become the child's legal guardian in the event of their death.

Courts generally have the power to appoint a guardian for an individual in need of special protection. A guardian with responsibility for both the personal well-being and the financial interests of the ward is a general guardian. A person may also be appointed as a special guardian, having limited powers over the interests of the ward. A special guardian may, for example, be given the legal right to determine the disposition of the ward's property without being given any authority over the ward's person. A guardian appointed to represent the interests of a person with respect to a single action in litigation is a guardian ad litem.

Some jurisdictions allow a parent of a child to exercise the authority of a legal guardian without a formal court appointment. In such circumstances the parent acting in that capacity is called the natural guardian of that parent's child.

### ***Recovery and Drug/Alcohol Abuse***

Alcohol is an established risk factor for brain injury. Of individuals with brain injuries, 50% had abused alcohol prior to the accident. Persons with brain injuries should refrain from the following types of substances:

- Alcohol (including beer)
- Narcotic drugs (cocaine, heroin, marijuana, etc.)
- Nicotine (cigarette smoking)

*Alcohol and/or Other Substances Can Cause:*

- Structural brain changes
- Edema (swelling of brain)
- Alteration in blood clotting
- Increased risk for seizures
- Cognitive deficits
- Decreased oxygen to brain tissue

A person with a brain injury jeopardized by the use of alcohol/substances has even less capacity to compensate for cognitive difficulties (thought, memory, concentration, etc.).

Several themes consistently surface in the literature on brain injury:

- When there is a habit of using alcohol and/or other substances prior to the brain injury, usage worsened after the injury.
- All physicians should discuss the risks associated with the use of alcohol and substances after injury. Let your doctor know if you are using alcohol or other substances.
- Abuse often begins as a response to depression, a common occurrence after injury. Alcohol may temporarily make a person more fun, social, or uninhibited (you may act in ways you would not normally), but alcohol is not a chemical "pick up" - it is a depressant.
- The desire for a social life and hanging out with old friends often takes priority over maintaining a substance-free lifestyle.

### ***Facts About Alcohol/Drug Use and Brain Injury***

- People who use alcohol/drugs after injury don't recover as well as those who avoid use.
- Brain injuries cause problems in balance, walking, or talking that get worse with the use of alcohol/drugs.
- Persons with brain injuries often say or do things without thinking first. This is worsened if you've been drinking/using drugs.
- Brain injuries cause problems with memory, thinking, and concentration. This is aggravated by drug/alcohol use.
- After brain injury, alcohol and drugs have a more powerful effect.
- Drinking alcohol/using drugs can cause seizures.
- People who drink alcohol/use drugs after brain injury are more likely to have another brain injury.

In the absence of professional and long-term intervention, it may be up to the family to seek help in the community. Family members may need to assume a monitoring or mentoring role. Many families report that the use of community programs such as Alcoholics Anonymous (AA) and/or the typical 30-day inpatient addictive programs have little value in overcoming the problem. The existing programs are designed for those whose primary issue is addiction. The person with brain injury may want to overcome the addiction but cognitive and memory deficits may sabotage efforts. Traditional 30-day treatment programs are too fast-paced and the person with brain injury has decreased ability to absorb, process, and understand educational material. Most programs require writing, memory, organizational, and abstract-thinking skills--capabilities affected in some individuals with brain injury.

### ***Suggestions For Avoiding Drug/Alcohol Use***

- If you forbid use, you risk rebellion. Rather than restricting use, discuss the hazards of using alcohol and other substances. Talk about the decrease in ability to function and problem solve and increased potential for loss of control, impulsiveness and aggression.
- Order and read published materials about injury and addiction.
- Try non-alcoholic drinks or soft drinks to fit in socially.
- Tell old friends the dangers you face by using alcohol/drugs after injury and ask for their cooperation.
- Plan social activities around something other than alcohol/substance use. Avoid places where alcohol/drugs are more available (bars, pool halls, etc.).
- Find something that stimulates and motivates you. For example, exercise, a hobby/sport, or volunteering. Your esteem will improve if you are making a contribution and busy people are less depressed, bored, and less likely to use alcohol/drugs.
- Seek the assistance of community-based programs. Where AA is recommended, find a routine time/place to reduce confusion in format/agenda.

# Notes

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