No one can prepare a family for the trauma of experiencing brain injury. Following the injury the subsequent move from the hospital to various rehabilitation settings can add to the feeling of being overwhelmed. Most family members admit to knowing very little or nothing about brain injury prior to personally experiencing brain injury. Understanding the various rehabilitation settings, and knowing what is best for your family member can seem a daunting task. The following information is offered as a starting point to understanding the rehabilitation process following brain injury.

First and foremost, know what your insurance policy covers and does not cover. Ask that a case manager be assigned if this has not already happened and speak directly to the case manager prior to the need to transfer from one level of care to the next. Auto insurances generally have a monetary cap which may be close to exhaustion (out of money) prior to moving your loved one. So know your medical insurance well. Call for a copy of the policy handbook and keep it available. Although you may feel the need to stay with your loved one twenty-four hours per day, schedule time away from your loved one’s bedside to gather the necessary insurance information you will need and take the time to understand it.

Selecting a Brain Injury Rehabilitation Facility
Your insurance coverage will impact on the choice of the facility your loved one is transferred to. Speak to the insurance case manager to find out what facilities are covered and plan to “drop in” to see the facility. There are also resources available to help you better understand what facilities exist and how to choose a facility that best meets your family member’s needs. The Brain Injury Alliance of New Jersey provides a comprehensive list of brain injury rehabilitation facilities, which details the different services that they offer, in the New Jersey Brain Injury Resource Guide. In addition, the Association also provides A Guide to Selecting and Monitoring Brain Injury Rehabilitation Services, a publication of the Brain Injury Association of America. The guide includes tips and suggestions in what to look for in a brain injury rehabilitation facility, including specific questions to ask when calling or touring a facility. Individuals can also contact an Information & Resource Specialist through the Brain Injury Alliance of New Jersey’s Helpline at 800-669-4023, 732-745-0200, or info@bianj.org.

Prior to selecting a rehabilitation program, you should visit the facility, speak with the admissions director and social worker, and learn more about the therapy your family member will receive. You’ll also want to find out the length of stay that your insurance or other funding source covers, and the discharge planning process for individuals who are leaving the facility.
Acute Rehabilitation
Following acute medical hospitalization and once an individual is stable enough to participate in therapy, many persons with brain injury are transferred to an acute inpatient rehabilitation program for comprehensive treatment of physical, occupational and cognitive impairments.

Acute brain injury rehabilitation services are offered through specialized rehabilitation units in hospitals, or freestanding rehabilitation facilities, which are accredited through CARF, the Commission on Accreditation of Rehabilitation Facilities. The services offered at an acute rehabilitation program include medical supervision, 24 hour nursing care and rehabilitative therapy such as physical, speech, occupational and recreational therapy. To receive certification as an acute rehabilitation program the staff must provide three hours a day for five out of 7 days a week of intensive therapy services. The progress of the rehabilitation team is supervised by clinical directors knowledgeable in standards of practice for rehabilitation. The directors may be neuropsychologists, physiatrists or physicians. Acute rehabilitation also encompasses skills training and functional assessments designed to help the person with brain injury re-integrate into the community upon leaving the rehabilitation program.

Subacute Rehabilitation
Subacute rehabilitation programs are designed for persons who have made progress in the acute rehabilitation setting and are still progressing, but are not making rapid functional gains; or for persons who are not yet able to participate in an acute rehabilitation program. Typically in a subacute setting a patient will receive only one to two hours of therapy a day, four to five days a week. Subacute rehabilitation can be provided in a variety of settings, including nursing homes and skilled nursing facilities.

Nursing Homes & Skilled Nursing Facilities
A nursing home is an option the rehabilitation team might discuss when planning for your family member’s discharge from rehabilitation. The State of New Jersey defines a nursing home as “a facility that is licensed by the Department of Health & Senior Services to provide health care under medical supervision and continuous nursing care for 24 or more consecutive hours to two or more patients who do not require the degree of care and treatment which a hospital provides and who, because of their physical or mental condition, require continuous nursing care and services above the level of room and board.”

A nursing home provides skilled nursing care and/or assistant care services to people with illnesses, injuries, or disabilities. Although most facilities typically serve the elderly, there are some nursing homes in New Jersey that provide services to younger individuals with special needs. Therapies that may be provided in a nursing home could include physical, occupational,
and speech therapy. Nursing homes typically do not provide specialized rehabilitation for people with brain injury, such as cognitive therapy or neuropsychological services, unless they offer specialized subacute care for people with brain injury.

A skilled nursing facility (SNF) is another option that may be discussed for an individual with brain injury being discharged from rehabilitation. A skilled nursing home is a traditional nursing home that provides 24 hour a day medical nursing care and a licensed physician supervises the care of each patient and is on call 24 hours a day. All skilled nursing facilities are stated licensed and are staffed 24 hours a day with an RN and certified nursing aides. Individuals who are in need of higher levels of care due to illness or disability would go to a skilled nursing facility.

Individuals at skilled nursing facilities typically are unable to care for themselves due to physical, emotional or behavioral conditions. If you are unsure of why your rehabilitation team is choosing a nursing home or skilled nursing facility instead of a brain injury rehabilitation facility be sure to ask the team how they came to their decision.

**Funding Rehabilitation**

Rehabilitation, in the beginning stages, can be funded through a variety of ways, including Personal Injury Protection (PIP) insurance through your motor vehicle insurance (if the injury involved a motor vehicle), health insurance, worker’s compensation, or Medicaid. Some facilities will not take a patient unless their Medicaid is in place while others will take “Medicaid pending”. As rehabilitation progresses you may begin to hear from your rehabilitation team that your insurance is putting limitations on continued therapy. For more information on how to appeal such decisions see the information below on Appealing Insurance Decisions.

A source of funding for a subacute rehabilitation facility is the TBI PAS. Through Medicaid, the TBI PAS funds treatment in a subacute facility that provides brain injury rehabilitation. PAS stands for Pre-Admission Screening, and is different from the TBI Medicaid Waiver (see below for more information on the TBI Medicaid Waiver). The screening process is done by a registered nurse who evaluates the patient to see whether he/she is clinically qualified for long term care in a brain injury specialty program. The TBI PAS is intended to be short-term and is reviewed every 6 months. Typically, if the rehabilitation team is recommending subacute care the social worker will handle obtaining a TBI PAS, and, if the family has any responsibilities in obtaining the TBI PAS, the social worker will explain what is required of the family. If a person with a brain injury is being transferred from an acute care facility to a nursing home, it is worthwhile to inquire about placement in a specialized TBI care facility as an alternative.
Appealing Insurance Decisions
First and foremost, know what your insurance policy covers and does not cover. The first and most important step in appealing an insurance decision is to review your benefits and the detailed appeal process. You and/or your doctor have the right to appeal a decision. The appeal process may vary from health plan to health plan so review your plan in great detail.

After reviewing your plan, you inform the company in writing that you disagree with their decision and the reasons why. If the decision is not changed or you are still unhappy, you have the right to have your appeal reviewed by a panel of doctors or other health care professionals. If at this point you are not satisfied with the decision, you have 60 days to submit a written appeal to the Department of Health and Senior Services. You will then receive the appropriate paperwork and instructions of how to proceed.

Upon the submission of your appeal it will be reviewed by independent experts through the independent health care appeals program. If your case is considered an emergency, a decision will have to be reached within 72 hours of receipt. The time line for the appeals process is the same with all health plans. In the first stage of appeal, the company has 5 days to reach a decision after receiving your written disagreement, again only 3 days if considered an emergency. In the second stage of appeal, the panel of doctors has 20 business days for their decision.

When writing an appeal letter, be sure to include your name, policy and group number and your claim number. Most importantly include your personal reason for appealing the decision. Some other important information to include would be:

- A brief history of the illness or injury
- Any information that may be relevant to the decision
- Your explanation as to why you feel the decision is wrong
- What you would like to see as the outcome

Remember an appeal is a very time sensitive matter and you must file all appeals within several days of the decision. Be sure to carefully review your plan and benefits before you start the appeal process. Also keep in mind that, if you should lose your appeal, you will be responsible for paying the medical bills not being covered by insurance.

The Rehabilitation Team
As long as your family member is involved in the rehabilitation process, he or she will have a rehabilitation team. It is important to remember that your loved one and you are also part of the team. Members of the team could include the following: physicians who provide medical care, such as neurosurgeons, neurologists, physiatrists (rehabilitation physicians); rehabilitation nurses; physical, speech, and occupational therapists;
psychologists, neuropsychologists, neuropsychiatrists, and behavioral neurologists who address cognitive, emotional and behavioral issues; and social workers or case managers who coordinate care and discharge. Other members of the team could include a respiratory therapist, orthopedic surgeon, pulmonologist, neuro-opthalmologist, recreational therapist, and vocational rehabilitation specialist. If you are not sure who is on your family member’s rehabilitation team or what they do, you shouldn’t be afraid to ask. Ask a member of the team to explain whatever you don’t understand.

The Social Worker (or facility based Case Manager)

The social worker (case manager) acts as a liaison between the patient or their family and the rehabilitation team, and can often be the first point of contact when you have a question or concern. The social worker should be able to assist the family when they don’t understand healthcare decisions, discharge plans, insurance denials, or anything else related to their family member’s care. Although they may not be able to answer every question, they should be able to connect the family member to the appropriate rehabilitation team member to answer the question. Social workers can also help family members learn about and get connected to agencies and programs in the community that may need to be accessed in the future.

Examples of resources the social worker might connect you with include the Brain Injury Alliance of New Jersey’s Helpline, government programs such as the TBI Fund for New Jersey residents or the TBI Medicaid Waiver, rehabilitation programs, residential programs, day programs, home care, etc. Social workers are often responsible for discharge planning and ensuring a smooth transition from the hospital or rehabilitation facility to another rehabilitation facility or home.

Discharge Planning - What is it?

Discharge planning, as defined by Medicare, is meant to be “a process used to decide what a patient needs for a smooth move from one level of care to another.” Unfortunately, many families affected by brain injury would define the process of discharge planning they experienced as anything but smooth. Years ago, when brain injury rehabilitation was measured in terms of months or even years, discharge planners had the luxury of time to plan for a smooth transition from the hospital setting to the rehabilitation setting to home. Today, brain injury rehabilitation is measured in days or weeks, leaving many discharge planners little time to prepare you for the transition.

Be aware that each step of your loved one’s hospitalizations are just steps and that discharge is always the goal. When you are given facility information and asked to determine if this is the next “step”, plan to visit within the next one to two days. It is important for you to follow up on visiting other facilities promptly to minimize your feelings of being rushed.
In addition, limits and caps on insurance handicap a discharge planner’s ability to offer multiple options for delivery of the services an individual needs once they leave the hospital or rehabilitation setting.

Family members often report feeling rushed, pressured and overwhelmed by the process of discharge planning. It is not uncommon for families to contact the Brain Injury Alliance of New Jersey’s Helpline stating that their family member is being discharged that day or the next, and that they feel unprepared for the impending discharge. They are often unaware of their rights or the resources and programs available. Sometimes they are even unaware of what a discharge plan is or who the discharge planner is.

The State of New Jersey Hospital Patient Rights defines discharge planning as the right to:

- Receive information and assistance from your attending physician and other health care providers if you need to arrange for continuing health care after your discharge from the hospital.
- Receive sufficient time before discharge to arrange for continuing health care needs.
- Be informed by the hospital about any appeal process to which you are entitled by law if you disagree with the hospital’s discharge plans.

Family members need to be aware of what their rights are regarding discharge planning, and what they can do when they feel uncomfortable with the discharge plan. While only a physician can authorize a discharge, it is often a social worker, nurse, or administrator who acts as the discharge planner. Medicare also defines a discharge plan as one that is “safe and adequate”, a term that can be open to interpretation by all involved. If a family member feels that the discharge plan is not safe or adequate, the first step would be to make the discharge planner aware of this and try to work on a resolution to the problem. If no resolution is possible, the family should speak with the physician authorizing the discharge about their concerns with the discharge plan.

**The Patient Advocate**

If at this time the family still is not comfortable with the discharge plan and their family member is still at the hospital level they can request to speak with the hospital’s patient advocate. A patient advocate acts as a liaison between the patient, or their family, and the healthcare provider. The patient advocate should be able to assist the patient, or their family, regarding their concerns about discharge planning. If no resolution can be made the patient, or their family, has the right to appeal the hospital’s decision. The patient advocate may be able to assist the family with that process.
Appealing the Discharge Plan
If the patient, or their family, has tried working with the rehabilitation team regarding disagreements about the discharge plan and has had no success, they have the option to appeal that decision. The NJ Patient Bill of Rights states you have the right “to be informed by the hospital about any appeal process to which you are entitled by law if you disagree with the hospital's discharge plans” and that “to question the medical appropriateness of your discharge” you should “contact your primary care physician.”

The discharge plan will provide for a transition to another healthcare setting, which could include a subacute rehabilitation facility, a brain injury residential program, or a nursing home. The discharge plan could also include a transition to home, in which case the patient and their family need to be adequately prepared for that transition. Family members providing home care need to be trained by the rehab team.

If the patient is returning home alone and needs home care, it should be set up to begin the day the individual returns home. If home modifications or assistive devices are needed, this should also be set up before the individual returns home. The family or individual needs to let the rehabilitation team know of any reasons they are uncomfortable with the discharge to home. Some examples of areas of concern are: you may not feel physically capable of transferring your family member, or you are being told your family member needs home care but you don’t know who will pay for it or who will provide it, or you’re told you’ll need a lift to transfer your family member but you don’t know where to get it or who pays for it, or you need to return to work and your family member requires 24 hour supervision, but no one has set up in home support or a day program. Family members sometimes feel pressured by the rehabilitation program to take their loved one home before they feel ready, and it is okay to let the rehabilitation team know this.

The National Alliance for Caregiving advises that “discharge planning is a short-term plan to get your relative out of the hospital. It is not a blueprint for the future.” It will not answer every question you have going into the future, but it should provide you with a feeling of comfort and safety. For more information on discharge planning, visit the National Alliance for Caregiving website at www.caregiving.org and view or download a copy of A Family Caregiver’s Guide to Hospital Discharge Planning, or contact the Brain Injury Alliance of New Jersey’s Family Helpline at 1-800-669-4323, 732-745-0200 or info@bianj.org.

Discharge to Home
Although it will always depend on the severity of the injury and a caregiver’s ability to provide care in the home setting, at some point in rehabilitation, the rehabilitation team may begin to discuss discharge to
Home with continued therapies on an outpatient basis, including outpatient therapies, day treatment, and community re-entry. Outpatient therapies could include physical, occupational, speech or cognitive therapy, as well as continued monitoring by a neurologist, neuropsychologist, physiatrist, or neuropsychiatrist. Day treatment could include structured rehabilitation in a group setting during the day, but returning home at night. Community re-entry could include a rehabilitation program that comes into your home and provides continued rehabilitation, as well as preparation to return to independent living.

**Discharge to Residential Programs**
For those individuals who are not yet able to live independently or cannot return to live with family, a residential facility may be an option. A number of residential programs exist throughout the state that are specifically geared towards people with brain injury. Typically, residential facilities will have several different levels to provide for people requiring more assistance and therapies as well as those who are living independently and being monitored.

**Down the Road**
Discharge from an inpatient rehabilitation setting and return to home is not the end of the rehabilitation process. The post-acute phase of rehabilitation can be the most challenging for persons with brain injury, as the structure and stability of scheduled therapy sessions is exchanged for the openness and unpredictability of community life. This phase is challenging for family members as well, as they struggle to fulfill new caregiver roles, and to achieve the balance between providing adequate supervision for their loved one, and allowing them to be as independent as possible.

**In Conclusion**
Brain injury rehabilitation often begins with care at the acute and subacute level but can continue down the road with day treatment, outpatient rehabilitation, residential programming, and community re-entry programs. The Brain Injury Association of New Jersey strives to be a resource to you as you continue through the path of rehabilitation that you or your loved one is on. If you should have further questions about the rehabilitation process or resources that may be available to you and your loved one do not hesitate to contact the Alliance’s Helpline at 888-669-4023, 732-745-0200, or info@bianj.org.