Brain Injury Alliance CONNECTICUT

BIAC's Mission: Raising voices and visibility of people with brain injury and improving lives through support, education, and advocacy.

Road to Rehabilitation after Brain Injury: Your GPS for Navigating CT's Healthcare, Social Service and Disability System

Updated. 2023

Dear Individuals with a brain injury, family members, friends, and all community members,

This booklet has been developed in hopes of assisting individuals with brain injuries and their families in negotiating the CT Healthcare system. There is a great deal of information covered, which we have separated by topics, so read only what is relevant. The intent is not to bombard you with information but to provide a knowledge base from which you can advocate for your loved one. Knowledge can be a powerful ally on this journey.

If you are reading this, you or someone you love, may have recently sustained a brain injury. For the individual with the brain injury, as well as family and friends this can be a challenging time. In addition to the emotional intensity, you may be faced with a whole new world of providers, strange medical terminology, and an uncharted road to rehabilitation. It will be important to expand your circle of support, to ask for help and to accept help as there will be many unknowns while moving forward.

Every person's brain injury is different, making each ones road to rehabilitation unique, and there are people who can be a part of your network, providing you with guidance, assistance & support along the way. Since they may not be readily visible, we will note throughout this booklet the many people who can be allies for you and/or your loved one.

We wish it were as simple as a GPS or a roadmap, but getting needed medical treatment for someone with a brain injury is not always easy in CT. Enlisting support at every turn is crucial. Getting to know your legislator is paramount for improving not only the treatment for your loved one but for all those touched by brain injury in our community.

It is our hope that through education, advocacy and increasing awareness in our community and with our state representatives, that CT grows towards becoming a state that will be able to meet the needs of all residents who sustain a brain injury. There is information on contacting your legislator in the booklet.

We wish you all the best on this journey and we thank you in advance for advocating for your loved ones.

Please feel free to contact BIAC with questions, or for information at any time. BIAC looks forward to working with all of you as we create a system which can provide a continuum of care for all stages of recovery from brain injury.

All the best,

Brain Injury Alliance of CT
(860) 219-0291
www.biact.org

Please Note: This publication continues to expand and grow. Phone numbers and contact information provided in this guide may change over time. We welcome your input and feedback.

Additional Note: Certain agencies have multiple functions and are therefore listed more than one time under each topic of relevance.

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Brain Injury Alliance of Connecticut

Since 1982, the Brain Injury Alliance of Connecticut (BIAC) has been Connecticut's resource for brain injury awareness, education, resources and support. BIAC's primary objective is to support individuals with brain injuries, their families, caregivers and brain injury professionals while increasing awareness of brain injury and its prevention.

HISTORY

The Brain Injury Alliance of Connecticut (BIAC) was founded in 1981 when Charlotte Kane, the mother of a traumatic brain injury (TBI) survivor, gathered a group of caregivers around her well-worn kitchen table in Connecticut. The topic of discussion was the painful lack of resources for the brain injury survivors they knew and loved. Since its incorporation in 1982, BIAC has grown to become Connecticut's only statewide, 501(c)3 non-profit organization dedicated to providing brain injury survivors, their families and caregivers with the resources, information, and emotional support necessary as they travel the often long and difficult road of recovery. In 2012, BIAC became a founding member of a new, national organization — United States Brain Injury Alliance — that is committed to improving lives through brain injury awareness, prevention, advocacy, support, research and community engagement.

OUR MISSION

BIAC's Mission: Raising voices and visibility of people with brain injury and improving lives through support, education, and advocacy.

WHAT WE DO

The following are some of the many initiatives sponsored by BIAC in support of brain injury survivors, their families, caregivers, professionals and the community:

- **Individual Consultation & Resources**
  Brain injury specialists provide support and resources for more than 4,000 inquiries from survivors, caregivers and professionals each year to ensure that the often complex and overwhelming challenges they face are negotiated more easily and effectively. Contacts are made through BIAC's toll-free HelpLine, email, social media and individual in-person consultations.
- **Brain Injury Navigator**
  A fee-based service that provides customized, in-depth and personal direction from an expert in brain injury, helping those impacted by brain injury find their way back to a life that brings meaning and joy, and the triumph of moving forward.
- **Outreach & Education**
  Through its Prevention & Education Programs, BIAC works to increase awareness and understanding of brain injury and its prevention through school, professional and community presentations. BIAC's Annual Conference is Connecticut's premiere brain injury education program, drawing more than 275 professionals each year to learn the latest developments in the field.
- **Support Groups & Social Events**
  BIAC sponsors numerous support groups throughout Connecticut that provide information, support and encouragement to survivors, their loved ones and caregivers, while offering social events and opportunities such as picnics and our Spring Social.
- **Legislative Advocacy**
  BIAC advocates for legislation to improve the quality of life for people living with brain injuries while supporting initiatives that help to prevent brain injuries from occurring.

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What is Brain Injury?

The brain controls everything we say, do, think, and feel. It controls the very functions that keep us alive: breathing, circulation, digestion, hormones, and the immune system. It is through the brain that we experience emotion and express ourselves.

"Weighing less than sixteen hundred grams (three pounds) the human brain in its natural state resembles nothing so much as a soft, wrinkled walnut. Yet despite this inauspicious appearance, the human brain can store more information than all the libraries in the world. It is also responsible for our most primitive urges, our loftiest ideals, the way we think, even the reason why, on some occasions, we sometimes don't think, but act instead." - From The Brain by Richard Restak, M.D.

Definitions and Causes
Brain injury refers to an injury in which an insult to the brain causes damage to the brain. Just as every individual is unique, every brain injury is unique, and no two injuries are ever the same. Brain injuries are often described as either traumatic or acquired based on the cause of the injury.

Traumatic brain injury (TBI) is an insult to the brain which is caused by an external physical force that may produce a diminished or altered state of consciousness, and which results in an impairment of cognitive abilities or physical functioning. It can also result in the disturbance of behavioral or emotional functioning. Traumatic brain injuries occur during everyday activities, including: falls, motor vehicle crashes, assaults, and sports injuries, including concussions.

Acquired brain injury (ABI) is an injury to the brain that is not inherited, congenital, or degenerative. Acquired brain injuries are caused by some medical conditions, including strokes, encephalitis, aneurysms, anoxia (lack of oxygen during surgery, drug overdose, or near drowning), metabolic disorders, meningitis, or brain tumors. Although the causes of brain injury differ, the effects of these injuries on a person's life are quite similar.

Results of a brain injury
Whatever the cause, a brain injury can result in an impairment of cognitive abilities and physical functioning. It can also result in the disturbance of behavioral or emotional functioning. Cognitive consequences may include memory loss, slowed ability to process information, trouble concentrating, organizational problems, poor judgment and difficulty initiating activities. Physical consequences can include seizures, muscle spasticity, fatigue, headaches, and balance problems. Emotional and behavioral consequences can include depression, mood swings, anxiety, impulsivity, and agitation. Brain injury affects not only the individual but also the family, close friends, co-workers, and other social networks of the individual. Roles and relationships change. The financial ramifications may be extensive.

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The silent epidemic

Brain injury has been called the “silent epidemic” because public recognition of brain injury is extremely low despite the staggering number of people who are injured each year. The effects of brain injury are often invisible to an unknowing observer. Likewise, the visible effects of brain injury—such as physical impairment, behavioral issues, and even cognitive deficits—are often not properly attributed to brain injury. Over 2.8 million people in the United States sustain traumatic brain injuries each year but only one sixth of them are admitted to hospitals. This number does not include people with acquired brain injuries. The annual incidence of TBI alone is higher than that of breast cancer, multiple sclerosis, spinal cord injury, and HIV/AIDS combined.

TBI in the United States

According to the Centers for Disease Control and Prevention(2014):

- 2.8 million Americans sustain a traumatic brain injury every year.
- From 2006 to 2014, the number of TBI-related emergency department visits, hospitalizations, and deaths increased by 53%.
- More than 56,000 people die every year as a result of TBI.

For additional national statistics, visit the CDC website: http://www.cdc.gov/ncipc/tbi/TBI.htm

TBI in Connecticut

According to the Connecticut Department of Public Health 2010 State Health Improvement Plan:

- Between 2008 and 2014, traumatic brain injury has increased by 61% in Connecticut, and the average number of ED visits between 2008 and 2014 was 32,668.
- In 2014 there were 2,708 hospitalizations related to traumatic brain injury.
- Considerable numbers of TBIs result from sports-related injuries and from falls among the elderly. In addition, the number of TBI cases in some communities has resulted from veterans returning from overseas combat.

For additional state statistics, visit the Connecticut Department of Public Health website:

- https://portal.ct.gov/en/DPH/State-Health-Planning/Healthy-Connecticut/Healthy-Connecticut-2020-Performance-Dashboard, and choose Traumatic Brain Injury from the list

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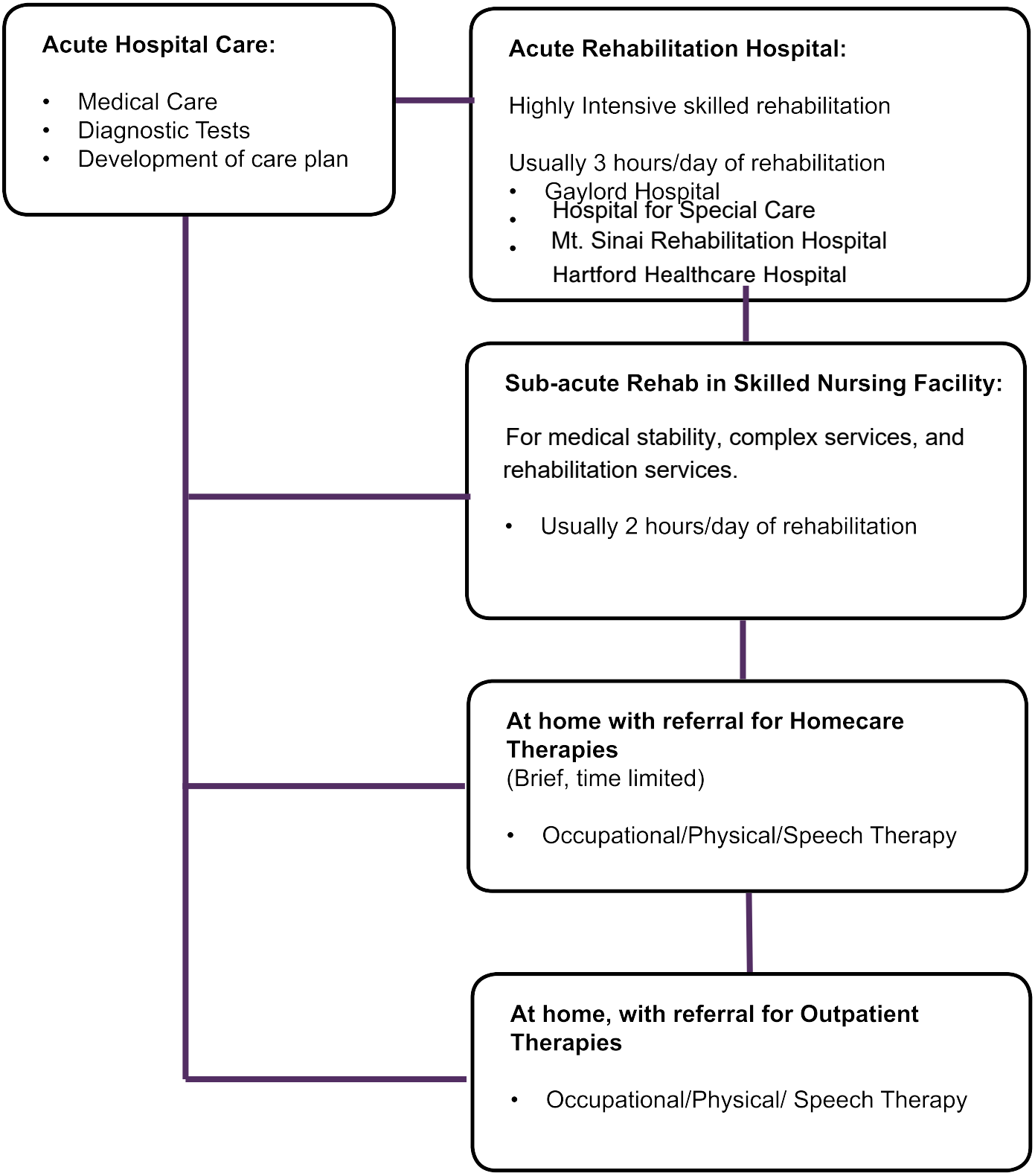
Levels of Care Following Brain Injury

The following represents what the Levels of Care may look like for someone following a brain injury. However, some individuals may not follow this continuum, depending upon their individual circumstances.



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What is Brain Injury Rehabilitation?

Inpatient rehabilitation is designed to help improve functioning after a moderate to severe brain injury and is usually provided by a team of people including physicians, nurses and other specialized therapists and medical professionals (see glossary for rehab team member descriptions).

Rehabilitation Basics

- The brain begins to heal once the individual's condition is stabilized.
- Injured — but not dead — brain cells or neurons can repair themselves.
- The brain rewires itself, growing new pathways among the billions of still-healthy
- neurons.
- Through a process called plasticity, healthy portions of the brain assume some of the functions previously performed by the injured areas.

This spontaneous recovery is not sufficient, though, to enable a patient to reach his/her full post-injury potential. For the best possible outcome, your loved one should participate in a specialized rehabilitation program.

Common Problems addressed:

- Thinking problems – difficulty with memory, language, concentration, judgment and
- problem solving.
- Physical problems – loss of strength, coordination, movement and swallowing.
- Sensory problems – changes in sense of smell, vision, hearing and tactile touch.
- Emotional problems – mood changes, impulsiveness and irritability.

Who is eligible to receive inpatient rehabilitation? You may be eligible if…

- You have a new brain injury that prevents you from returning home to your family's care.
- Your medical condition is stable enough to allow participation in therapies.
- You are able to make progress in therapies.
- You have a social support system that will allow you to return home or to another community care setting after reasonable improvement of function.
- You have insurance or other ways to cover the costs of treatment.

Cognitive Rehabilitation (CR)

CR refers to therapy programs which aid persons in the management of specific problems in perception, memory, thinking and problem solving.

Cognitive rehabilitation may be performed by a neuropsychologist, or a speech or occupational therapist though most frequently the speech therapist provides this service. It can be done in inpatient and outpatient settings.

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Cognitive rehabilitation is therapy to improve cognitive skills and has two main approaches: **Relearning and Compensating.** Much of what a survivor has learned in his/her lifetime is still present in the brain after the trauma. Severed connections block access to this information and the patient can't recall how to perform many activities. Through directed training and persistent practice, rehab re-programs the brain, establishing new connections among these still-present pockets of information, enabling the patient to reacquire forgotten skills.

For areas that are not amenable to retraining, one can be taught the use of compensatory skills. For example, a person with a diminished memory is taught to keep a detailed, daily schedule to assist in keeping appointments.

At other times, compensation means using assistive devices, such as a watch alarm to remind the survivor to check his/her daily schedule, or to get ready to go to the movies.

Important Note: Whatever facility you stay in, request that they share with you patient education materials on brain injury.

What happens if I do not agree with the Transition Plan?
There may not always be agreement on when it is time to transition to the next level of care or even what the next level of care should be. After leaving the acute hospital setting someone may go:

- To an acute care rehabilitation
- To a sub-acute rehabilitation in a skilled nursing facility (SNF)
- Home, with referral for homecare
- Home, with referral for outpatient rehabilitation

The family members, the physicians, the insurance company and the individual with the brain injury may not all be on the same page. If the insurance company is the only one who thinks your loved one is ready to transition, or there is disagreement about the appropriate level of care, contact the **Office of the Healthcare Advocate**. The Office of the Healthcare Advocate can provide Connecticut consumers with free information and assistance on understanding rights and effectively resolving managed care problems or situations.

- **Office of the Healthcare Advocate**
  450 Capitol Ave., 2nd floor Hartford CT, 06106
  Phone: 1-866-HMO (466)-4446
  E-mail: Healthcare.advocate@ct.gov
  Website: http://www.ct.gov/oha

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Where can I find in-patient rehabilitation in Connecticut?

Inpatient rehabilitation can be found at an acute care rehabilitation hospital or at the Sub-acute level, it can be found in a Skilled Nursing Facility (SNF).

What is Acute Inpatient Rehabilitation?
An inpatient rehabilitation program that utilizes an inter-disciplinary coordinated team approach that involves about three (3) hours of rehabilitation services daily. These services may include physical therapy, occupational therapy, speech therapy, cognitive therapy, or a combination thereof.

Where can I find Acute Care Rehabilitation?
The 4 acute care rehabilitation hospitals in Connecticut with programs for someone in recovery from a brain injury are:

Gaylord Hospital
50 Gaylord Farm Road, Wallingford
www.gaylord.org

- Inpatient Admissions: 203-284-2810, includes Early Recovery Program
- Brain Injury Residential Program: 203-741-3488, This is the only transitional living program in the state of CT for people with brain injuries. See the Appendix for more info.
- Outpatient, Cognitive Therapy Program, Aphasia Therapy Program: 203-284-2818

Hospital for Special Care (HSC)
2150 Corbin Ave, New Britain
www.hfsc.org

- Inpatient Admissions 860-827-4841 or 800-220-7723
- Neurobehavioral Program (NBP) 860-827-4715
- Outpatient Rehabilitation Center: 860-832-6258
- HSC Outpatient Department of Psychology: Clinical Neuropsychology & Rehabilitation Psychology : 860-827-4751

Mt. Sinai Rehab Hospital of CT (St Francis Medical Group)
490 Blue Hills Ave, Hartford
https://www.trinityhealthofne.org/location/mount-sinai-rehabilitation-hospital-1

- Inpatient Admissions: 860-714-3500
- Day Treatment: 860-714-2210
- Outpatient Physical Medicine & Rehab (Physiatry): 860-714-2647
- Outpatient therapies: 860-714-3437 (ask about additional sites)

Hartford Healthcare Hospital
80 Seymour Street, Hartford, CT 06106
https://hartfordhospital.org/services/physical-rehabilitation
Admissions: 860-972-0990
Main Number: 860-545-5000
Pre-Registration: 860-972-2115

What is Sub-acute Rehabilitation?

Sub-acute Rehabilitation in a Skilled Nursing Facility (SNF)
This level of care plan may be appropriate for people who are not yet ready to return home and who would benefit from continuing their rehabilitation therapies in a structured environment. Sub-acute care is generally more intensive than traditional nursing facility care and less intensive than acute care. The nursing facility can provide nursing care and ongoing rehabilitation, (usually about 2 hours a day) therapy in specialized rehabilitation wings (Sub-acute rehabilitation), usually for up to three months. A licensed physician supervises each patient's care and a nurse or other medical professional is almost always on the premises.

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Custodial Care in a Skilled Nursing Facility (not considered rehabilitation)
Non-skilled personal care, such as help with activities of daily living like bathing, dressing, eating, getting in or out of a bed or chair, moving around, and using the bathroom. Custodial care does not require the skills of a trained professional or supervision of a physician. In most cases, this level of care is not covered unless someone is on Medicaid or has purchased special long term health care insurance.

Out of State Placements
Given the lack of expertise in brain injury at some levels of care, some people have inquired about out of state options. It would be important to check with your insurance provider to see what type of coverage you have for out of state services and also if there is a network of approved out of stateproviders.

If someone is on **Husky Health** (also known as Medicaid or Title 19), the individual would have to be denied admission to CT's skilled nursing facilities (SNF) in order to be considered for an out of state placement. There would need to be evidence that a service is needed that CT does not offerand that it is medically necessary. There are a limited number of out of state facilities that CT has a contract with. For additional information about this process, have the Hospital Social Worker contact the Department of Social Services.

To research out of state facilities with expertise in brain injury it would be good to start by contacting the brain injury affiliate in the state you are looking in. Below is information for some of our surrounding states. (If you are on Medicaid, the facility must have a contract with CT).

- **BIA of New Hampshire**, Phone: 602-225-8400, E-mail: mail@bianh.org, Website: www.bianh. org

- **BIA of New Jersey**, Phone: 732-745-0200, E-mail: info@bianj.org, Website: www.bianj.org

- **BIA of Massachusetts**, Phone: 508-475-0039, E-mail: biama@biama.org , Website: www. biama.org

- **BIA of New York State**, Phone: 518-459-7911, E-mail: info@bianys.org, Website: www.bianys. org

- **BIA of Rhode Island**, Phone: 401-228-3319, Website: www.biari.org

Where can I find Sub-Acute Rehabilitation in Connecticut?
In terms of Sub-acute rehabilitation in Connecticut, there are no specialized programs that we are aware of currently for rehabilitation of people with traumatic brain injury. That will hopefully change movingforward. In our experience, if someone sustaineda brain injury as a resultof a stroke, the skillednursing facilities are more open to workingwith thistype of braininjury and may advertise Stroke Rehabilitationas a service.

Advocating for your loved one throughout the rehabilitation process ways to advocate for your loved ones to ensure needs are met in any facility.

- Ask Questions. Be direct.

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- Let your rehab team know you are in contact with the Brain Injury Alliance of CT. We can provide information on brain injury through literature or in person through our Education and Outreach Program. Call 860-219-0291.

- Be vigilant. Visit often. This can have a positive impact on staff interactions with your loved one.

- Be sure the attending physician and therapists document even the slightest progress in your loved one's condition. In these days of managed care, there is great pressure to demonstrate measurable improvement at a steady pace or risk having insurance coverage denied.

- If your loved one is not getting the care he/she needs, keep detailed notes to support your concern. Be vocal about concerns and address issues as they arise.

- Many issues can be resolved with improved communication. In addition, know what the grievance procedure is at your facility.

- Document, Document, Document. This is important in terms of identifying what is helpful, what is not helpful, who is responsible for what, and in what time frame. This information can be used to advocate for your loved one in their care planning and also for legislative advocacy.

How do I choose a Skilled Nursing Facility?

- **Contact the Brain Injury Alliance of Connecticut's Helpline.** BIAC is an independent, non-profit organization dedicated to supporting individuals with brain injuries, their families, and caregivers while increasing awareness of brain injury and its prevention. Through BIAC's HelpLine, 1-860-219- 0291 or 800-278-8242 or general@biact.org, brain injury specialists provide individual support and guidance to survivors and caregivers to ensure that the often complex and overwhelming challenges they face are negotiated more easily and effectively. BIAC is located at 200 Day Hill Rd, Suite 250, Windsor, CT 06095. Visit their website at www.biact.org.

- **Ask for referrals**. Does your family physician or specialist have any recommendations? Ask your doctor if he or she provides care at any local nursing homes. If so, ask which nursing homes he or she visits so you may continue to see your doctor while you're in the nursing home? Do you know any friends or families who have used different homes? Knowing someone with first-hand experience with a home can help you narrow your choices.

- **Use Nursing Home Compare** on the Medicare web site to find an information summary for a specific facility, http://www.medicare.gov/NHCompare,or call 1- 800- MEDICARE (1-800- 633-4227) to ask that a printed copy of Nursing Home Comparison be mailed to you (includes comparison of quality ratings, health inspection results, nursing home staff data). If you need help understanding the data, call the division of health systems regulation at your state department of public health (in CT, call 1-860-509-7400) and ask for a nurse consultant for assistance.

- **Contact the Long Term Care Ombudsman Program (LTCOP)** through the State of CT, www.ct.gov/LTCOP. They can discuss general information about nursing homes and nursing home care. LTCOP can help you compare a nursing home's strengths and weaknesses.

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LTCOP can answer questions, such as how many complaints they have gotten about a specific nursing home, what kind of complaints they were, and if the issues were resolved in a timely manner. LTCOP Ombudsman has volunteers who visit nursing facilities regularly and are familiar with their strengths and weaknesses. An ombudsman cannot recommend a nursing facility, but can provide the results of the latest state inspection and information about the facility's complaint history. Statewide call toll free 1-866- 388-1888 or 860-424-5200.

- **Contact your local Aging & Disability Resource Center (ADRC)**. ADRCs, also called 'Community Choices' offers a range of information about long-term care community supports, from a simple name and phone number to detailed help concerning community services, policies and procedures, and assistance with completing benefits applications. Contact Community Choices by calling 1-800-994-9422.

- **Review Nursing Home Facilities Licensed by the State of Connecticut** published by the Department of Public Health (DPH). It can be viewed online at the link below or call (860) 509- 7400 and request a hard copy. Please note 2011-2012 is the latest version on the DPH website. https://portal.ct.gov/-/media/Departments-and-Agencies/DPH/dph/facility_licensing_and_investigations/pdf/nursinghomebookpdf.pdf?la=en.

- **Call Infoline by dialing 2-1-1 or search the online database at www.211CT.org.** Provides contact information only, no comparison feature.

How do I select a Facility and decide what would be the best match
Plan to make visits, ask for the admissions coordinator when calling to schedule a visit, and ask many questions.

Below are suggested questions to ask on your visit.

Basics – Are these all part of the facility's program?

- **Evaluation and assessment** of the patient's unique physical, cognitive, communication, emotional, behavioral, and social impairments.

- **Physical therapy** to regain mobility, strength, balance, coordination, and endurance.

- **Occupational therapy** to relearn self-care and daily living skills.

- **Speech and language therapy** to treat communication and swallowing disorders.

- **Cognitive rehabilitation:** Treat challenges with concentration, memory, problem-solving, planning, and decision-making.

- **Neuropsychology or rehabilitation psychology** to help the individual with the brain injury accept the consequences of his/her injury and to treat any emotional and behavioral problems (in a SNF, there usually is not an onsite neuropsychologist. Ask who handles emotionaland behavioral issues).

- **Recreational therapy** to relearn leisure skills and, maybe, develop new interests.

- **Access to other specialists**, such as neurologists, orthopedists, physiatrists,

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neuropsychologists and pain management doctors, to provide treatment for other problems. Ask how it is determined if a consultation is needed with a specialist.

What to look for in staff:

- **Staffing.** How many nurses are on permanent staff and how many come from agencies that supply temporary nursing staff? The majority of nurses at the facility should be staff members who are familiar with residents' ongoing care needs. To find the ratio of staff to residents at each facility, visit Medicare Nursing Home Compare on the official government web site for Medicare patients.

- **Physician affiliation.** State and federal guidelines require all skilled nursing facility residents to be under the care of a physician so that their plan of care and medications can be evaluated at least every 30 days. Is your physician affiliated with the facility so that he or she can continue to follow your care after you move there? Does the facility have a physician who cares for many of the patients? Does the physician monitor medication on a more frequent basis when changes need to be made?

What to look for in current residents and their families:

- Are residents clean, dressed and active?

- Do the residents appear happy, engaged or excessively groggy and overmedicated?

- Try to observe social gatherings such as meals or other activities. If needed, are residents getting timely help to eat, and with getting to and from the gathering areas?

- If you see a family visiting, ask them their impressions of the home and how their loved one has been treated. Ask if there is a family council and if you could attend. A Family council is a group of family members who meet regularly to discuss issues of concern and generally act as "patient advocates."

What to look for in a facility:

- Does the facility have a separate dedicated Sub-acute unit?

- Has the facility provided treatment for people with brain injuries?

- Does the facility appear clean and odor free?

- Openness: Do you feel welcome observing activities, walking around, and asking questions?

- Is there a home orientation suite, which enables the patient to practice skills in a home setting?

- Visit the facilities that interest you or ask a trusted friend or family member to do it for you. Make unscheduled visits at different times to observe as many interactions as possible.

Admission/Availability

- Is a bed available and if not, how long before one becomes available?

- Can you add your name to a waiting list?

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Note: Nursing homes don't have to accept all applicants, but they must comply with local, state, and federal civil rights laws that prohibit discrimination. If someone is denied admission, you can ask the reason. Sometimes it is a funding issue and other times it may be related to medical issues. However, a person can not be denied admission to a skilled nursing facility simply because they have the diagnosis of brain injury.

Communication

- If you are making arrangements for a family member, how often will staff contact you with an update on his or her condition?

- Can the individual still see their personal doctor?
- Who will help them arrange transportation if they choose to continue to see personal doctors and they don't visit the nursing home?
- Are they open to collaborating with professionals who may have expertise in this area?
- Will they coordinate with the program or service the person is transitioning from in order to facilitate a smooth admission and transition?
- Is senior management and treating staff readily available for consultation or to answer your questions?
- Does the program regularly obtain medical consultation for client health issues?
- Are the progress reports, charts, medical records and therapy documentation accessible upon request?
- Does the program directly employ staff rather than use contract therapy and medical staff?

Rehabilitation

- Do you have a fully equipped Rehabilitation Department? How many days of the week is it available?
- Does the program provide a daily schedule? What role do patients have in directing the schedule and selecting the program components?
- What types of professionals will make up my interdisciplinary rehabilitationcare team?
- Does your staff have experience working with individuals who have acquired brain injuries?
- Do you offer cognitive retraining? Who provides the service?
- What approaches are used to treat cognitive deficits?
- Is neuropsychological testing used to determine the patient's core cognitive problems (this would be done typically on an outpatient basis as there are not usually neuropsychologists in the SNF's)?

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- If neuropsychological testing is not performed, how are cognitive problems diagnosed (a neuropsychological evaluation does not happen immediately post injury, as the brain is given time to heal to get more accurate test results)?

- How are the results of these assessments used?

Addressing Behavioral Problems

- How does the program treat behavioral concerns?

- What is the role of medication in addressing behavioral concerns? Who determines the medication? Does this person have a background in brain injury? If not, will the facility make use of consultation services?

- How does staff handle behavioral problems such as agitation, or wandering?

- What types of interventions have been used successfully by this facility when working with other individuals with brain injury?

- How will the family, medical team and individual work together on behavioral concerns?

Daily Living

- What are the rights and responsibilities of the patient?

- Is therapy available on Saturday and Sunday?

- What do residents do in the evening and on weekends?

- How does the program accommodate special diets and personal food preferences?

- What kind of help is available with meals, and do meals have to be eaten at the same time every day or in a common area?

- Activities: What quality of life activities are available for residents? Are outside activities arranged as well, health permitting?

- Is outside food permitted to be brought to a loved one?

- What do people generally do during unscheduled times?

- Does the nursing facility provide interesting daily activities for residents to engage in?

- Can you provide a sample activities schedule?

- Are religious services included?

Care Plan

A comprehensive health assessment must be completed within 14 days of admission. You should expect to get a health assessment at least every 90 days after your first review, and possibly more often if your medical status changes.

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The Physician will:

- Evaluate your physical abilities, along with your thinking and behavior.
- Prescribe medication as necessary to manage mood, sleep, pain and nutrition.
- Prescribe tailored therapy orders for physical therapy, occupational therapy and speech therapy.
- Determine how often you need these services.

The nursing home staff will get your health information and review your health condition to prepare your care plan. You (if you're able), your family (with your permission), or someone acting on your behalf has the right to take part in planning your care with the nursing home staff.

Your care plan is very important. A good care plan can help make sure that you're getting the care you need. Your health assessment (a review of your health condition) begins on the day you're admitted.

- Who makes the plan of care and how do they know what I want, need, or what should be in the plan?
- Will I be included in planning my care?
- Will my interests and preferences be included in the care plan?
- Who will be able to change the plan if there is a need?
- Will I be able to choose which of my family members or friends will be involved in the planning process?
- Will I get a copy of my care plan?

Family Education & The Role of the Family

- What role do family and friends play in the program?
- Is the family welcome to regularly attend therapy sessions?
- What is the visitation policy? Can a family member sleep in the survivor's room?
- Are family members and friends involved in team meetings? How frequently? If you live far away, how much telephone contact will there be with the patient and the medical staff?
- What kind of family training and support is offered?
- How does the program handle medical emergencies? How are the caregivers notified and in what time frame?
- How is a person's ability to get around and to use community services and resources evaluated and addressed?
- What local resources are used by the program to address the needs of the individual?

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Discharge Planning

- Ask about and discuss the discharge process early on in your stay, since the time in inpatient rehabilitation can be short.
- How is the length of stay determined? Who decides when inpatient rehab ends?
- How is this decision made? What role does the survivor and family have in these decisions?
- Does the staff teach the family how to continue rehab at home?
- How is the patient prepared for going home?
- Will therapists visit the home and offer an assessment of how to prepare for the special needs of the person with a brain injury?
- Will a survivor be allowed home visits before he/she completes the program? What if I need more help than my family can provide for me?

Rights and Protections
You have the right to make a complaint to the staff of the nursing home or any other person without fear of being punished. The nursing home must address the issue promptly.

Get Proper Medical Care:
You have the following rights regarding your medical care:

- To be fully informed about your total health status in a language you understand.
- To be fully informed about your medical condition, prescription and over-the-counter drugs, vitamins, and supplements.
- To be involved in the choice of your doctor.
- To participate in the decisions that affect your care.
- To take part in developing your care plan. By law, nursing homes must develop a care plan for each resident. You have the right to take part in this process. Family members can also help with your care plan with your permission.
- To access all your records and reports, including clinical records (medical records and reports) promptly during weekdays. Your legal guardian has the right to look at all your medical records and make important decisions on your behalf.
- To express any complaints (also called “grievances”) you have about your care or treatment.

Grievances
The Medicare and/or Medicaid-certified nursing home must have a grievance procedure for complaints. If your problem isn’t resolved, follow the facility’s grievance procedure. You may also want to bring the problem to the resident or family council.

If you have a problem at the nursing home, talk to the staff involved. For example, if you have a

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problem with your care, talk to the nurse or Certified Nurse Assistant (CNA). The staff may not know there is a problem unless you tell them. If the problem isn't resolved, ask to talk with the supervisor, social worker, director of nursing, administrator, or your doctor.

Ask what the facility's grievance procedure is ahead of time. Ask if it has a family council and how does one get involved?

Internal Grievance Process at a Skilled Nursing Facility

Be direct. Communicate with staff about concerns. Follow the internal grievance procedure at the facility (keep a log of issues identified, what the follow up was).

Reporting a Grievance to the Long Term Care Ombudsman Program (LTCOP)

The Long Term Care Ombudsman Program (LTCOP) responds to and investigates complaints brought forward by residents, family members, and/or other individuals acting on their behalf. Ombudsmen offer information on consultation to consumers and providers, monitor state and federal laws and regulations, and make recommendations for improvement. The program also recruits, trains, and supervises Volunteer Resident Advocates who assist residents in resolving resident complaints. These Advocates can work with you and your nursing home to solve problems, including financial issues.

To contact the Ombudsman's office call the statewide toll free number **1-866-388-1888** or contact Central Office by calling **860-424-5200**
E-mail: ltcop@ct.gov Website: www.ct.gov/ltcop

Southern Region Intake:	860-823-3366
Northern Region Intake:	860-424-5221
Western Region Intake:	203-597-4181

Reporting a Grievance to the Connecticut Department of Public Health

Consumers and their families may file complaints about health care facilities with the Connecticut Department of Public Health. (DPH)
https://portal.ct.gov/DPH/Practitioner-Licensing--Investigations/PLIS/Reporting-a-Complaint
Send written documents to:
Facility Licensing and Investigations Section Connecticut Department of Public Health
410 Capitol Ave., MS# 12 HSR, Hartford, CT 06134-0308
Phone: 860-509-7400
Fax: 860-509-7538

Additional options:

- Call **Community Choices** 1-800-994-9422 if you…
  - Don't know where to go for help
  - Have a complaint about services
  - Have been denied benefits or services for which you feel you are eligible
  - Need information and/or assistance about community resources, options counseling, referrals for employment assistance, referrals for care management, or planning for the future.

- Call **Disability Rights Connecticut (DRCT)** at 860-297-4300 or 800-842-7303
  - DRCT was established to advocate for the civil and human rights of people with disabilities in Connecticut. DRCT advocates for people with all types of disabilities and of all ages

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within the mandates and requirements established by federal statutory mandates. DRCT responds to all requests for Information and Referral, regardless of disability.

- **Additional options cont.:**
  - Attend a Family Council Meeting at the facility
  - Some nursing facilities have very active family councils—groups of family members who meet regularly to discuss issues of concern and generally act as "patient advocates." Members can be informative and reassuring to someone just entering the decision-making process. Ask if a family council meets at the facility that interests you and if you can attend a meeting.

Your Rights in a Skilled Nursing Facility
Long Term Care Ombudsman Program - Rights as a Resident of a Skilled Nursing Facility/ Long Term Care Facility

You have the right to:
- Be treated with respect and dignity.
- Participate in making decisions about your care, and about aspects of your life in the nursing home that are significant to you.
- Be free from chemical and physical restraints.
- Manage your own finances or receive help from the nursing home to manage them.
- Voice grievances without fear of retaliation.
- Associate and communicate privately with any person of your choice.
- Send and receive personal mail.
- Have your personal and medical records kept confidential.
- Apply for state and federal financial assistance without threats or discrimination.
- Be fully informed prior to admission of your rights, services available, and any charges.
- Be given advanced notice and the right to appeal a transfer or discharge.

Taken from: www.ct.gov/ltcop

Using Care Planning to Resolve Problems
Long term care residents have the right to make choices about care, services, daily schedule and activities, and to be involved in the planning of their care.

An effective care plan should:
- Be specific, individualized and written in language that everyone can understand.
- Reflect the resident's concerns, and support her/his wellbeing, functioning and rights.
- Use a multi-disciplinary team approach and utilize outside referrals if needed.
- Be re-evaluated and revised routinely.

Here are some ways in which residents and their family members can be more involved in the care planning process:

Residents:
- Before the care plan meeting think about your questions, concerns and expectations. Ask your doctor or the staff about your condition, care and treatment. Ask the staff to hold the meeting when your family can attend, if you want them there.
- During the meeting ask about different options for treatments. Be sure that medical terms and procedures are explained fully to you. Ask for a copy of the care plan and find out who to talk to if you want to change it.

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- After the meeting, be sure that your care plan is being followed, and let staff know if it is not.

Families:

- Support your relative's agenda, choices and participation in the meeting.
- Involve your relative as much as possible in care planning even if s/he has
- cognitive or communication problems. Always assume that s/he may understand and be able to communicate at some level.
- Share with staff the ways you have learned to communicate with your relative and what preferences s/he may have that are not being communicated otherwise.
- Observe how the care plan is being followed.
- Work with staff to make changes if problems arise.

Beware of care plans that:

- Incorrectly label behaviors as problems.
- Are driven by staff problems not resident's problems.
- Have goals and objectives that are too broad or not individualized.
- Do not reflect the resident's concerns and preferences.
- Do not have the resident's agreement.
- Do not address needs identified in the assessment.
- Are outdated or neverchange.
- Contain conflicting goals from different disciplines.
- Are difficult to understand.

Participating in a care plan conference can be helpful when:

- Residents and families need information.
- Residents or family members have concerns about delivery of services.
- Several people need to be present to resolve a problem.
- The facility's complaint process has failed.
- The facility is not following an established plan of care.
- The resident receives a discharge notice.

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Are there any transitional living program available prior to going home?

There is only 1 Transitional Living Center in all of Connecticut. The Louis D. Traurig House, http://www.gaylord.org /Our-Programs/Stroke/Stroke-Residential-Program, is the only transitional living center for people with acquired brain injury in Connecticut. Located in Wallingford on the campus of Gaylord Hospital, Traurig House is an 8-bed, co-ed facility with an average length of stay of 4-6 weeks. Traurig House provides the necessary transition to ease the individual from hospital to home.

Who is eligible for admission?

Individuals, as young as 14 or older, who have experienced an acquired brain injury and have completed any necessary inpatient rehabilitation program will be considered for the program. The following guidelines are used in considering someone for admission. A person should:

To be considered for the Brain Injury Residential Program, you should …

- Have been diagnosed with an acquired brain injury (traumatic brain injury, stroke, aneurysm, or other neurological diagnosis) and be medically stable
- Have the ability to communicate your basic needs (using verbal expression, written communication, gesturing, a communication device, or some other means)
- Be ambulatory (or be able to maneuver a wheelchair as a primary means of mobility) at the time of your transition (transfers or ambulation should be executed with minimal or no assistance from staff)
- Have no current substance abuse issues (a prior history of chemical dependency will require education and support programs to address your issues)
- Have the financial resources to pay for the program (through health care insurance or other means)
- Be able to benefit from a structured environment (to maximize your independence and work towards a specific discharge plan)

Participants will work toward: Acquiring the basic skills of independent living; Regaining the necessary skills for reentering the community; and Maximizing their mobility, communication and thinking skills.

What services do residents receive? Cognitive retraining; Psychotherapy; Community activities; Communication skills; Independent living skills; A full range of therapies including psychology, occupational therapy, physical therapy, speech and language therapy, and recreational therapy; and Social work and case management.

Does insurance pay for this? Discuss your particular insurance coverage with your care coordinator to determine if you are eligible.

Who do I contact for more information? Call the Care Coordinator of Traurig House at: 203-741-3488 or (203) 284-2773.

Taken from Gaylord brochures and website www.gaylord.org

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What about medical, food and cash assistance? Department of Social Services and Social Security Administration?

Medical, food and cash assistance:

- **Department of Social Services (DSS):**

To see if you qualify to receive medical benefits, help buying food, and/or cash assistance visit ConneCT: https://connect.ct.gov/access/accessLogout?fwlat=1382490866023 or call the DSS Client information Line and Benefits Center at 1-855-626-6632 (1-855-6-CONNECT).

Question: I have a disability. Can I receive special help when I apply for benefits?

Answer: You may, at any time, come into one of the 12 DSS regional offices and request special assistance in order to apply for benefits. You can also ask a family member or friend to apply on your behalf. The Department of Social Services is required to give a 'reasonable accommodation' in order to make it easier for an individual with a disability to access DSS programs. If you ask, they can help you fill out forms, tell you what the letters they send mean, assist you in obtaining documentation. If you cannot come into the office to complete your application, DSS can do your interview over the telephone or they can visit you at your home. To reach the ADA Coordinator, and request an accommodation, call 860-424-5040.

- **What about benefits through the Social Security Administration?**

The Social Security and Supplemental Security Income disability programs are Federal programs that provide assistance to people with disabilities.

Social Security Disability Insurance (SSDI) pays benefits to those who are unable to work for a year or more because of their disability and are "insured," meaning that you worked long enough and paid Social Security taxes. Medicare is available to those receiving SSDI benefits after 24 months.

Supplemental Security Income (SSI) pays benefits to individuals who are unable to work for a year or more because of a medical condition and who also have limited income and resources.

When can I apply?

Applying for benefits is a lengthy process. The course of recovery from a brain injury is often unknown. If it appears an individual will be out for a year or more because of the disability then start the application process and simply discontinue it if the individual has a faster rate of recovery.

- Complete your application online. You can visit http://www.ssa.gov/applyfordisability/ . There are Disability Starter kits online that can take you through the process.
- Call the toll-free telephone number 1-800-772-1213.
- Call or visit your local Social Security office. Find your local office by visiting https://secure.ssa.gov/ICON/main.jsp.

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Additional information about medical coverage:

- **Access Health CT:** CT's official health insurance marketplace. Enroll online at https://www.accesshealthct.com or call 855-805- 4325. Ask about Enrollment Centers and In-Person help.
- **HUSKY Health:** HUSKY Health offers coverage to eligible children, parents, relative caregivers, elders, individuals with disabilities, adults without minor children, and pregnant women. For information about eligibility guidelines and applying call 1-877-CT-HUSKY (1-877-284-8759) or visit online https://portal.ct.gov/HUSKY.

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What about community living? Are there Home and Community Based Services Available?

Community Living:

1. If you are in a facility speak to the **Social Worker/Discharge Planner** to discuss options for benefits, long term care, and community living options.

2. **My Place CT** is a website, www.myplacect.org that provides information about finding and affordingcare and support, finding housing and transportation, and letting you know what your health care options are. Email: info@myplacect.org or call dial 2-1-1.

3. Call **Community Choices-Aging and Disability Resource Centers** at 1-800-944-9422 to learn about additional community living options.

- **Acquired Brain Injury (ABI) Waiver Program**
  A Medicaid Waiver program that employs the principles of person-centered planning to provide a range of non-medical, home and community based services, to adults who have an acquired brain injury (not a developmental or degenerative disorder) in the community.

  Eligibility criteria include:
  - Without these services, the adult would otherwise require placement in an institutional setting.
  - Person must require assistance with at least 2 activities of daily living (dressing, bathing, eating,toileting, transfers).
  - Adults must be age 18-64 to apply.
  - Must be able to participate in the development of a service plan in partnership with a Department of Social Services (DSS) social worker, or have a Conservator to do so, and must meet all technical, procedural and financial requirements of the Medicaid program.
  - An adult deemed eligible for the ABI Waiver is eligible for all Medicaid covered services.

  To learn more about the ABI program or to obtain an ABI waiver request form, call the Department of Social Services at 1-800-445-5394.Press Option 1-English Press Option 2-Spanish Press Option 5 for ABI Waiver. More details can be viewed online at www.ct.gov/dss - enter Acquired Brain Injury Medicaid Waiver in the search box to view the information sheet and applicaiton.

  IMPORTANT NOTE: There is currently a wait list for this program. It will be important to enlist the support of your legislator on this issue as services are not provided while you are on the wait list.

- **Money Follows the Person (MFP)**
  Are you or a loved one currently living in a nursing home or other long-term care facility? Do you want a choice in how and where you live? Would you like to return to living in the community? Money Follows the Person (MFP) is a federal demonstration program that helps Medicaid-eligible individuals currently living in long-term care facilities – such as nursing homes, hospitals

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and other qualified institutions – successfully transition back into the community. Based on your individual needs, MFP provides the funds, services and support you need for a successful transition into the community. In addition to returning to your own home, housing options include individual apartments, assisted living and group homes. Your Transition Coordinator will be your advocate in the transition process, working with you and your care team on a one-to-one basis to develop a plan that's right for you.

Eligibility criteria include:

- Are eligible for Medicaid in the community
- Have been living in a long-term care or hospital setting for at 60 days
- Are interested in living in the community
- Are eligible for one of the community service packages (including the Acquired Brain Injury Waiver Program listed above)

For more information, or to apply by phone, call 1-888-99-CTMFP (1-888- 992-8637) or complete the application online at https://ctmfp.com/. You can also visit the website for more information about the program. www.ct.gov/moneyfollowstheperson.

- **Community First Choice (CFC)**

  A program in Connecticut offered to active Medicaid members. It is through the CT Department of Social Services (DSS). This program allows individuals to receive supports and services in their home. These services can include— but are not limited to—help preparing meals and doing household chores, and assistance with activities of daily living (bathing, dressing, transferring, etc.). CFC is open to any Medicaid member that can self-direct services and meets Institutional Level of Care. Institutional Level of Care means the individual would likely need to be in an institution, such as a nursing home, if they did not have home and community based services. This program allows an eligible person to have care and support in their home. Apply online at https://ctmfp.com/ or call 2-1-1 and Choose Option 3.

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Assistive Technology and Adaptive Vehicles

ASSISTIVE TECHNOLOGY (AT): Any item or piece of equipment that is used to increase, maintain or improve the functional capabilities of individuals with disabilities in all aspects of life.) A broad range of assistive technology devices and services, such as: Wheelchairs and scooters / equipment Assistive listening devices/ Augmentative communication devices/ Electronic aids to daily living / Visual aids with voice output or magnifying features/ Computers and adaptive peripherals/ Home modifications for accessibility/ Motor vehicles that have/need modifications Assistance / Service Animals.

- **Center on Technology & Disability (CTD):** www.ctdinstitute.org. The Center is designed to increase the capacity of families and providers to advocate for, acquire, and implement effective assistive and instructional technology (AT/IT) practices, devices, and services.

- **Connecticut Tech Act Project (CTTAP) Programs:** The Connecticut Tech Act Project's mission is to increase independence and improve the lives of individuals with disabilities through increased access to Assistive Technology for work, school and community living.

  CT Tech Act Project, 55 Farmington Ave, 12th floor, Hartford, CT 06106
  Phone: 860-424-4881
  860-424-4839 (TTY)
  http://www.cttechact.com

1. **AT Device Demo:** An Assistive Technology Device Demonstration is an opportunity for a person to interact with an AT device, learn about the different features and compare with other similar devices. An AT Device Demo allows a person to make an informed decision about whether the device is the right one.

   Locations for Demo are at CTTAP partner agencies:

   - **The New England Assistive Technology (NEAT) Center** at Oak Hill Is located on the corner of Holcomb and Coventry Streets (on the property of CIB/Oak Hill) in Hartford, CT. To find out more about NEAT, visit their website at www. neatmarketplace.org or call toll free 866- 526-4492.

   - **Access Independence** is one of five Independent Living Centers in Connecticut. Access Independence is a satellite center for NEAT that offers an Assistive Technology Demonstration Center and Equipment Recycling Center at their location, 80 Ferry Blvd., Suite 210 in Stratford. Visit their website at http://accessinct.org/services/core-services/ or call (203) 378-6977.

   - **Eastern CT Assistive Technology Center** in Willimantic, CT Is an AT Demonstration Center that contains a computer access station, equipment for persons with visual or hearing impairments, learning disabilities and devices to reduce barriers in the work place. ECAT is located at Windham Regional Community Council, 872 Main St., Willimantic, CT. Phone: 860-423-4534.

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- **Western CT Assistive Technology Center** Located at the Western Connecticut Area Agency on Aging (WCAAA), the WCAT Center offers the opportunity for residents of Western Connecticut to view a variety of Assistive Technology devices for daily living, aging in place, computer access and more. Visit WCAAA at 80 Progress Lane, Waterbury, CT or contact them via their website http://wcaaa.org/programs/assistive-technology-center or phone at 800-994- 9422.

2. **AT Device Loan**: An AT Device Loan allows a person to borrow a device for a short period of time to help decide if the device will meet the person's needs.

The **New England Assistive Technology (NEAT) Center at Oak Hill** is located on the corner of Holcomb and Coventry Streets (on the property of CIB/Oak Hill) in Hartford, CT. You can go to try out Assistive Technology devices, participate in AT device demonstrations, participate in their lending library, donate used equipment or buy AT devices. To find out more about NEAT, visit their website at www.neatmarketplace.org or call toll free 866-526- 4492.

AT Device Loans for Vocational Rehabilitation (VR) Consumers - VR consumers may be eligible for a short term loan of an AT device to use during Working Interviews, On the Job trainings, Work evaluations or once hired to help have more successful employment outcomes. If you are a VR consumer with the Bureau of Rehabilitation Services interested in a device loan, talk to your VR Counselor for more information.

3. **AT Reutilization/Refurbishment** The NEAT Center at Oakhill refurbishes used Durable Medical Equipment, such as wheelchairs, scooters, etc. They inspect, repair and ensure that the devices are properly working then sell them at a significant discount. NEAT also accepts donations of equipment. Through NEAT's Satellite Centers residents of Connecticut have three locations to drop off or find the equipment they need. Visit their website at www.neatmarketplace.org or call 866-526-4492.

   Satellite Centers:
   - The **Eastern Connecticut Assistive Technology Center** located at is located at Windham Regional Community Council, 872 Main St., Willimantic, CT. 860-423-4534.

   - **Access Independence** is located at 80 Ferry Blvd., Suite 210 in Stratford. Visit their website at http://accessinct.org/services/core-services/ or call (203) 378-6977.

   - The **Lighthouse Voc-Ed Center** in Groton. Call 860-445-7626 for location. http://lhcampus.com/

4. **AT LOAN PROGRAM (ATLP):** Connecticut Tech Act Projoect (CTTAP) offers a low-interest loan specifically for the purchase of AT devices or services, to individuals who qualify. For assistance filling out an application, to request an alternative format, or to check on the status of your application, call The Connecticut Tech Act Project at (860) 424-4881, toll free in CT at (800) 537-2549 or visit website at www.cttechact.com.

   Additional resources:

   - **Butterfly Equipment**
     West Haven, CT 06516

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Phone: 203-934-7077
Website: http://cdr-ct.org/programs-and-resources/butterfly-equipment/
Thrift shop that carries a variety of new and pre-owned equipment. Open by appointment.

- **Hospital for Special Care Equipment Exchange Program**
  2120 Corbin Avenue New
  Britain, CT 06053
  Phone: 860-612-6302
  Website: https://hfsc.org/community/equipment-exchange/
  Equipment is made available, free of charge to community members. It is Managed and staffed entirely by volunteers and all equipment is donated.

5. **Adaptive Vehicles**

- **MV-1 of CT/Harte Auto Group**
  341 South Broad Street, Meriden, CT 06450
  Phone: 203-237-5561 or 866-811-8745
  www.mv1ofct.com
  Only vehicle specifically designed for wheelchair accessibility.

- **Wheelchair Getaways**
  32 Stony Hill Road, Bethel, CT 06801
  Phone: 203-790-9998 or 800-228-0185
  Website: https://www.wheelchairgetawaysct.com/
  For profit agency offering rental, sales and service of full-size or mini-vans for the people with disabilities. Vans come with driving adaptations and wheelchair lock-ins, and are lift-equipped.

- **Advanced Wheels of Technology**
  33 Bradley Park Road, East Granby, CT 06026
  Phone: (877) 943-3573 (1-877-WHEELS-3)
  Website: http://www.advancedwheels.com/
  Automotive company adapts, modifies, sells and rents cars, vans, and mini-vans for people with physical disabilities.

- **Mobility Works**
  104 Pitkin Street, East Hartford, CT 06108
  Phone: 860-215-4100
  Website: https://www.mobilityworks.com/
  New England-based company adapts, modifies, sellsand rents cars, vans, and mini-vans for people with physical disabilities. Ride-Away offers 24 hour road service to customers.

For additional resources search INFOLINES database at http://www.211ct.org or call 2-1-1.

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Transportation Resources

Transportation in the State of Connecticut can be difficult to navigate. Below you will find general information related to statewide transportation options, travel training opportunities, and driver assessment locations.

Mobility Managers: They connect people with disabilities to reliable transportation in their local communities and work to cover the gaps in services.

- **North Central Region** (Greater Hartford): 860-667-6207, www.waytogoct.org
- **Eastern Region** (Greater Norwich & New London): 860-859-5792, www.ectcinc.com
- **South Central** (Greater New Haven): 475-667-6207, www.knowhowtogoscct.org
- **Southwest**: 203-365-8522 x264, http://waytogoct.org/mobility-management/
- **Northwest Region**: 475-298-3103, http://waytogoct.org/mobility-management/

Getting on Board Guides: Guides to accessible transportation resources in an area. Call 1-877-287-4337 for a printed copy or view online at www.ct.gov/dot

Paratransit services are required by the federal Americans with Disabilities Act and are provided for customers whose disability or health condition inhibits them from using regional fixed route bus services for some or all of their travel. Passengers who are determined to be ADA eligible and who are traveling within a 3/4 mile radius of a regions fixed-route bus may use this service during the days and hours that the fixed routes are running. Call Helpline 860-219-0291 and request local number. or visit their website at https://www.ctada.com/.

Dial-A-Ride
This is a paratransit transportation option available in some towns to people of all ages who have a disability which makes accessing and using public transportation difficult for a variety of reasons. In some areas it is only available to seniors. Call Helpline 860- 219-0291 and request local number, or learn more at https://www.myplacect.org/services-and-supports/transportation/transportation-services/dial-a-ride/.

Freedom RIDE
This is an accessible taxi program to benefit eligible individuals who require on- demand accessible transportation services. The program operates 24/7, 365 days a year, and has locations in greater Hartford area and the New Haven area. For more information/determine eligibility please contact:

- **The Greater Hartford Transport District** at 860-247-5329 x3100 or visit their website at https://www.hartfordtransit.org/freedom-ride.html

- **New Freedom Fund Taxi Voucher Program through M7**: Wheelchair Accessible/Paratransit Transportation at 203-777-7777 or visit their website at https://www.m7ride.com/loyalty-cards/new-freedom-fund/

TransitNet: Transit Network for Connecticut - http://transitnetct.org/
A website for people with disabilities, older adults, caregivers, and providers who want to learn more about what transportation options are available for them in Connecticut.

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TRAVEL TRAINING
Do you need assistance in learning to ride the bus or a train? If so, the Kennedy Center, has a program that teaches people with disabilities how to properly and safely use the local bus and rail system. They provide the services on a one-to-one basis throughout the state of CT.

- **The Kennedy Center, Inc.**
  2440 Reservoir Avenue, Trumbull, CT 06611
  Phone: 203-365-8522
  Website:https://www.thekennedycenterinc.org/what-we-do/programs-services/mobility-services/travel-training.html.

NOTE: The Board of Education and Services for the Blind (BESB) provides orientation and mobility services for individuals who are blind. They can be contacted at 1-800-842-4510.

DRIVING ASSESMENT
In terms of a driving assessment, the following agencies and professionals conduct a clinical assessment, as well as an on the road assessment. At the end of the assessment, a recommendation is given regarding a person's ability to safely operate a motor vehicle. An assessment takes approximately 2-3 hours.

- **Easter Seals Mobility Center**
  158 State Street, Meriden, CT 06450
  Phone: 203-630-2208
  Website: https://www.easterseals.com/waterburyct/our-programs/driver-assessment-program/

- **McLean Driver Rehabilitation Program**
  75 Great Pond Road, Simsbury, CT 06070
  Phone: 860-658-3745
  Website: https://mcleancare.org/app/uploads/Driver-Rehabilitation-Program.pdf

- **The Next Street Driver Rehab Services**
  76 Westbury Park Road, Suite 300E, Watertown CT 06795
  Phone: 860-483-7009
  Website: https://rehab.thenextstreet.com/

- **Norwalk Hospital (partof NuvanceHealth) Driver Rehabilitation Program**
  34 Maple Street, Norwalk, CT 06856
  Phone: 203-852-3400
  Website: https://www.norwalkhospital.org/departments/outpatient-rehabilitation-and-physical-therapy- services/specialty-rehabilitation-programs/driver-rehabilitation

- **Bureau of Rehabilitation Services Driver Training Program (must have a physical disability)**
  55 Farmington Avenue, 12th floor, Hartford, CT 06105
  Phone: 1-800-537-2549
  Website: https://portal.ct.gov/AgingandDisability/Content-Pages/Programs/Driver-Training-Program

For furtherinformation regarding transportation options in the State of Connecticut, please call INFOLINE at 211 or visit their online searchable database http://www.211ct.org

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Getting Help - Case Management

Many people after a brain injury ask about case management or care coordination services. Often the residual effects of brain injury can include issues with problem solving, planning, difficulty with concentration and memory loss. Any one of these residual effects can make it more challenging to access benefits, services and follow up care.

Unfortunately this is not a service readily available. There may be an opportunity to private pay. Call the Helpline at 800-278-8242 if you would like contact information.

For many people, private pay or self- pay, due to financial circumstances is not an option. You still need to get to appointments and apply for benefits. Here are some things you can do to be your own care coordinator.

- **Recruit an Ally:** Enlist the support of a family member or friend to partner with you in getting connected to providers and service agencies. For many people, the person with the brain injury and a person who is a part of their support network (family/friend/etc.) will end up working together and becoming the care coordinator. If remembering appointments is an issue, you can ask for the Doctor's office to provide a reminder phone call. If you need additional reminders on the day of the appointment, have a friend or family member call you and/or set an alarm. Carry a calendar with you where you write all appointments. When you leave the office, immediately write down the time and date of the next appointment on your calendar.

- Contact your Town Social Service or Human Service Office: Most of the towns in CT have a social services department that provides services to town residents only. This is different from the State of CT Department of Social Services. Some towns offer very limited services, while others are more extensive and may even have case management, food pantries, holiday donation programs, and temporary financial assistance. To see what your town has to offer call your town hall and ask for the Social Services or Human Services department, or contact INFOLINE at 2-1-1, http://www.211ct.org

- **Ask for an accommodation:** Applying for and maintaining benefits at the State of CT Department of Social Services (DSS) can be extremely challenging. If someone has trouble with memory and concentration after a brain injury it may be difficult to negotiate the system and to successfully complete the application process for DSS programs. If you are having trouble as a result of your brain injury, you can ask the DSS worker for an accommodation to assist you in accessing benefits (help completing paperwork, help understanding the forms, having a phone interview versus having an in person interview, etc.). These accommodations will be noted in your file for future work with this agency.

- **Contact your local Community Action Agency (CAA):** Community Action Agencies will help to prepare new State of CT Department of Social Services (DSS) applicants for eligibility determination interviews by explaining DSS's cash and medical programs, by helping them to assemble required documentation, and by helping them to complete the DSS application. CAAs help clients with the application process but do not determine eligibility for DSS's cash and medical programs. This service can be helpful after a brain injury for someone who may have issues with planning, memory, and/or other cognitive deficits. There is NO FEE. Contact INFOLINE/2-1-1 or visit the Community Action Agency website: http://www.cafca.org/ The CAA also can see if you are eligible for their services, which can include: case management,

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employment and training, child care, assistance with food, eviction prevention, housing eviction programs, and energy assistance programs.

- **Contact your local Independent Living Center:** Another option is to go to your local Center for Independent Living. Although they cannot provide case management, they will assist you in completing paperwork to apply for benefits. They also offer some life skills training and may be able to provide some feedback in terms of how to coordinate a schedule that includes multiple providers and multiple appointments. See below for further details and contact information. The Centers for Independent Living (CIL) are governed and managed by people with disabilities. There are 5 Centers throughout the state of Connecticut and each covers a different geographic area. They are a part of the Community Choices Aging and Disability Resource Centers (more details follow).

  The 4 core services include:
  - peer counselling
  - independent living skills training
  - information and referral and,
  - advocacy services (systems and individual).

They provide a variety of other services that benefit persons with disabilities such as assisting persons with disabilities in transitioning from institutions into community-based settings. The primary purpose of the agency is to support persons with disabilities to live in the community as an alternative to institutionalization. The Independent Living Centers are part of the Community Choices-Aging and Disability Resource Centers listed on next page.

- **Independence Northwest**
  1183 New Haven Road Suite 200
  Naugatuck, CT 06770-5033
  Phone: 203-729-3299
  Website: http://www.independencenorthwest.org

- **Center for Disability Rights**
  369 Highland St.
  West Haven, CT 06516
  Phone: 203-934-7077
  Website: http://cdr-ct.org/

- **Disabilities Network of Eastern CT**
  19 Ohio Avenue, Suite 2
  Norwich CT 06360
  Phone: 860-823-1898
  Website: http://www.dnec.org /

- **Access Independence**
  80 Ferry Blvd, Suite 210
  Stratford, CT 06615
  Phone: 203-378-6977
  Website: http://www.accessinct.org /

- **Independence Unlimited**

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151 New Park Avenue North Annex, Suite D
Hartford, CT 06106
Phone: 860-523-5021
Website: http://independenceunlimited.org /

Aging and Disability Resource Centers (also known as "Community Choices")
Community Choices is a powerful information hub linking older adults, persons living with disabilities, and caregivers in Connecticut to the services and supports they seek. Staff can connect individuals to everything from a name and phone number to more detailed information regarding community services through activities such has benefit screening, options counseling, and care transitions.

Who they support?
- Persons aged 18 & over living with disabilities
- Caregivers
- Persons who want help communicating their needs
- Persons planning for future long term care needs
- Persons who want help navigating a complex system of federal, state, and local programs.

How they provide support?
- Short Term Care Management
- Care Transitions
- Application Assistance
- Benefits Screening
- Long Term Care Planning

They can also connect you with services such as:
- Adult Day Care
- Disability Services
- Employment, Financial, Housing, and Equipment assistance
- In-home Services
- Legal Services
- Mental Health/ Substance Abuse Services & Transportation

Contact Community Choices by calling 1-800-994-9422 or visit one of the following offices:

- **Eastern Connecticut**
  Senior Resources: Agency on Aging
  19 Ohio Avenue, Suite 2, Norwich, CT 06360
  Phone: 860-887-3561 or 800-994-9422
  Website: http://www.seniorresourcesec.org/

- **Southwestern Connecticut**
  Southwestern Agency on Aging
  1000 Lafayette Blvd, 9th Floor, Bridgeport, CT 06604
  Phone: 203-333-9288 or 800-994-9422
  Website: http://www.swcaa.org

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- **Central Connecticut**
  Connecticut Community Care
  43 Enterprise Drive, Bristol, CT 06010-7472
  Phone: 860-589-6226 or 866-845-2224
  Website:https://www.ctcommunitycare.org

- **Western Connecticut**
  Western Connecticut Area Agency on Aging
  84 Progress Lane, Waterbury, CT 06705
  Phone: 203-757-5449 or 800-994-9422
  Website: http://www.wcaaa.org

- **South Central Connecticut**
  Area Agency on Aging of South Central Connecticut
  117 Washington Avenue, Suite 17, North Haven, CT 06473
  Phone: 203-785-8533 or 800-994-9422
  Website: https://www.aoascc.org /

- **North Central Connecticut**
  North Central Area Agency on Aging
  151 New Park Avenue, Hartford, CT 06105
  Phone: 860-724-6443 or 800-994-9422
  Website: https://www.ncaaact.org

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Return to Work Resources

- Bureau of Rehabilitation Services: Works with individuals with disabilities to obtain and maintain employment.
  Phone: 1-800-537-2549 or 860-424-5055
  Website:https://portal.ct.gov/AgingandDisability/Content-Pages/Bureaus/Bureau-of-Rehabilitation-Services

- Connect to Work Project: Allows individuals who receive Social Security Disability benefits to better understand the impact returning to work will have on their disability benefits.
  Phone: 1-800-773-4636
  Website: https://portal.ct.gov/AgingandDisability/Content-Pages/Programs/Connect-to-Work-Project

- Connect-Ability Staffing: The Bureau of Rehabilitation Services (BRS) Connect-Ability Staffing is designed to connect businesses with qualified job seekers.
  Website: https://portal.ct.gov/AgingandDisability/Content-Pages/Programs/Connect-Ability-Staffing

- Job Accommodations Network: A source of free, expert, and confidential guidance on workplace accommodations and disability employment issues.
  Phone: 1-800-526-7234
  Website: www.askjan.org
  Brain injury information: https://askjan.org /disabilities/Brain-Injury.cfm?

- Goodwill Career Center: Provides free career counseling and workshops and operates career centers.
  Website: http://gwct.org /career-centers
  - Bridgeport Career Center 203-581-5040
  - Enfield Career Center 860-749-6937
  - Hartford Career Center 860-856-2301
  - Norwalk Career Center 203-840-0361
  - Shelton Career Center 203-567-7975
  - Torrington Career Center 860-489-8670
  - Waterbury Career Center 203-596-1216

- American Job Center through the Department of Labor: American Job Centers are located throughout the state, offering resources ranging from employment workshops and résumé assistance for job seekers to recruitment services and tax credit programs for employers. Centers also provide Labor Market Information, an electronic job bank and specialized veterans' services.
  Phone: 860-263-6000
  Website: https://www.ctdol.state.ct.us/ajc/americanjobcenters.htm

- O*Net Online: An online database, developed for the U.S. Department of Labor, that includes information on skills, abilities, knowledges, work activities, and interests associated with occupations which can be used to facilitate career exploration and vocational counseling.
  Websites: https://www.onetonline.org /
  https://www.mynextmove.org /explore/ip (Tool to help you find out what your interests are and how they relate to the world of work.)

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Pediatric Brain injury Resources

There are limited services in CT that are specifically designed for children with a brain injury. Typically families access the general supports that are available for children with any type of disability.

- **Pediatric Neuropsychologists:** A pediatric neuropsychologist is a clinical psychologist who has special training in how the brain affects a child's functioning. Pediatric neuropsychologists can conduct evaluations that can guide medical professionals, therapists, teachers, and parents in supporting children and adolescents with brain injury. For information on pediatric neuropsychologists in your area of the state, contact the BIAC Helpline at 1-800-278-8242 or general@biact.org.

- **Department of Developmental Services (DDS):** A statewide system which provides support and services to persons with intellectual disability. Is brain injury considered an intellectual disability? According to the American Psychiatric Association, intellectual disability can be caused by head trauma during childhood and some types of acquired brain injury during childhood (anoxia, infections to the brain).

  Regional Eligibility Liaisons:
  - North Region: DDS.NREligibility@ct.gov (860) 331-2042
  - South Region: DDS.SREligibility@ct.gov (203) 974-4268
  - West Region: DDS.WREligibility@ct.gov (203) 806-8726

  Website: https://portal.ct.gov/DDS

- **The Katie Beckett Waiver through the Department of Social Services**: A program that allows the State of Connecticut Department of Social Services to provide Medicaid services to individuals 21 years of age and younger who have a physical disability and may or may not have a co-occurring developmental disability, who would normally not qualify financially for Medicaid due to family income. The purpose of the waiver is to provide home and community-based services to clients who would prefer to reside in their home or in the community instead of an alternative institution.
  Phone: 1-800-445-5394 or 860-424-5582
  Website: https://portal.ct.gov/-/media/Departments-and-Agencies/DSS/Health-and-Home-Care/Community-Options/Katie-Becket-Waiver-Program.pdf?la=en

- **Children & Youth with Special Health Care Needs (CYSHCN):** A program for children and youth (ages birth-21) that require health and related services beyond that required for children in general. A care coordinator from the Child Development Institute (CDI) works with each family to identify their needs and the community resources that can help their child and family.
  Phone: 1-800-505-7000
  Website: https://cdi.211ct.org /program/children-youth-with-special-health-care-needs/

- **PATH Parent to Parent/Family Voices of Connecticut:** A network of families providing informational and emotional support to others who have a child with developmental or health related needs.
  Phone: 1-800-399-7284 (PATH) or 203-234-9554
  Website: http://pathct.org/

- **Connecticut Family Support Network (CTFSN):** A statewide agency providing

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information and resources for families of children with special needs.
Phone: 1-877-379-2329
Website: https://ctfsn.org/

Special Education Resources

- **Brain Injury Alliance of Connecticut** can assist in facilitating a smoother Hospital to School transition after a child sustains a brain injury. BIAC offers outreach and education and can do a presentation for educational professionals on brain injury. Call the BIAC Helpline at 1-800-278-8242. In addition, BIAC has publications to assist parents and school professionals in supporting students with brain injury, free to download at www.biact.org/educationalresources.

  LEARNet: An interactive web-based problem-solving program designed to improve the educational outcomes for students with brain injury. LEARNet is a resource for teachers, clinicians, parents, and students.
  Website: http://projectlearnet.org/project_learn.html

- **Connecticut Parent Advocacy Center (CPAC):** The CT Parent Advocacy Center, Inc. (CPAC) is a statewide nonprofit organization that offers information and support to families of children with any disability or chronic illness, age birth through 26 in addressing educational support. Services are free.
  Phone: 1-800-445-2722
  Website: https://cpacinc.org/

- **Disability Rights Connecticut:** A federally mandated Protection & Advocacy agency for Connecticut dedicated to identifying and advocating for the elimination of barriers that people with disabilities face in exercising their civil, legal and human rights. This includes ensuring that students with disabilities are afforded educational services necessary for success in post-secondary or work environments.
  Phone: 1-800-842-7303
  Website: https://www.disrightsct.org/

- **State Education Resource Center (SERC):** SERC is a nonprofit agency primarily funded by the CT State Department of Education. SERC provides information dissemination in the latest research and best practices to educators, service providers, and families throughout the state.
  Phone: 860-632-1485
  Website: https://ctserc.org/

- **SpEdConnecticut:** A non-profit organization, which, through the commitment of dedicated, trained volunteers, serves families of children with special needs by working to increase awareness and understanding of children who learn differently and to secure appropriate educational services for this population in accordance with state and federal laws
  Phone: 860-560-1711
  Website: https://www.spedconnecticut.org/

- **State of Connecticut Department of Education's Bureau of Special Education Services:** The administrative arm of the Connecticut State Board of Education responsible for the oversight of special education services, including complaint resolution, procedural safeguards,

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parent information and Connecticut special education regulations.
Phone: 860-713-6910
Website: https://portal.ct.gov/SDE/Special-Education/Bureau-of-Special-Education

- **Collaborative on Postsecondary Education and Disability:** A national leader in promoting access to postsecondary education for students with disabilities by combining research- based evidence and professional training to inform the field and advance postsecondary education opportunities for students.
  Website: https://cped.uconn.edu/

- **Gateway Community College Step Forward Programs:** A comprehensive transition program for young adults with mild cognitive disabilities that focuses on interpersonal communication, daily living skills, and workplace and college readiness.
  Phone: 203-285-2505
  Website: https://www.gatewayct.edu/Step-Forward-Programs

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Brain Injury & Mental Health Resources (Dual Diagnosis)

If a client of Department of Mental Health and Addiction Services (DMHAS) has a brain injury an important resource is the Acquired Brain Injury Community Services Program.

Phone: 860-262-6725
Website: www.ct.gov/dmhas/ABI

The quickest way to access services is to fill out the referral form and send it in. Anyone can fill out the referral form. It will be received at the main office and then assigned to a Community Integration Specialist (CIS/Social Worker). The CIS will then reach out to set up a time to meet with the individual for a consultation. The mission of the ABI Community Services is to facilitate person-centered recovery and encourage personal empowerment for persons living with an acquired brain injury.

Eligibility criteria is that a person living with an acquired brain injury:

- Has been accepted For DMHAS services and currently receiving qualifying services.
- Has a qualifying Acquired Brain Injury (ABI) as determined through appropriate documentation.
- Has functional limitations attributed to the ABI in one or more of the following areas: psychological, social, or occupational.
- Does not have a primary diagnosis of a degenerative cognitive disorder.
- Voluntarily accepts the services.

Client Population
The DMHAS ABI Community Integration Specialist serves clients who are 18 years of age or older, are receiving services through DMHAS and have a qualifying ABI as determined through appropriate documentation.

DMHAS Community Integration Specialists (CIS)
The ABI Services has Community Integration Specialists (CIS) stationed across the DMHAS Local Mental Health Network. The CIS is the primary staff/point of contact regarding qualification for services, as well as issues pertaining to individuals who have an Acquired Brain Injury.

Program Services

- Consultation Services
- ABI Substance Abuse Services
- Training and Education
- Advocacy Supports

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Legal Resources

- **BIAC Helpline:** BIAC has a listing of attorneys who have experience with brain injury.
  Phone: 1-800-278- 8242
  Website: www.biact.org

- **Statewide Legal Services:** Gives free legal advice to low-income (household income at or below 125% of the federal poverty level) people with problems in Connecticut. For some problems they may send you to another legal aid program or to a volunteer attorney.
  Phone: 800-453-3320
  Website: https://www.slsct.org/

- **CTLawHelp.org:** Connecticut's Legal Aid programs created this website to help people with very low income find help for their legal problems. This website will give legal information and tools to help you represent yourself.
  Website: https://ctlawhelp.org

- **Connecticut Legal Rights Project**: Provides legal services to low income individuals with mental health conditions, who reside in hospitals or the community, on matters related to their treatment, recovery, and civil rights.
  Phone: 877-402-2299
  Website: http://www.clrp.org/

- **Connecticut Fair Housing Center:** Dedicated to enforcing housing laws. The Center provides advocacy, attorney referrals and information in connection with individual housing discrimination complaints.
  Phone: 860-247-4400
  Website: https://www.ctfairhousing.org/

- **Connecticut Free Legal Answers:** Connecticut Free Legal Answers is an online civil legal service for people who cannot afford to pay for an attorney. The service is a cooperative effort of the Connecticut Bar Association and the American Bar Association.
  Website: https://ct.freelegalanswers.org/

- **Connecticut Veterans Legal Services:** A medical-legal partnership that works with veterans in treatment recovering from mental health issues, substance abuse, or homelessness.
  Phone: 203-794-4291
  Website: https://ctveteranslegal.org/

- **Disability Rights Connecticut:** A federally mandated Protection & Advocacy agency for Connecticut dedicated to identifying and advocating for the elimination of barriers that people with disabilities face in exercising their civil, legal and human rights
  Phone: 1-800-842-7303
  Website: https://www.disrightsct.org/

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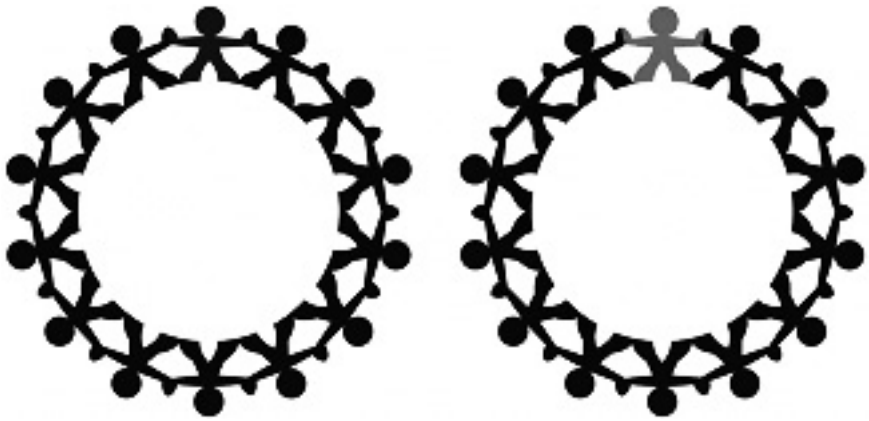
Support Groups

- **Brain Injury Support Groups:** BIAC sponsors approximately 18 support groups throughout Connecticut, giving individuals with brain injuries and their caregivers the opportunity to connect and share their stories.
  Phone: 1-800-278-8242
  Website: http://www.biact.org/get-help-now/support-groups

- **Brain Tumor Support Groups:** The CT Brain Tumor Alliance provides information on brain tumor support groups in Connecticut that are open to brain tumor patients and their families.
  Phone: 860-264-5776
  Website: https://www.ctbta.org/resources/support-groups/

- **Stroke Support Groups:** The American Stroke Association provides information on stroke support groups in Connecticut that are open to individuals who experienced a stroke and their families.
  Phone: 1-800-242-8721
  Website: https://www.stroke.org/en/stroke-support-group-finder

- **Aphasia Support Groups:** The National Aphasia Association provides information on aphasia support groups in Connecticut that are open to individuals with aphasia and their families.
  Email: naa@aphasia.org
  Website: https://www.aphasia.org/



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Social and Recreational Opportunities in CT

- **Hospital for Special Care (HSC) Sports & Fitness:** Hospital for Special Care offers a variety of sports and fitness programs for individuals of all ages, abilities and special needs, including adaptive individual and team sports and adaptive summer camp. They also provide recreational therapy programs that include therapeutic horse riding and aquatic therapy.
  Adaptive Sports Program (New Britain): 860-832-6220
  Manes & Motions Therapeutic Riding Center (Middletown): 860-685-0008 Aquatic & Fitness Center (New Britain): 877-472-7665
  Website: https://hfsc.org/sports-and-fitness/

- **Sports Association of Gaylord Hospital:** Provides adaptive sports and recreational programs for individuals 16 and up with physical disabilities and visual impairments in the state of Connecticut, including alpine skiing, water skiing, archery, golf and more.
  Phone (Wallingford): 203-284-2772
  Website: https://www.gaylord.org/About/Sports-Association

- **Specialty Programs at Mount Sinai Rehabilitation Hospital:** Provides specialized rehabilitation through adaptive sports programs, including Golfers in Motion and the CT Adaptive Rowing Program.
  Phone (Hartford): 203-714-2421
  Website: https://www.trinityhealthofne.org/find-a-service-or-specialty/rehabilitation/specialty-programs

- **SAIL Connecticut Access Program:** A volunteer group founded in 1989 to offer persons with special needs the opportunity to enjoy sailing – not only as passengers, but as skippers – and to encourage people with and without special needs to share the experience.
  Phone (Westbrook): 860-304-6588 Website: https://www.sailctaccess.org

- **Leap of Faith (LOF) Adaptive Skiers:** Provides training in recreational and competitive water and snow skiing for children, adults and veterans with disabilities. Water skiing takes place at Lake Zoar in Sandy Hook and snow skiing takes place at Mount Southington in Plantsville.
  Phone: 203-426-0666
  Website: http://lofadaptiveskiers.org/

- **Oak Hill Adaptive Sports & Fitness:** A state-of-the-art adaptive fitness facility dedicated to improving the health and wellness of youth, adults, veterans and seniors with physical disabilities, as well as their caregivers and families.
  Phone (Hartford): 860-243-2869
  Website: https://sportsandfitness.oakhillct.org/

- **Whispering Brook Farm & Art Studio, Art for Persons with TBI:** A creative outlet for kids and adults with brain injury to participate in art therapy and animal assisted therapy.
  Phone((Tolland): 860-794-5650.
  Website: https://www.whisperingbrook.org/

- **Connecticut Music Therapy Services:** Providing quality home, school and community-based music therapy services to individuals and groups with special needs throughout Connecticut.
  Phone: 1-800-796-4914
  Website: http://www.ctmusictherapy.com/

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- **Infinity Music Therapy:** Providing music therapy services to children and adults of all ages in individual, group, and family settings in home, school and facility settings throughout Connecticut.
  Phone: 860-518-5557
  Website: http://www.infinitymusictherapy.com/

- **American Music Therapy Association:** In addition to the music therapy services listed above, the American Music Therapy Association maintains a directory of certified music therapists in private practice.
  Phone: 301-589-3300
  Website: https://www.musictherapy.org/

- **Accessibility at Connecticut State Parks and Forests:** The Department of Energy & Environmental Protection is working to ensure that all visitors have access to the many outdoor recreational opportunities available at Connecticut State Parks and Forests. They maintain a listing of accessible locations on the state website at https://portal.ct.gov/DEEP/State-Parks/Access-for-Persons-with-Disabilities, which includes accessible campgrounds, beaches, fishing platforms, boat launches, and trails.

  - *Accessible Trail:* The Saugatuck Universal Access Trail in Redding is wheelchair accessible. Visitors will be rewarded with views of the Saugatuck Reservoir from the trail's overlook platform.

  - *Accessible Camping:* Hammonasset Beach has six campsites that are designated for use by individuals with disabilities. The sites are in close proximity to restroom facilities, have electrical outlets and can be reserved. To make reservations call Reserve America toll free 1-877-668-CAMP (2267).

  - *Accessible Swimming/Beach Chairs:* Five parks, Hammonasset Beach, Rocky Neck, Sherwood Island, Silver Sands and Squantz Pond have beach wheelchairs available for visitors. The chairs are free of charge and are on a 'first come/first served' basis.

  - *State Parks and Restrooms:* The majority of state parks provide accessible restroom facilities.
    - American Legion State Forest, Pleasant Valley
    - Black Rock State Park, Thomaston
    - Hammonasset Beach State Park, Madison
    - Housatonic Meadows State Park, Cornwall Bridge
    - Kettletown State Park, Southbury
    - Lake Waramaug State Park, New Preston
    - Rocky Neck State Park, Niantic

- **Camp Harkness** is located in Waterford on the shores of Long Island Sound. It is one of the few state parks in the country dedicated for exclusive use by citizens with disabilities, accompanied by their family and friends. Facilities include cabins, year-round cottages, seasonal tent sites, barnyard animals and horseback riding, picnic pavilions & grills, accessible playscape, scenic walkway and overlook, bathhouse, beach with boardwalk, gardens, dining hall, lodge, and infirmary. Any Connecticut resident with a disability may obtain a free Camp Harkness Pass. For more information, visit http://www.campharknessfund.org/.

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Legislative Advocacy

IMPORTANT ALLIES: Your Senator and Representative are important people on this road. They have the ability to influence change at the legislative level. This is the only way to improve care for residents of CT who have sustained a brain injury.
Enlist their support!

- Who are my Representative and Senator and how do I contact them?
  Goto: http://www.cga.ct.gov/asp/menu/CGAFindLeg.asp
  This link will take you to the page: State of Connecticut Districts so you can find your Representatives, Senators and Congresspersons. It will ask for your address and then "Find Your Legislator".

- What is the address and phone number of the Capitol and Legislative Office Building? Often an in person meeting can be quite powerful.
  - State Capitol, 210 Capitol Avenue, Hartford, Phone: (860) 240-0100
  - Legislative Office Building, 300 Capitol Ave., Hartford

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Online Brain Injury Resources

- **BrainLine:** A national multimedia project offering authoritative information and support to anyone whose life has been affected by brain injury or PTSD: people with brain injuries, their family and friends, and the professionals who work with them. BrainLine also provides military-specific information and resources on traumatic brain injury and post-traumatic stress disorder (PTSD) to veterans, service members, and their families.
  - Main Website: www.brainline.org
  - Military website: www.brainlinemilitary.org
  - Children with TBI: https://www.brainline.org/children-tbi

- **Brain Injury Alliance of Connecticut:** BIAC maintains informationon brain injury on their website, as well as through a monthly online newsletter(BUZZ) and social media sitesBIAC website: www.biact.org
  - BUZZ signup: http://www.biact.org/e-newsletter
  - BIAC Facebook page: www.facebook.com/BrainInjuryAllianceCT BIAC
  - Twitter page: https://twitter.com/BrainInjuryCT
  - BIAC YouTube page: https://www.youtube.com/channel/UC0_lByeN5nT5OFHN0D5fDWg/featured

- **Coma Guide for Caregivers:** A resource guide for family members with a loved one in coma or experiencing disorders of consciousness.
  - Website: http://dhss.delaware.gov/dsaapd/files/coma_guide.pdf

- **Model Systems Knowledge Translation Center and the Traumatic Brain Injury (TBI) Model System:** The MSKTC works closely with researchers in the 16 Traumatic Brain Injury (TBI) Model Systems to develop resources for people living with traumatic brain injuries and their supporters. These evidence-based materials are available in a variety of formats such as printable PDF documents, videos, and slideshows.
  Website: https://msktc.org/tbi
  Website Fact Sheets: http://www.msktc.org/tbi/factsheets

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GLOSSARY: Who is Who on the Rehab Team?

- **Physiatrist:** Physician whose specialty is rehabilitation medicine. He/she is in charge of your overall treatment and directs your rehabilitation program. The physician will:
  - Evaluate your physical abilities, along with your thinking and behavior.
  - Prescribe medication as necessary to manage mood, sleep, pain and nutrition.
  - Prescribe tailored therapy orders for physical therapy, occupational therapy and speech therapy.

  At the Sub-acute level, a Physiatrist only may be available on a consultation basis as it is usually a general physician who oversees SNF.

- **Neuropsychologist:** Neuropsychologist has expertise in brain/behavior relationships. They focus on thinking skills, behavior, and emotional processing. He/she will assess (and some will treat) problems you may have with thinking, memory, mood and behavior. The neuropsychologist may complete a neuropsychological evaluation which can be a very valuable tool in care planning. If this evaluation is suggested, it is not usually immediately post injury but further along in recovery.

- **Physical Therapist :** The physical therapist (PT) will help you improve your physical function and mobility. The PT's role is to teach you how to be as physically independent and as safe as possible within your environment. This is accomplished through therapeutic exercises and re-education of your muscles and nerves, with the goal of restoring normal function. Specific goals to be accomplished in the physical therapy gym include strengthening your muscles and improving endurance, walking and balance.

- **Occupational Therapist:** Occupational therapists (OT) provide training in activities of daily living to help you become more independent. These activities typically include eating, bathing, grooming, dressing, and transferring to and from your bed, wheelchair, toilet, tub and shower. The OT will work with you on underlying skills, such as strength, balance and trunk control. Depending on the center, occupational therapists may also:
  - Assess your thinking skills, such as orientation, memory, attention, concentration, calculation, problem-solving, reasoning and judgment.
  - Assess your visual problems.
  - Help you manage more complex activities such as meal preparation/cooking, money management, and getting involved in community activities. Recommend and order appropriate equipment you may need before returning home.

- **Speech-Language Pathology Therapist:** Speech-language pathology therapist is responsible for the treatment of speech, swallow and communication problems. Most often, they are the professional that will provide cognitive rehabilitation. She/he will:
  - Help you with communication problems such as difficulty understanding what others say or expressing yourself clearly.
  - Teach you exercises and techniques to improve your ability to speak and express yourself, including exercises to strengthen the muscles used in speech/swallowing, and speech drills to improve clarity.
  - Evaluate and treat any problems you may have with cognitive skills such as orientation, memory, attention, concentration, calculation, problem-solving, reasoning and judgment.
  - Provide a communication device if you have breathing tube (tracheostomy).
  - Evaluate your swallowing abilities if you have difficulty

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swallowing (dysphagia).

- If needed, make recommendations about the types and consistencies of foods and drinks that you can consume safely.

- **Recreation Therapist:** The role of the recreation therapist is to provide recreational resources and opportunities in order to improve your health and well-being and get you reconnected in the community. Returning to recreation and/or finding new recreational activities is an important part of recovery. This may include outings or in hospital social and group activities.

- **Social Worker:** The social worker will provide you and your family with information about community resources and help plan for your hospital discharge and return to the community.

- **Neurologist:** Medical specialist who concentrates on disorders of the nervous system. May be involved in the initial diagnosis of brain injury and may continue to monitor the neurological recovery even after an individual is dischargedfrom the hospital.

- **Neurosurgeon:** A neurosurgeon is a medical specialist who treats diseases and conditions affecting the nervous system, which includes the brain, the spine and spinal cord, and the peripheral nerves. Neurosurgeons provide non- operative and surgical treatment to patients of all ages.

- **Neuro Optometry:** Neuro-optometric rehabilitation is an individualized treatment regimen for patients with visual deficits as a direct result of physical disabilities, traumatic brain injuries, and other neurological insults.

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Appendices:

A. Letter to the Editor

B. Advocating for the Loved One

C. Ask the Neuropsychologist; Neuropsychological Evaluations

D. Brain Injury and the Law: A Primer for Survivors and Families

E. Is Conservatorship Right for Your Loved One?

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I. A Fresh Look at Behavior Problems after Brain Injury

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Appendix A: Letter to the Editor

Brain Injury Treatment: Constituent vs. Congresswoman Melinda Montovani, West Hartford

10/21/2020

The constituent with a brain injury goes to inpatient rehabilitation and stays for 19 days. The congresswoman with a brain injury goes to rehabilitation and stays for five months.

Constituent options: Go home with 24 hour supervision (not a covered benefit) or to a nursing home. The congresswoman takes advantage of a long-term stay in the specialized rehab facility.

The constituent can no longer work. The person's partner quits a job to provide the constituent with 24- hour supervision. Incomes are lost, savings are exhausted and therapies end. Being unable to provide for your family requires going on state assistance for health insurance and food.

The congresswoman continues outpatient therapy and daily visits to the hospital, and retains 24-hour assistance from a home-care provider.

What has been said about the congresswoman? A remarkable and miraculous recovery. Staff credits almost six months of rehabilitation at a high-end facility with dramatically improving the chances of returning to a normal life. They have drawn attention to her progress and benefits as a member of Congress covered by federal workers compensation insurance.

What has been said about the constituent? You should have run for Congress. The Hartford Courant, 2020

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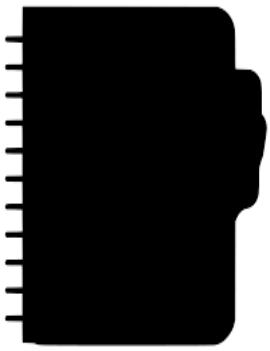
Advocating for a Loved One

By Carrie Kramer, M.A., CRC

Your husband has just come out of a coma after a serious car accident and you are filled with relief and gratitude that he has survived the worst. Then the realization begins to slowly seep in that you don't know where to begin. You are overwhelmed with anxiety regarding how you will possibly move forward in negotiating all of the large and small details of your lives as you begin to pull the pieces back together.

Where to go? How to start? This pull – out section will provide you some helpful hints to ensure that you are able to navigate the complex medical and social services system to advocate for your loved one's needs.

Step One: Create a Binder



- Document information that is given to you by medical and social service professionals
- Create a log that includes the date, time, contact person and summary of what was discussed (this will help you keep track of important information that you will need to refer back to)
- Retain copies of all medical records, social security information, progress notes, etc. in your binder
- Maintain a section where business cards of professionals that are working with you and your loved one can be placed
- Ensure that the binder is easily labeled, portable, and quickly accessible

Step Two: Investigate Discharge Plans

Discharge planning is a complex process that will vary depending on the type of facility your loved one is in. Find out if there is a case worker assigned to your loved one for this purpose. Often, a brain injury survivor will be discharged to a rehabilitation hospital or facility that specializes in brain injury rehabilitation.

In many facilities, social workers serve as discharge planners and are available to guide families through this process and assist in locating services and supports after discharge whether the survivor is being admitted to another medical facility or is being discharged to home. Some questions to ask the discharge planner might include:

- Who makes the decision about discharge options and what is the survivor's and family's role?
- What are all of the options after discharge including facilities as well as community based programs?
- Who determines when the brain injury survivor is ready for discharge?
- What type of follow-up is offered after discharge for the brain injury survivor or his or her family?
- Are medical records given to the family upon discharge?

Step Three: Explore Financial & Benefits Arrangements

Rehabilitation costs can be staggering for a family after a brain injury. In addition to the high cost of inpatient medical services, insurance companies are increasingly limiting and sometimes eliminating all together reimbursement for essential outpatient services after discharge from the hospital. Some of these services might include physical therapy, speech therapy and occupational therapy.

- Request documentation of your loved one's coverage policies in writing by his or her insurance

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carrier
- Become familiar with the appeal process for denied claims
- Investigate the Social Security and Supplemental Security Income disability programs as they are the largest of several Federal programs that provide assistance to people with disabilities

Step Four: Establish a Circle of Support

It has been proven that individuals with brain injuries can maximize their outcomes and success when being supported by family and friends. Initially, it can be helpful to pull in close family and friends into a circle of support. It will be critical for your loved one to have additional community supports upon discharge. Finding creative ways to involve your circle of support will benefit the caregivers as well as the brain injury survivor.

Examples might include:

- Ask for assistance from a friend to take over some necessary phone calls on your behalf to prevent burnout
- Request that someone transport your loved one to and from outpatient therapy sessions
- Encourage a friend to come over to visit with your loved so that the primary caregiver can have some time away from home
- Accept offers for help with meals or cleaning the house
- Attend support groups
- Contact the Brain Injury Alliance of Connecticut on their toll free number at 1-800-278-8242 for information and support
- Familiarize yourself with services for persons with disabilities in your area (many towns in CT have their own social services department or program– inquire whether or not your town has one and use them as a starting point)
- Explore additional resources

The above categories are by no means an exhaustive list. Rather, they should serve as a starting point for you to begin to navigate the challenges ahead. Advocating for your loved one is one of the biggest challenges you can face after a family member sustains a traumatic brain injury. There are many unknowns about the recovery process and what to expect. You are entering into uncharted territory. However, being armed with strategies that can assist you as you move forward will provide you with greater control.

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Ask the Neuropsychologist: Neuropsychological Evaluations

By John Stanwood, PhD

"I was in a car accident recently and my doctor told me I should have a neuropsychological evaluation. What does it involve and what kind of information will it tell me?"

If your doctor referred you for a neuropsychological evaluation after a car accident, he/she must be concerned about the possibility of some change in how your brain is working because of this injury. There are many possible problems that can occur after such an injury, from thinking problems, memory issues, personality changes, to physical problems. Sometimes these changes are temporary, but sometimes the changes are permanent.

Neuropsychology is a specialty within psychology that focuses on brain functioning. The field blends neurology and psychology with a focus on how a person's cognitive (or thinking) abilities affect their behavior. A Neuropsychologist is a licensed clinical psychologist who has had special training in the administration and interpretation of the tests used to obtain this information. Such tests as a CT scan or an MRI give your doctor an idea of how your brain looks physically and chemically, but they cannot tell your doctor how your brain is actually working. Only a neuropsychological evaluation can do that.

A neuropsychological evaluation involves assessment of the various areas of brain functioning, such as general intellectual ability, problem solving, attention, concentration, learning new information, memory, language, perceptual (senses) abilities, motor skills, behaviors, emotions, and personality traits and how well these areas work together to accomplish tasks. The exact tests given, and the time testing will take, will vary depending on your specific situation and the questions asked by your doctor. The Neuropsychologist will select which tests will be most useful to gather the information needed for your personal situation. Testing often takes six to eight hours face-to-face and usually starts with an in- depth interview, so the Neuropsychologist can understand your individual situation and needs.

The results of the evaluation can help clarify whether or not you have any problems from your accident and help your doctor make formal diagnoses. The results may help set treatment goals to assist in your recovery and rehabilitation, or help with planning for the future, such as the need for ongoing support or treatment, especially in terms of school or work. The first evaluation may also serve as a "baseline" to use to compare to future testing to monitor changes in how your brain is functioning. Repeated testing after an accident is not uncommon, as this allows your doctor to monitor how your brain is recovering.

If you would like more information about neuropsychological evaluations, you can log onto the website for the Connecticut Neuropsychological Society at https://commons.trincoll.edu/cns/.

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Brain Injury & the Law:
A Primer for Survivors & Families
By Attorney Paul Slager

In working with brain injury survivors and their families, I often find they view pursuing a legal claim for compensation to be a stressful and daunting prospect. At first glance, this concern seems well founded: navigating a lawsuit can be difficult for survivors and their loved ones, and the final result of any case is always impossible to predict. At the same time, many brain injuries are the result of careless, even reckless, conduct by people other than the survivor. In some of these cases, a survivor's injuries will require a lifetime of costly care and therapies, much of which will not be covered by health insurance or public assistance. To make matters worse, many survivors may be unable to return to the jobs they held before their injuries, and their ability to earn a living can be seriously affected by the impact of their injuries. Under these circumstances, it may be prudent to ask a qualified attorney to review whether the brain injury survivor has legal claims worth pursuing.

In my discussions with potential clients, I find many struggle with the questions and concerns addressed below.

Q. How do I know if I have a case?
You won't know this until you seek the advice of a qualified lawyer who is experienced in representing brain injury survivors. When a person or company causes another to suffer a serious injury, state and federal law offer a wide variety of potential remedies. Lawyers who devote a significant part of their practice to brain injury cases should know how to investigate each potential claim, advise you whether any viable claims exist, and make sure your potential claims are filed in a timely fashion so that you don't give up your right to make the claim. In many brain injury cases, the injury is simply a tragic, unavoidable accident. When this is the case, a responsible lawyer will advise you that there is no case to pursue. When you believe the injury may have resulted from another's careless conduct, however, you should not hesitate to have one or more lawyers review whether the survivor has legal claims.

Q. If I decide to find a lawyer, when should I make contact?
The short answer: as soon as possible. In cases of brain injury, the timing of your seeking legal advice is often, and appropriately, delayed by the acute medical care the survivor receives and the immediate effects on the lives of the survivor and family members. Seeking prompt legal advice, however, can be critical to successfully pursuing a case. This is true for a couple of reasons.

First, all claims in Connecticut are governed by statutes of limitation. This means that you must file any claims within a time period prescribed by the legislature or the claims will be barred as a matter of law. The length of time you have to file your claims depends on the nature of the claims and the identity of the potential defendants. If an employee of a city or town is a potential defendant, for example, Connecticut law may require that you provide the city or town with notice of potential claims within six months of the injury. If a private individual who is not a city or town employee was negligent and caused the injury, then you may have two years to bring any claims. Since you won't know what the time limitation is for bringing a lawsuit, you want to be sure you give your lawyer enough time to assess who all the responsible defendants are, to advise you about these statutes of limitation and to prepare timely claims. Over the years, I have many times had the unfortunate experience of having to tell clients with significant cases that they called too late for me to help. In some of these cases,

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this could have made the difference between a significant settlement or judgment for the brain injury survivor and no financial recovery at all.

Another reason to contact an attorney promptly is that preserving evidence is often critical to successfully preserving a survivor's claims. Sometimes police will maintain custody of important evidence for only a limited time, then will release or dispose of the evidence. As time passes, the likelihood increases that important witnesses will move away or become difficult to locate. Losing this key evidence and information from witnesses can make a winnable case unwinnable.

Q. Once I decide to contact a lawyer, how do I find the right one?

Admittedly, this is one of the toughest questions you'll face. Although there's no golden rule that will guide you to selecting the right lawyer, I do have a few suggestions:

1. Meet with more than one qualified lawyer before deciding who will represent you.

Most lawyers who represent brain injury survivors in lawsuits will be willing to meet with you, free of charge, to discuss your potential case. Before meeting, be sure to confirm that there is no charge for the initial consultation. During these meetings, your discussions will be confidential, provided you are consulting the lawyer in order to discuss your case and obtain legal advice. You should be honest about the background facts surrounding the incident that led to the injury and should discuss any concerns you have about the process. Although the lawyer you are meeting with is assessing your potential case, you should view this meeting as your chance to evaluate the lawyer. If you are meeting with more than one lawyer, you should let the lawyers know this. Don't worry about getting a negative response: if you get a bad reaction from an attorney when you disclose you're meeting with more than one, consider it a strike against them. After all, you probably don't want to hire an attorney who has a problem with your being careful to make sure you're hiring the right person for you.

2. Find out whether the lawyer has experience handling brain injury cases.

Brain injury cases are not easily handled by lawyers who are inexperienced in handling similar cases. You should confirm that a good deal of the lawyer's practice is devoted to brain injury cases, and that the lawyer is knowledgeable about brain injuries. These cases nearly always involve sophisticated medical issues and the lawyer should be familiar with these issues. You also want to be sure the lawyer regularly monitors advances in technologies related to diagnosing and treating brain injury, as well as legal issues related to the admissibility of these technologies. Because many serious brain injuries have serious effects on a person that are not obvious on a superficial level, brain injury cases also present unique challenges in the courtroom. Juries may expect a person with serious injuries to look or sound impaired, and many who are seriously affected by brain trauma do not fit this mold. Lawyers who are experienced handling brain injury survivor's cases are usually best equipped to handle these challenges.

3. Make sure you are comfortable with the lawyer you choose.

Your interaction with your lawyer will be a long term relationship that involves issues that go far beyond money. There is more than one lawyer who is qualified to handle your case, so your feelings about whether your personalities fit is important. You should find the lawyer approachable and supportive. If the lawyer you interview seems prickly, distracted, disinterested or unpleasant during your initial meeting, chances are that this will become more, not less, of a problem as you move forward.

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4. Make sure you clearly understand the fee arrangement offered by the lawyer.

Any potential lawyers you contact should be willing to provide you with written fee agreements and provide you detailed explanations of the terms before you decide whether to retain them. Many lawyers who handle brain injury cases will charge a contingency fee, which means the attorneys' fees are deducted as a percentage from any recovery in the case. This usually, but not always, means that if a lawyer decides your case has merit, the lawyer will pursue your case from beginning to end without any out of pocket costs in the beginning of the case or while the case is proceeding. If this type of fee arrangement works for you, you should confirm how it works and make sure that the things your lawyer explains match the terms of the written agreement you are given. You should take as much time as you need to review the written agreement on your own. Do not feel pressured to sign a written fee agreement until after you've had plenty of time to review it outside of the presence of the lawyer. If you feel pressured to sign a lawyer's fee agreement before you've had time to review and understand it, I suggest you look for another lawyer.

How long does a lawsuit take?

The length of a lawsuit varies depending on what claims are made, who the defendants are and where the lawsuit is filed. Cases proceed at different speeds in state and federal courts, and the length of cases varies considerably within the state court system, depending on what courthouse the case is filed in. The congestion in the dockets of different judicial districts across Connecticut varies, and cases filed in Hartford move at a different pace from cases filed in Waterbury or other districts. Also, some cases settle before trial, while other cases require a jury verdict followed by an appeal. Understanding that accurately predicting the length of a case is impossible, I usually estimate that a brain injury case takes an average of three years from the time it's filed to the time it's resolved.

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Is a Conservatorship Right for Your Loved One?
Connecticut's conservator laws; a new look
By Attorney Sharon Pope

Tom's family is concerned about him. Since the automobile accident, Tom has had problems keeping up with his finances. The family has seen past due notices scattered on Tom's desk; Tom has complained of getting calls from collection agencies, too. They wonder how they can help him.

Sara's friends and family are concerned about her. Since she took that fall a few months ago, they notice that she is not taking care of herself the way she used to. It appears that she is not showering on a regular basis and her apartment is uncharacteristically messy. Her refrigerator always seems to be either empty or filled with rotting food. Her friends and family would like to help her but they don't know what to do.

Many of us will be faced with the prospect of deciding how best to help a friend or family member who can no longer take care of him or herself. That person may be having difficulty keeping track of and paying the bills. Perhaps he or she is making unwise decisions. Maybe that person is unable to take care of his or her physical body or maintain personal hygiene.

There were significant changes to Connecticut's conservator laws, effective October 1, 2007. These new laws affect every involuntary conservatorship matter whether the appointment is new or decades old.

This article explores one of the options available to aid a person who is having difficulty performing the activities needed to take care of his or her person and finances.

A conservatorship is the most restrictive option to consider because in order to take advantage of the protections of a conservatorship, the conserved person must be declared, "incapable of caring for one's self" by a Probate Court.

What is a Conservator?
A conservator is a "guardian, protector or preserver." In the State of Connecticut, there are two types of conservators. The Conservator of the Estate is appointed to manage the financial affairs of a person who is considered incapable of doing so. The Conservator of the Person is appointed to take care of a person's physical well-being when a person is considered incapable of doing so.

Who Can Be a Conservator?
Any person, including a "municipal or state official, or a private profit or non-profit corporation except a hospital or a nursing home" can be a conservator. Being a conservator is a responsibility that should be assumed with care as the conservatorship is monitored by the Probate Court and the conservator is responsible to the Probate Court for reports and accountings.

What is the Procedure for Conserving an Individual?
In order to conserve an individual, an application must be made to the Probate Court in the town where that person lives. There are penalties for filing a fraudulent or malicious application for conservatorship.

A conservatorship can be temporary. A temporary conservatorship is usually used in emergency

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situations such as a sudden change in the capacity of an individual due to illness or accident. A conservator is appointed by the Probate Court for a term of 30 days. If there is a controversy over whether the conserved person continues to need a conservator, another hearing is held so the Probate Court can determine if a permanent conservatorship is needed.

After the application is received by the court, the court will issue a citation to appear before the court. The citation is personally delivered to the following parties: the person who is the subject of the hearing or respondent, that person's attorney, that person's spouse (if applicable), parents and or children. The court will also give notice to the applicant; the person in charge of welfare in the town where the respondent lives; the Commissioner of the Department of Social Services and the Commissioner of Administrative Services, if the respondent is receiving aid from the state; the Commissioner of Veterans Affairs, if the respondent is receiving veteran's benefits; children, parents, brothers or sisters of the respondent; the person in charge of the hospital or nursing home if the respondent resides in a hospital or nursing home.

The conservatorship process involves the input of the State of Connecticut and other parties in determining the capacity of your loved one. Before applying to conserve a loved one, the family must determine how much the family wants the State and the courts involved in a private family matter.

What Rights Does Your Loved One Have in the Conservatorship Process?
Your loved one has the right to be represented by counsel of his or her choice in the conservatorship hearing. If he or she is unable to obtain an attorney, the court must appoint one, unless he or she knowingly refuses. The court may pay for attorney's fees as defined under the court's rules. If your loved one is unable to travel to the court for the hearing, the hearing must take place at a location which would facilitate his or her participation, for example, at the hospital or home.

If the court decides that your loved one is incapable of paying bills, taking care of him or herself, or otherwise unable to manage his or her affairs, the court may review any alternative plans which your loved one might have to get assistance in handling his or her own affairs that do not require the appointment of a conservator. If a conservator is appointed your loved one may take part in the choice of his or her conservator.

Be aware that the appointment of a conservator limits the civil rights of your loved one in the following areas:

- access to and the budgeting of money
- decisions as to where your loved one will live
- the making of medical decisions
- the paying of bills
- the managing of real or personal property.

As a family member or friend of a person who may be conserved, you must weigh the importance of taking care of your loved one's fiscal and personal well being against the loss of civil rights and autonomy which that person would experience if conserved. Being conserved includes the loss of rights which most of us take for granted. How would being conserved affect the dignity of your loved one?

What Information Does the Court Use to Determine Incapacity?
After the court has determined that it has clear and convincing evidence that it has jurisdiction in the case and your loved one has been advised of his or her right to retain an attorney, the court will look

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at evidence regarding your loved one's capacity to care for him or herself. This evidence may include a written report or the testimony of one or more physicians who have examined your loved one within the last 45 days. The report must contain specific information on your loved one's condition and how it affects his or her ability to care for his or herself. The court may also accept the testimony of other professionals or friends and family who are familiar with your loved one and his or her capabilities. Under the new statute, all who testify must be sworn in as in any court proceeding and any evidence presented must conform to the rules of evidence used by the Superior Court of the State of Connecticut.

In deciding if a conservator should be appointed the court will consider the following factors regarding the individual in question:

- his or her abilities
- ability to state what he or she prefers regarding the care of his or her own person or the management of his or her affairs
- any relevant material obtained from the individual
- evidence of past preferences and life style choices
- cultural background
- the desirability of maintaining continuity in the individual's life and environment
- whether the individual has previously made adequate alternative arrangements for the care of his or her person for the management of her affairs such as a power of attorney
- any relevant evidence from family or acquaintances regarding past practices and preferences any supportive services, technologies or other ways that are available to help the individual to meet his or her needs.

The Appeals Process or If You Don't Like the Decision of the Probate Court, What Can You Do?

If you are unhappy about the Probate Court's decision, an appeal can be filed with the Superior Court in the same jurisdiction as the probate court within 45 days of the Probate Court's decision. The Superior Court will not substitute its judgment for that of the Probate Court unless there are serious violations of procedure made by the Probate Court. In other words, it is difficult to reverse the judgment of the probate court. This is another reason for carefully considering all of the consequences before applying for a conservatorship for your loved one.

Is a Conservatorship Right for Your Loved One?

This article has explained the conservatorship process. It is a lengthy process which restricts the rights of your loved one. It is difficult to make the decision to conserve a loved one. This decision must be made by considering all of the alternatives to a conservatorship. Although a loved one's needs may be taken care of by a conservator there are several alternatives to a conservatorship which are less restrictive and give you and your loved one more control over your loved one's care. We will be exploring these alternatives in our next article.

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The Power of a Power of Attorney
By Attorney Sharon Pope

Meet John, who suffered a traumatic brain injury in a motorcycle accident years ago. When his wife, who handled their bill paying, died, John soon fell behind. Confused by the mounting paperwork and concerned that his condition would grow worse, John, who is not incapable but does need help, decided that he needed his family's assistance managing his financial affairs — and the same is true for many individuals.

What is a power of attorney (POA)?
A POA is a legal document that appoints an attorney-in-fact to represent an individual in his/her personal, financial, and business dealings. Simply put, a power of attorney is the granting of legal rights and powers by one individual — the principal, to another — the agent, who:

- must use the principal's assets for the principal's benefit, unless the POA authorizes the agent to
- make another use of those assets
- may do whatever the principal may do (withdraw funds from bank accounts, trade stock, pay bills, cash checks), except as limited by the POA
- relinquishes POA authority if the principal becomes incapacitated, unless the POA specifically states that the authority remains effective after incapacity.

What is a durable power of attorney?
A POA that survives incapacity is a durable power of attorney, but even under a durable POA, the authority of an agent ends if it's revoked by the principal or at the principal's death.

What are general and special durable POAs?
Under a general durable POA, a principal authorizes an agent to transact all business, financial, and personal affairs on his/her behalf — most commonly if they become incapacitated. The principal may choose the person who will manage his/her affairs as his/her agent and will customize that agent's authority to meet his/her needs. If an individual becomes incapacitated without a general durable POA, it may be necessary for a court to appoint a guardian or conservator for that individual through a relatively expensive and time-consuming public, court-supervised proceeding.

Under a special durable POA, a principal can limit his/her agent's authority to specific acts, such as the sale of a parcel of real property, the funding of a trust, or the execution of tax returns.

What level of capacity is needed to execute a durable POA?
A principal must be able to understand (1.) that a durable POA authorizes the agent to act on his/her behalf, and (2.) that he/she will be bound by the agent's acts on his/her behalf.

When does a durable POA become effective?
A durable POA can become effective immediately upon signing. An immediately effective durable POA should be used if the principal requires assistance right away or will in the near future.

When a principal does not want his or her agent to act unless he or she becomes incapacitated, then a springing durable POA should be established, with the principal selecting the date or event that will trigger effectiveness. However, one of the problems with a springing durable POA is determining

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when the principal has become incapacitated.

Does a durable POA take away a principal's rights?
No. Only a court can take away a person's rights through a guardianship or conservatorship proceeding. A principal's agent simply has the power to act for him/her in accordance with the terms of the durable POA, as tailored to the principal's needs.

Who should one select as an agent?
The selection of an agent is the most important decision an individual must make when establishing a POA. The agent should be someone in whom the principal has complete confidence — someone trusted for their honesty. However, honesty is not enough. It's also important that an agent have good judgment and the education/experience required to fulfill the role successfully, be readily available, and be capable of assuming his/her duties without any conflict of interest.

What if an agent can't or won't serve?
Since a principal can execute a POA without the agent knowing that he/she has been appointed, it's important for any principal to name a successor agent, if possible. Better still, there should be a discussion with any potential agent about his/her willingness to serve if called upon.

Can more than one agent be appointed?
Yes. A principal may appoint co-agents to act either independently or jointly. If co-agents are appointed, then consider providing for the arbitration that might be needed should the co-agents disagree.

What are an agent's duties?
An agent is a fiduciary, and as such, must act for the principal's benefit with the utmost good faith and loyalty. Unless the POA specifies otherwise, an agent must:

- use care and skill
- keep the principal informed
- obey instructions
- act only as authorized
- avoid conflicts of interest
- keep his/her funds separate from those of the principal
- and keep good records.

When should a POA be created?
An individual can have difficulties handling his/her financial affairs suddenly, such as due to an accident, or gradually over time. Whatever the situation, when someone you love is capable enough to recognize that he or she needs help, then help should be provided — and a POA is an excellent way to do so.

How does one go about establishing a POA?
While no particular form is required here in Connecticut, the Connecticut General Statutes, Sections 1- 42 to 1-56, inclusive, is a short form that can be used.
It is important to know that a POA is a state-specific legal document that may not be honored in other states and that financial institutions have additional POA forms they require be used.

Is a POA just a form?
Absolutely not. Each POA should be customized to meet a principal's needs in terms of family, financial, and personal wishes. Among the matters that should be considered when preparing a POA

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are whether an agent should be...

- compensated, and if so, how much and how is this determined?
- required to keep your family informed about his/her actions on behalf of your loved one?
- authorized to make gifts of your loved one's property, and if so, to whom and are there any limitations?
- authorized to create trusts on the principal's behalf or designate beneficiaries on life insurance policies or retirement plans?
- authorized to transact business with him- or herself on the principal's behalf?
- or authorized to maintain joint bank accounts with the principal?

Also important are the following considerations.

- Does the principal have a business, a professional practice, or real property that must be managed?
- Does the principal have dependents, and if so, do any have special needs?
- Is there out-of-state property that will require the POA to comply with the laws of another state(s)?
- In the event of incapacitation, does the principal want to remain home as long as it is practical?
- Does the principal own any pets that must be cared for if he or she becomes incapacitated?
- Does the principal want to limit agent liability for honest mistakes?

Can a POA be revoked?
Yes. A principal may revoke his/her POA whenever he/she chooses, at which time all original copies of the POA should be destroyed. If a principal's agent has possession of such originals, the principal should notify the agent of the revocation by certified mail and request their return.

Once the agent has received such notice, he/she has no legal authority to act under the POA; however, a principal should also notify all third parties with whom the agent has acted on his/her behalf that the POA has been revoked. If a POA has been recorded in the clerk's office, then the principal should also record a notice of revocation. I recommend that any principal wishing to revoke a POA consult with his/her attorney immediately.

Is a principal responsible for his or her agent's actions?
Yes, if the agent was acting within the scope of his/her POA authority.

What about accountings?
Both principal and agent may apply to a Court of Probate for an accounting, as provided in subsection (b) of Section 45a-175 of the Connecticut General Statutes.

Should an attorney be consulted before signing a durable POA?
Yes. A POA is not just a simple form but a powerful, flexible legal instrument that creates legal duties and responsibilities. Competent counsel is required to ensure that it meets a principal's specific needs. In Conclusion Life is unpredictable. Since a sudden or gradual disability can interfere with an individual's ability to handle his/her affairs safely and successfully, a general durable POA is always a good way to avoid the costly, time-consuming appointment of a court-appointed and supervised guardian or conservator while providing someone you love with responsible assistance when needed.

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How Special Needs Trusts Work:
Poverty and Disability Should Not Go Hand in Hand
By Attorney Sharon Pope

Mom is afraid to leave an inheritance to her son who gets services through the Acquired Brain Injury Waiver (Title 19) because she thinks he might lose his services and his benefits.

L.G. has a medical malpractice suit pending and does not want to apply for Medicaid (Title 19) waiver services. She needs the service but she has heard that any award will just go to the State of Connecticut and none of it will benefit her.

It is a common misunderstanding that you must be impoverished in order to qualify for Medicaid (Title 19) and the ABI Waiver or other Medicaid waiver programs. It is also commonly thought that if you have a child with a disability you will have to disinherit that child in order to preserve important benefits.

How can persons with disabilities receive or retain assets if they need the medical or home care assistance through the Medicaid (T-19) waivers for acquired brain injury programs? Under Medicaid and SSI rules there are certain assets which are not counted toward the asset limitations. Assets, in a properly drafted special needs trust, can be protected so that they can only be used to enhance and supplement the quality of life for persons with disabilities while at the same time preserving the important Medicaid or SSI benefits.

In 1993, Congress made significant revisions to the Social Security Act which have forever changed the potential quality of life for persons with disabilities. Under OBRA: “These 1993 revisions, certain types of trusts were designed as a means of protecting the beneficiary’s assets while preserving benefits and entitlements. The money, or other property in these trusts, is deemed non-countable/ unavailable to the beneficiary of the trust for Medicaid purposes and for some other programs such as SSI.”

Fundamentally, there are 2 types of funding for these trusts: one is self-funded (such as an award from a personal injury lawsuit, back payment from social security, or savings) and the other is funded with “other people’s money” such as money inherited through a properly drafted last will and testament with special needs trust language.

First, let’s talk about the rules for a self-funded trust:

1. The trust must contain assets of the individual with a disability, i.e. self-funded, typically from savings, a personal injury settlement, inheritance, or divorce.
2. The individual must be considered disabled according to criteria under the Federal Supplemental Security Income (“SSI”) program. Individuals receiving SSI or SSD
3. (Social Security Disability) would qualify. However if the individual does not receive SSI or SSD, the State of Connecticut has an equivalent method for finding this person disabled.
4. The trust must be established for the benefit of such individual by that individual’s parent, grandparent, legal guardian, or a court.
5. The individual must be under the age of sixty-five (65) years. (there is another type of special needs trust available if you are 65 or better)
6. Upon the death of the individual, the state shall have the right to recoup from the remaining assets of the trust an amount equal to the Medicaid benefits that it had paid on behalf of the

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disabled party during his or her lifetime.

How does this trust work? There are 3 parties to a trust: 1) the person who establishes the trust, also referred to as a settlor; 2) the trustee who determines distributions from the trust and, 3) the beneficiary who is the person with a disability.

The trust can be established by a parent, grandparent, legal guardian or court. Once the trust is established, the settlor plays little or no role in the trust unless the settlor also happens to be the trustee, which is permitted. So a parent could both establish a trust and be the trustee. However, under no circumstances can the beneficiary be the trustee because this would make the assets countable for purposes of benefits/entitlements.

A trustee must be identified. This is typically a trusted family member or a trusted friend. If the beneficiary is married, for example, the spouse can serve as trustee. If the person with a disability has no one to serve as trustee, PLAN of Connecticut could be considered.* The trustee has the sole, absolute and uncontrolled discretion regarding any distribution from the trust. The trustee can consult with the beneficiary and the family or friends of the beneficiary to help determine what distributions are needed.

Goods and services can be paid for with trust funds, but under no circumstances should money be given directly to the beneficiary; this would violate the terms of the trust document and jeopardize the beneficiary's benefits/entitlements. The beneficiary of the trust is the person with a disability. The assets in the trust must be used for the sole benefit of the beneficiary. The assets can be used for such things as supplemental therapy, field trips, vacations, dental care and so forth. The assets are not to be used for items which are covered by benefits. For example, Medicaid pays something for dental care but one may not be very pleased with the limited services, so money in the trust could be used for dental care not covered by Medicaid.

Next let's talk about trusts funded with, "other people's money". This is the case of an inheritance; this is someone else's money. Let's say that C.J. wants to make sure her son will be provided for after she passes away. She could have her last will & testament drafted to include language which would establish a special needs trust for her son. Upon her death, a special needs trust would be established for her son. This way he would retain his benefits so that money in the trust could be used for supplemental items such as the ones mentioned under the self-funded trusts.

In addition when her son passes away, the money in the trust can go to other people she named in her will. This end result is quite different from the self-funded trust which requires that the state be repaid for medical benefits prior to any distribution to other beneficiaries.

In order to create a special needs trust that protects assets and does not jeopardize benefits, it is very important to get good advice, usually from an attorney who specializes in this area of law. This is a very important legal document and requires the skill and knowledge of a legal expert.

* For more information see PLAN of Connecticut at: www.PLANofCT.org or call (860) 523-4951 for details.

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Neuroplasticity: The Brain's Ability to Reorganize

By Sarah Raskin, PhD

The field of neuroplasticity — or brain plasticity — has emerged only recently, but it has generatede considerable excitement about the kinds of changes that are possible in the brain. From the earliest reports that new brain cells actually grow in specific brain regions of birds as they learn new songs each spring to exploratory work with individuals with motor, sensory and cognitive deficits, it is a rapidly growing field.

Recently, it has been shown that the brain can change in response to an animal's life experiences. For example, some researchers separated rats into two groups. The first group was placed in what was termed an "impoverished" environment. This was essentially a normal cage, with the rat placed alone. The other group of rats was placed in what was termed an "enriched" environment. This environment had rats housed together, with toys and exercise wheels. The rats in the enriched environment had heavier brains, higher levels of some brain neurotransmitters, more nerve cell connections, and increased neuronal branching — and these rats performed better on learning tasks.

After many studies, it began to look like exercise in the enriched environments was a big part of creating these brain changes; however, brain changes are specific. Thus, animals trained to use a specific paw to press a bar for food showed greater cortical representation of that paw. Likewise, animals trained to use visual cues in a maze show greater representation of visual areas. So exercise, while extremely useful, is not the answer alone.

It seems that just working on a task that requires new learning leads to new neurons being generated by stem cells. Moreover, adult brains can grow new cells in the hippocampus and these new nerve cells are functional. But you don't need to grow new nerve cells to see the effects of experience on the brain.

When you spend a lot of time doing something, the brain starts to devote more area to that task. This is called reorganization. Reorganization can occur in all sensory modalities as a result of experience.
For example, there is a certain amount of the cortex of the brain that controls each finger. If a monkey is trained to use a particular finger for a task, the amount of brain cortex used for that finger becomes enlarged. In humans, there has been a demonstrated increase in the representation of the left hand in violin players.

In addition, practice with a cognitive task has been demonstrated to lead to reorganization of the brain. For example, when people were required to think of a noun when given a verb, the brain areas that were activated changed with practice. One of the most interesting studies of the effects of practice is the series of studies done on London taxi drivers.

Learning to navigate in London as a taxi driver requires very complicated spatial skills. It turns out that taxi drivers have larger areas of the brain required for navigation than other people. These areas also increase in size according to years spent as a taxi driver.

These principles have only recently been applied to remediation after brain injury. Avery promising approach has been constraint-induced therapy. Constraint-induced therapy has been used with

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success in people with stroke, brain injury, spinal cord injury, and hip replacement — mostly with people who have muscle paralysis or weakness on one arm. The person puts their fully functional arm in a sling or mitt so that he or she is forced to use the impaired arm. By doing so in a structured way over a long period of time, the impaired arm improves in function and brain reorganization is observed.

More recently the same principle has been applied to remediation of language after a stroke, when those with trouble using language were placed in a room with a microphone so that they could not use any form of facial expression or gesture to get their ideas across. By practicing this way over time, they improved in their language functions.

Other studies have suggested that cognitive rehabilitation techniques themselves may cause brain reorganization. This has been especially promising in approaches aimed at rehabilitating attention deficits after brain injury, and early work has suggested that some remediation techniques might help children with dyslexia. Furthermore, it may be that what you do each day can help keep your mental processes sharp.

For example, in a series of studies with nuns who all live together, share the same environment, food, etc., they compared nuns who stay mentally active through reading, writing, doing crossword puzzles and those who did not and found that the nuns who were mentally active had much lower rates of dementia as they got older.

Right now we are only beginning to understand how we can work to maximize increases in plasticity after brain injury. We know that repeated practice helps strengthen skills and functions. Of course, some plasticity changes reflect compensation while others reflect recovery, so treatment must be specifically designed with one or the other in mind. In other words, in some cases the plasticity is one of an intact cortical region taking on the tasks once mediated by the damaged region, while in other cases, it is now suggested that damaged regions can actually recover and resume previous functions. So the first lesson to be learned is “use it or lose it!” Keep your brain active and engaged. Read, play chess, do puzzles — whatever you enjoy. Keep your environment as stimulating as you can. And remember, whatever task you spend a lot of time doing is giving your brain the message that this is the most important task and other functions will start to receive less brain area, so don't spend all day just watching television. Be sure your brain knows that thinking, problem-solving, reading and writing are all important!

The second lesson? Since exercise seems to be important to making brain changes possible, get regular exercise to the extent that you are able!

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A Fresh Look at Behavior Problems After Brain Injury

By Barbara Nadeau, MA, OTR/L

What do the following words have in common? Non-compliant, inappropriate, resistant and oppositional.

As brain injury survivors will tell you, they are all often used to describe someone with a brain injury. There is no doubt that a brain injury can cause changes in behavior. Damage to the frontal lobe can cause behavioral disinhibition (impulsivity), poor judgment and perseveration (repetition of thoughts or actions). Sometimes a brain injury will cause behaviors that are dangerous, disruptive or otherwise difficult. It is important for an individual with a brain injury to be given support to change the behaviors that interfere with their ability to move forward with their life.

Positive behavioral support focuses not only on reducing problem behaviors but on enhancing an individual's overall quality of life. This means utilizing proactive strategies for changing the environments that tend to trigger the maladaptive behavior, teaching new skills to replace problem behaviors, incorporating daily activities that give meaning to one's life, and always treating the individual with a brain injury with compassion and respect.

The first step, when there is maladaptive behavior, is to look at the environment in which the behavior is occurring. Is the environment too overwhelming? After a brain injury it is common for people to be more sensitive to bright lights and noise. Places like busy malls and restaurants and can initially be overwhelming after a brain injury. Likewise, family gatherings or visiting with friends, while fun at first can become over -stimulating, increasing the likelihood of a behavioral outburst. Recognizing these outbursts for what they are – a response to overstimulation --rather than inappropriate behavior, will help caregivers intervene in an effective manner.

Environments where an individual with a brain injury is not sure what comes next can also lead to problem behavior. Chaotic environments where there are frequent changes in caregivers, expectations, and activities can be very anxiety provoking for someone with a brain injury. People often function better when they have an established routine that they follow each day. When the routine is changed, such as when a caregiver is going on vacation or there is a special event coming up, people will do better when given an explanation, advance warning and reminders.

Other environmental considerations may include determining if there are particular times during the day when the individual has more difficulty controlling their behavior, or if there are specific activities or events that result in behavior problems. Making simple changes in an individual's environment can be the quickest and easiest way to improve behavior.

When an individual exhibits disruptive behavior it is more effective to teach him or her a new response than to just attempt to eliminate the problem behavior. It is not enough to reprimand an individual for poor behavior; they must also be given a specific alternate response to use instead. For example, teaching responses to frustration, such as asking to take a break, or counting to ten will, over time, result in the individual being able to tolerate more challenging situations and activities.

Individuals with brain injuries, like all adults, should have the opportunity to participate in community life, develop and maintain satisfying relationships, express personal preferences and develop personal competencies. However, due to the changes in the brain, sometimes they need more support to do so. This support may be provided by family members and friends, but it is often given by

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new caregivers and professionals– people who didn't know the individual before their brain injury. To provide effective support it is necessary to make a sincere effort to get to know the person. What is important to them? What parts of their life have they been the most proud of? What would he or she like to change about their life?

When caregivers take the time to truly listen and understand they can begin to work collaboratively with the individuals they serve. A caregiver's role is to guide, not control. A caregiver should sound like a mentor, not a parent, for when an individual is treated like an adult he or she is more likely to act like an adult. A respectful communication style can go a long way towards eliciting appropriate behavior and growth.

Next time you are tempted to describe someone with a brain injury as non-compliant, inappropriate, resistant or oppositional, stop and ask yourself these questions. Could the environment be causing the problem? Has the individual been taught another way to respond in this situation? Does the individual consistently have the opportunity to select and engage in meaningful activities? Do I always communicate respect toward the individual in my words, tone and demeanor? There is a reason behind most difficult behavior. All people deserve the right to be treated with compassion and respect and are entitled to lives of quality as well as effective services.

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Brain Injury and Your Vision

By William V. Padula, OD, DPNAP, FAAO, FNORA

Following a Traumatic Brain Injury (TBI), patients often report visual symptoms, such as visual fatigue, eye strain, intermittent blurred vision, and headaches. However, people who have had a TBI can experience other symptoms that actually arise from problems with visual processing in the brain. These can cause difficulty with balance, dizziness, vertigo, double vision, photophobia (glare sensitivity), words in print moving, difficulty functioning in crowded and/or busy environments, panic attacks, and visual hallucinations. Such post-TBI visual difficulties are often overlooked and/or attributed to other non-related problems, which, when treated, usually fail to stop the visual symptoms.

What is vision?

Vision is a dynamic, interactive process involving motor and sensory functions. Our brains use our eyes to help organize and control the movement of our bodies and to stabilize what we see around us. This is called the visual process. When it is out of balance, it interferes with all aspects of performance, including cognitive perception.

A common misunderstanding is that “seeing” — or perceiving something with our eyes — delivers information to the brain much like a computer, but seeing is much more complex. It is related to movement, posture and our motor system in general. Because our brains usually coordinate these functions so rapidly and so well, most people take the entire process for granted. Only recently have we begun to understand how vision, movement, and perception are connected.

Our two kinds of vision

The focal process carries images through the central part of the eye and helps us see details. It also enables fixation (or the ability to look directly at something) and supports attention and concentration. However, the focal process only delivers information about an object to the brain if the eye is directly fixated on it.

The other kind of vision — the ambient process — delivers information to the brain from the peripheral vision. Peripheral vision, or what we see in the “margins” of our vision, affects our awareness of where we are in F space and where things are around us. This part of our vision is very important to the body's motor system. It also serves to organize our focal process by spatially orienting us before we look at details. The ambient visual process must work in conjunction with the focal visual process for effective vision.

Post-Trauma Vision Syndrome

In any neurological condition such as TBI, cerebrovascular accidents, and multiple sclerosis, imbalance can occur between the ambient and focal visual process. Research using visual evoked potentials (brainwave tests) has documented this dysfunction. It is called Post-Trauma Vision Syndrome (PTVS), and in my experience, PTVS is common in TBI.For a person with PTVS, there is an inability to organize information spatially. When this occurs the person becomes overly fixated on visual details and has to work harder to use his/her vision, which results in an effort and intensity that leads to visual fatigue, headache, and eyestrain.

PTVS can also cause individuals to visually fixate on individual letters instead of words when reading, and it can cause such individuals to have difficulty releasing (moving) their vision away from letters and words. This causes words to appear to jump and move about the page as the person attempts to read. It can also cause intermittent blurring and double vision, or diplopia. Some persons with

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PTVS also find it more difficult to function in busy, crowded environments, such as supermarkets or shopping malls. They identify people walking around in the peripheral vision as detail and that becomes confusing. In some cases, persons with severe dysfunction of the focal and ambient visual process will become anxious or even develop panic attack syndrome as their visual world is being reordered.

Symptoms of PTVS

- Double vision
- Headaches
- Blurry vision
- Dizziness or nausea
- Attention or concentration difficulties
- Staring behavior (infrequent blinking)
- Spatial disorientation
- Losing your place when reading
- Not being able to find the beginning of the next line when reading
- Visual memory problems
- Pulling away from objects when they are brought close to you
- Seeing objects as moving when they are actually stationary

Visual Midline Shift Syndrome

The ambient visual system also works with the other senses and the neuromotor system to give the brain information on how the body is oriented in space for posture and balance, which some people have difficulty with following a TBI.

For example, our ambient vision and motor system tell us where the midlines of our bodies (an invisible line that runs down the center of your body from head to toe) are in space. Normally, you know where your midline is; however, if either your ambient vision or your motor system is impaired, your sense of midline may be shifted from front to back or from side to side, distorting your sense of space. This has been termed Visual Midline Shift Syndrome, or VMSS, and when a person has VMSS, part of the visual process causes the brain to experience the floor as being tilted. He or she then begins to lean and/or “drift” to one side when walking due to the VMSS. Posture may be distorted, affecting seated posture. He or she may even experience back pain or muscle rigidity.

Simple tests can determine if a person has VMSS. When observing an individual with TBI walk, it is common see increased weight bearing on one side or the other, as well as a tendency to drift to one side when walking, sometimes bumping into objects more on one side than the other.

Symptoms of VMSS

- Dizziness or nausea
- Spatial disorientation
- Consistently drifting to one side of hallway or room
- Bumping into objects when walking
- Poor balance or posture — leaning forward, backward or to one side when walking, standing, or sitting in a wheelchair
- Back pain or muscle rigidity

Neuro-Optometric Rehabilitation

We tend to think about our individual sensory processors involving our eyes, ears, nose, tongue, mouth and fingers as separate systems, so we have highly specialized professions to treat each of

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them.

Optometry and opthalmology deal with sight and the eyes, audiology focuses on hearing, and specialists in olfaction concentrate on smell. We can usually get effective treatment for a specific sensory organ, but this specialized approach is not effective in dealing with the dual sensory/motor problems that can occur in persons with a TBI. However, individuals with TBI can benefit from a neuro- optometric rehabilitation evaluation.

A neuro-optometric rehabilitation evaluation is very different from a routine eye exam because its purpose is to analyze in depth the relationship between the ambient visual process and the neuro-motor system using a variety of tests. Once a comprehensive evaluation is made, various types of lenses and glasses capable of countering VMSS can be prescribed. Often, yoked-prism glasses, which shift the visual midline affecting balance and posture, will be recommended.

Yoked-Prism Glasses
A prism is a wedge of glass or plastic that produces an optical effect. When you look through a prism at an object, it appears to shift in position toward the apex — or thin part — of the prism. Prisms accomplish this effect by expanding or compressing part of the visual field, and it is this compression and expansion of the prism that, when properly prescribed, can effectively treat PTVS and VMSS. In some cases, yoke prismed glasses can dramatically improve posture and balance, enabling the individual to shift his/her weight in the direction necessary for better balance and a reduced risk of falls. Such glasses are usually prescribed for therapeutic use in short intervals each day and should only be used under the direction of the prescribing doctor, who may also recommend using these prisms during physical or occupational therapy.

Binasal Occlusion
Another therapeutic aid that can be employed is binasal occlusion, which involves placing two strips of opaque vertical tape on the part of each lens that is closest to the nose. Because the ambient visual system does not see detail but instead organizes space and orients to vertical lines and boundaries in the visual environment, the binasal occlusion provides a new vertical boundary to which the malfunctioning visual process can anchor itself.

Prisms and binasal occlusion can also be used to treat PTVS by reducing symptoms and enhancing visual performance. Individuals with PTVS experience a compression in the peripheral vision and these tools can help counter that effect by reducing the central field of vision and expanding the periphery. This reduction of stress in the visual system frequently improves attention, concentration, memory and cognitive function.

Summary
PTVS and VMSS are often part of the problem affecting such things as balance, posture, attention, and concentration following a TBI, but treatment through use of lenses, prisms and therapy can reduce symptoms and improve an individual's functioning. Neuro-optometric rehabilitation is proving itself to be an interdisciplinary approach capable of maximizing the potential of other therapies, as well, such as physical, occupational, speech, and cognitive therapies.

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Substance Use and Brain Injury: An Interview with John Corrigan

By Barbara Nadeau

A few years ago there was a well-known television commercial that showed a plain white egg while a voice announced “this is your brain.” The next image was of an egg frying as the voice said “this is your brain on drugs.”

This commercial might be the first image that pops into your mind when you think about substance use and brain injury but the damage that drug use does to the brain is only a piece of the relationship between brain injury and drugs and alcohol.

Studies have found that between 50 to 60 percent of the individuals admitted to rehabilitation after a brain injury have prior histories of substance use disorders. In addition, 10 to 20 percent of the individuals who sustain a traumatic brain injury will develop a substance use disorder for the first time following the injury. Substance abuse and brain injury is a big problem.

In May, Dr. John Corrigan came to Connecticut as part of the Brain Injury Alliance of Connecticut’s Professional Development Series. Dr. Corrigan is the founder and director of the Ohio Valley Center for Brain Injury Prevention and Rehabilitation and directs the TBI Network, a community-based treatment program for substance abuse after brain injury.

While he was in Connecticut, BIAC met with Dr. Corrigan to talk about brain injury and substance use.

BIAC: Our first question is probably the one you are asked most often. Is it ever okay to have a drink after a brain injury?

Dr. Corrigan: Before answering that question I want to make sure people realize that even for people without a brain injury the recommended daily maximum is no more than 2 alcoholic drinks for adult men under age 65 and no more than 1 drink for women or for men over the age of 65. So the question becomes is it okay to have 1 -2 drinks per day after a brain injury and the answer I have to give is that there is no safe amount to drink after a brain injury.

BIAC: So even having an occasional social drink is a bad idea?

Dr. Corrigan: Research is showing us that the brain can continue to recover for many years after an injury. I believe most people want to do everything possible to maximize that recovery. When you have a drink you are introducing a toxin into the brain. While we do not know for sure, there is reason to believe that people who drink after a brain injury may be limiting their recovery. We are also concerned that deficits from the brain injury that can re-emerge in people as they age will be exacerbated by the use of alcohol.

BIAC: I have heard that alcohol and drugs have a more powerful effect in the brain after a brain injury. Is this true?

Dr. Corrigan: After a brain injury people find that they get high more easily than they did before and this only makes the impairments from the brain injury worse. After drinking, or using drugs, people will have more difficulty walking, talking and thinking. People also become more impulsive which can lead to all kinds of problems including sustaining another brain injury.

BIAC: Are there certain types of substance abuse treatments that work better for someone with a

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brain injury?

Dr. Corrigan: We are doing research at Ohio State to look at this. We have examined a few different approaches including motivational interventions, cognitive behavior therapy and behavioral treatment. Each of these can be successful for certain people. The key is finding a program that appreciates the effect of the brain injury on recovery and is willing to make accommodations for the individual's unique style. Successful programs also help a person address inappropriate behavior and understand that behavior is often the result of the brain injury and not due to personality flaws or a lack of motivation.

BIAC: What about AA or NA?

Dr Corrigan: Self help can be effective for many people, especially those who have been involved with these groups before their injury. If AA or NA is new to a person who has had a brain injury it is a good idea to have a friend or family member go along to the first few meetings. Having someone to share the experience with and talk about it afterward can make the difference between dropping out or staying with the group.

BIAC: What else can family members and friends do to help?

Dr Corrigan: Family members or friends may need to assist in advocating for the right to appropriate treatment. This may include advocating for wheelchair accessible services or for the allowance of continued use of prescription medications while receiving substance abuse services. Family members or friends can also help by staying supportive and involved and working collaboratively with substance abuse treatment professionals.

BIAC: Where can I go for more information about brain injury and substance abuse?

Dr. Corrigan: The Ohio Valley Center for Brain Injury Prevention and Rehabilitation - www.ohiovalley.org has a number of articles on this topic.

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www.biact.org	Call 860.219.0291	BIAC, 200 Day Hill Rd., Ste. 250, Windsor, CT 06095

The Brain Injury Alliance of Connecticut is federally recognized as a tax-exempt 501(c)3 non-profit organization.
We rely on and are grateful to the many individuals, organizations, local businesses, foundations and corporations who understand the importance of our work and generously supportour mission. As such, BIAC welcomes donations in any amount.

BIAC offers the following programs and services in support of brain injury survivors, their families and caregivers, professionals and the community:

Brain Injury Helpline	Brain Injury Navigator	Statewide Support Groups	Outreach & Education
Through BIAC 's HelpLine, brain injury specialists provide individual support and guidance to survivors and caregivers to ensure that the often complex and overwhelming challenges theyface are negotiated more easily and effectively.	A fee-based service that provides customized, in-depth and personal direction from an expert in brain injury, helping those impacted by brain injury find their way back to a life that brings meaning and joy, and the triumph of moving forward.	BIAC sponsors numerous support groups throughout Connecticut thatprovide infor- mation, support and encourage- ment to survivors, their loved ones and their caregivers.	BIAC works to increase aware- ness and understanding of brain injury and its prevention through school, professional and community presentations. Professionals in the brain injury community can also attend BIAC 's Annual Conference to learn the latest developments in the field.

To learn more about BIAC 's free **programs and services**, visit www.biact.org or call 860.219.0291.

Brain Injury Alliance of Connecticut
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