



We do more than
improve your function.

We help rebuild your life.

Find your strength.

Dear Patient/Family/Friends

When a head injury occurs to a loved one, it affects your entire family. Each injury is unique and recovery can be slow and demanding. We are here to support and educate you on the services available to you.

We strongly encourage all family members to take advantage of every service the Spaulding Rehabilitation Network provides. Family members become an important part of our team. This starts with a weekly family education group at Spaulding Hospital Cambridge where you can connect with other families, talk with support staff, and gain valuable education about brain injury. Please ask any staff member on your loved one's unit about the next group. We look forward to seeing you.

Thank you,

Marilyn Price Spivack
Neurotrauma Outreach Coordinator, Spaulding Network
Founder and Past President of the Brain Injury Association of America
Mother of Deborah Lee Price injured in 1975

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The Spaulding Rehabilitation Network Disorders of Consciousness Program

The Spaulding Rehabilitation Network (SRN) offers the Disorders of Consciousness (DoC) Program. SRN has two hospitals working together to offer this program:

Spaulding Hospital for Continuing Medical Care in Cambridge (Spaulding Cambridge)
Spaulding Rehabilitation Hospital in Charlestown (SRH)

Spaulding Cambridge treats and cares for patients who need complex medical care. SRH treats and cares for patients who can tolerate intensive rehabilitation of three hours a day five or six days of the week. As a Network we admit the patient to the facility that can meet the patient's needs at the time they are discharged from the acute care hospital.

The DOC program is for patients who have had severe acquired brain injury. These patients have not yet regained the level of consciousness that allows them the ability to follow instructions in a consistent manner, to reliably communicate or perform basic self care.

We use a systematic, evidence based approach to set rehabilitation goals. These goals are developed and revised based on the patient's progress. Progress is measured using standardized protocols.

Our mission includes three aims:

- Clinical:* To optimize functional recovery through evidence based assessment and treatment.
- Research:* To identify mechanisms that contribute to disorders of consciousness. To develop diagnostic assessment methods and to investigate the effectiveness of treatment interventions.
- Education:* To share knowledge and provide resource to other healthcare professionals, family members, caretakers, payors and policy makers involved in the care of patients with brain injury.

Program Objectives

- Determine level of consciousness
- Identify physical and cognitive barriers to communication and movement
- Treat medical problems that interfere with consciousness
- Prevent complications
- Encourage wakefulness and responsiveness
- Assess for specialized communication and environmental control aids
- Establish an accurate prognosis
- Assess and plan long term care needs
- Educate and support patients, families and friends
- Participate in cutting edge research



Program Structure

The DoC Program offers a broad range of clinical services for patients recovering from severe brain injury. As patients recover, their needs change. The clinical services are adjusted to match the patient's current level of function.

The DoC Program is organized into three levels of care. Each one addresses the clinical needs of the phases of recovery.

- Patients who are not conscious
- Patients who are awake but not able to communicate consistently
- Patients who can communicate but who are confused and need help with care

These phases may include:

Interdisciplinary Team Conference (ITC)

The patient's progress is discussed on a weekly basis. The team reviews progress and short term goals. The long term outcome and discharge needs are also discussed. The case manager will update the family after each ITC. We will ask you to name a spokesperson.

Family Team Meeting

This is the time for the team to provide information to the family and to discuss the patient's progress. We will work with you to plan for discharge. Typically, a family meeting with the members of the team will be planned after two weeks of care and again after six weeks.

Discharge Planning

Recovery from brain injury usually requires a series of transitions. Our patients usually go to various facilities during their recovery. Discharge planning starts shortly after admission. The case manager and social worker work closely with the family and the team to make the plan that is best for the patient. Once a plan is chosen, the case manager will send all the necessary clinical information to the next level of care.

Some examples of discharge plans are:

- Acute Rehabilitation Hospital – at least three hours of aggressive therapy
- Skilled Rehabilitation Facility – ongoing therapy at a less demanding pace
- Long term care facility
- Homecare
- Outpatient Rehabilitation

Insurance Coverage

The case manager is the point person with the insurance company. Our case manager works with the insurer to make the best use of benefits. Coverage is generally reviewed weekly. Our case manager will also discuss the coverage for the next level of care.

Program Structure (cont'd)

After rehabilitation, the patient may still need help with activities of daily living. This can take place at home or at a long term care facility.

Traditional insurance does not pay for long term care. It is best to start the application process for services funded by state and federal government as early as possible. It is critical to do the paperwork as recommended by your case manager and social worker. Keep in mind that waiting lists are long and the process can be slow. We will help you apply for MassHealth, social security disability income, state head injury services and other benefits and services, including Medicare.

Family Support/Coffee Hour

We offer a family education meeting each week. Families receive information and education about the consequences of acquired or traumatic brain injury. Knowledge is important to the healing process. We encourage you to take advantage of the information shared by the staff in formal and informal settings. Getting the best of the expertise in the Spaulding Network will make a difference in your role as caretaker and advocate for your loved one.

We are here to help every family in the process.



Your Core Rehabilitation Team

Medical Staff	
Physical Medicine & Rehabilitation MD	
Nurse Manager	
Nurses	
Nursing Assistants	
Physical Therapist	
Occupational Therapist	
Speech Therapist	
Dietitian	
Case Manager	
Social Worker	
Other important names to remember	

THE REHABILITATION TEAM

Medical Staff

- Manages the patient's medical conditions

Physical Medicine & Rehabilitation MD

- Manages the rehabilitation program

Nursing Staff (RN, LPN, CNA)

- Provides daily care for patients
- Insures a safe and supportive environment
- Administer medications, perform treatments, monitor patients, and update the medical staff

Physical Therapist (PT)

- Develops a treatment plan to maximize functional abilities
- Addresses impairments such as strength, range of motion and motor control needed for mobility

Occupational Therapist (OT)

- Addresses skills needed for every day activities such as feeding, bathing, dressing
- Works to improve cognitive and visual/perceptual skills

Speech-Language Pathologist (SLP)

- Specializes in the treatment of communication and swallowing disorders
- Works to improve cognitive skills

Dietitian

- Evaluates the patient's nutritional needs and proper diet

Case Manager

- Oversees and helps develop the patient's ongoing treatment plan and discharge goals
- Coordinates insurance benefits and funding sources

Social Worker

- Supports the family through counseling, education about brain injury, referrals to brain injury resources, housing resources, assistance with guardianship, finances, behavioral health and substance abuse treatment

In addition, the following specialists may be a part of the brain injury patient's rehabilitation team.

Pulmonologist

- Doctor that specializes in conditions of the lungs, diagnosing conditions and recommending treatments

Respiratory Therapist

- Specializes in providing techniques and technology used to help a patient breathe and keep airways open

Psychiatrist

- Available on a consultative basis to assist the team in meeting the psychosocial needs of the individual patient and his or her family

Neurologist

- Specializes in the evaluation and treatment of neurologic deficits impaired as a result of acquired brain injury

Neuropsychologist

- Specializes in the relationship between the brain and behavior

Therapeutic Recreation Specialist

- Specializes in rehabilitating a patient's level of functioning and independence in life activities

The Family

The family is one of the most important members of the rehab team. "Family" includes all of those persons touched by the injury. Family members provide valuable information about the patient, such as pre-injury history, interests, and motivators. These factors can be crucial to the success of the rehabilitation process. Education and communication with family members begins on the day of admission and continues throughout the patient's stay.

The brain injury team encourages families to be involved in the patient's treatment program and will guide you in the best way to help your family member. Since each person and each injury is different, each patient progresses in a different way. We encourage the family to be an active member of the rehabilitation team. The team will help you to understand the level of involvement that is needed at different stages of the treatment program.

The team members will demonstrate effective ways to communicate, approaches to use in handling problems, and techniques that reinforce the patient's abilities and successes. Family members are encouraged to attend therapy sessions as a way of receiving training in the above.

We will ask you to name a family spokesperson to manage all updates from the team.

Please Tell Us Important Things About Your Loved One

Please fill in the following so that we can get to know your family member.

Nickname: _____

Birthday: _____

Important People in My Life:

Pets: _____

School: _____

Work: _____

Hobbies: _____

Favorite Things: _____

Least Favorite Things: _____

Favorite Movie/TV Show/Music: _____

I Learn Best By: _____

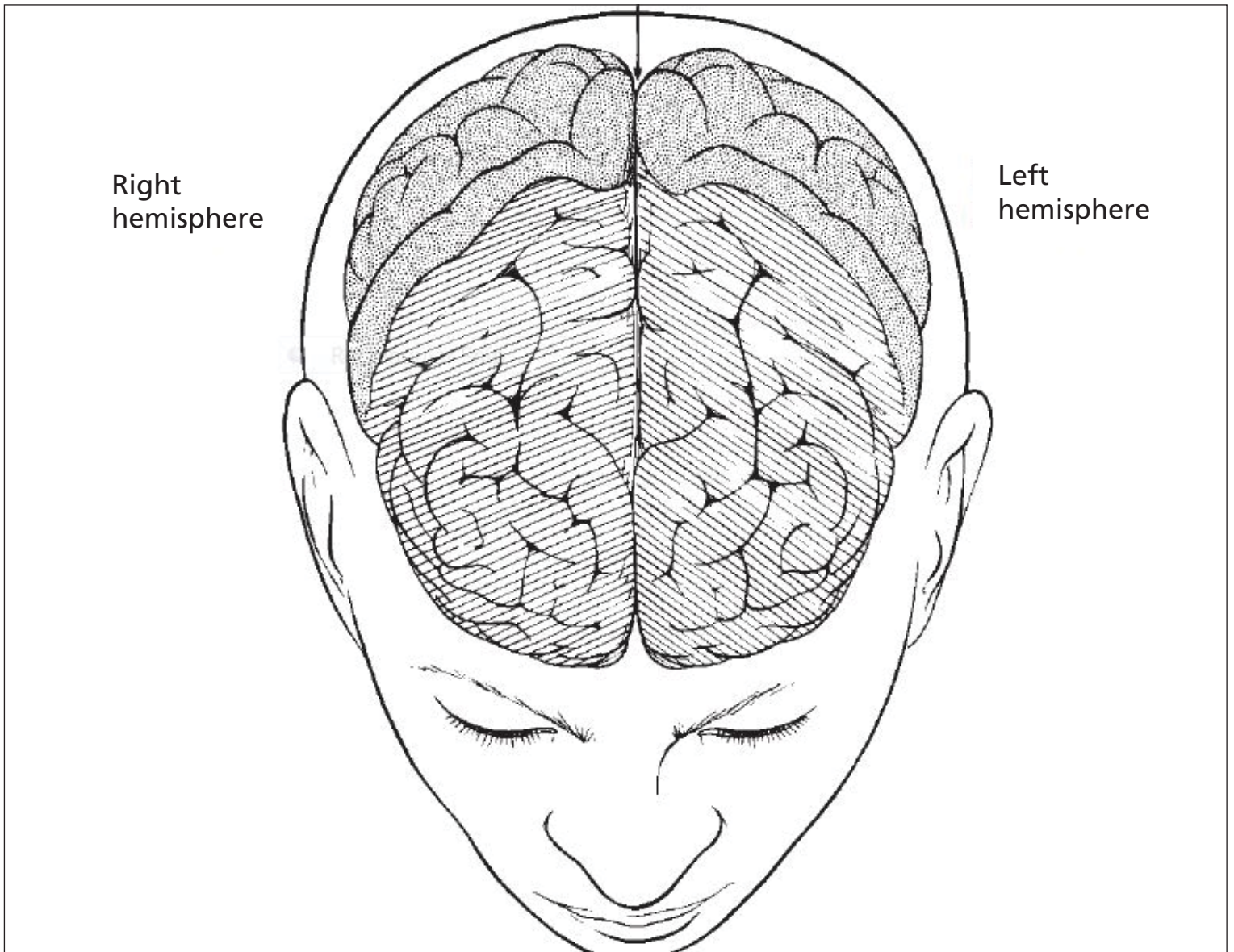
Things That Comfort or Calm Me: _____

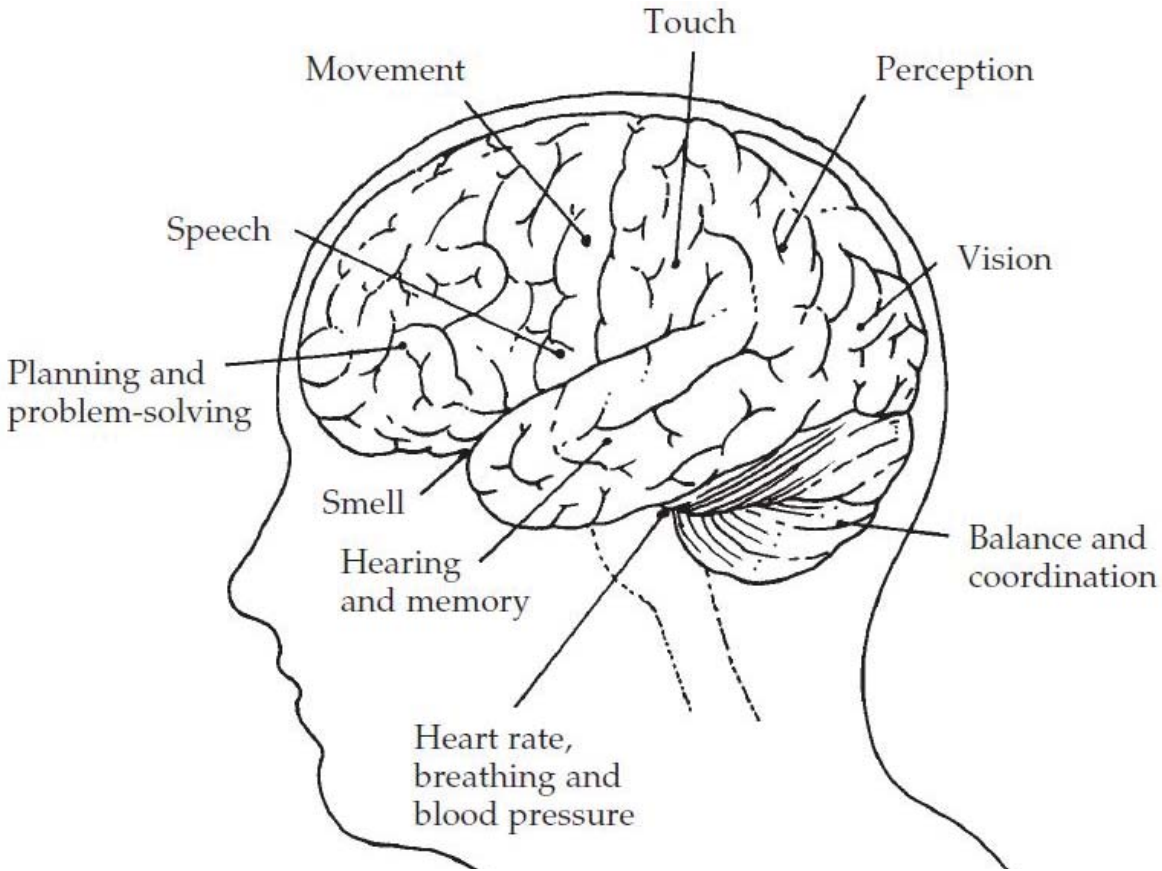
Things That Stress Me: _____

What Else?? _____

Brain Anatomy

The brain is described by its different areas, called lobes, hemispheres, and two special areas called the cerebellum and brainstem. Generally, each area of the brain has a specific job or function.





Left Hemisphere: Written & spoken language; reasoning; number skills; scientific knowledge; right arm/leg control

Right Hemisphere: Insight; spatial perception; art and musical awareness; imagination; left arm/leg control

Frontal Lobe: Conscious thought; “executive functioning” (planning, organization, abstract thought, attention, behavior, emotions, morals; problem solving; emotional responses)

Parietal Lobe: Visual-spatial awareness; understanding and interpreting language; integration of senses

Temporal Lobe: Hearing; smell; taste; memory; emotion

Occipital Lobe: Vision; recognition of color and shapes

Cerebellum: Coordination; balance; posture; motor learning

Brainstem: Automatic functions (breathing, heart rate and blood pressure, temperature control, digestion); swallowing; sleep/wake cycle and level of alertness. Connects brain to the spinal cord

Types Of Brain Injury

A Brain Injury is any injury that damages brain function. A brain injury is described by two broad categories:

Traumatic: Any external force to the brain such as a fall, car accident, gunshot wound or blunt trauma

Non-traumatic: Any internal event such as a stroke, aneurysm, tumor, infection or disease

A brain injury interferes with the way the brain normally works. When nerve cells in the brain are damaged, they can no longer send information to each other in the normal way. This causes changes in the person's behavior and abilities. The injury may cause different problems, depending upon which parts of the brain were damaged most.

There are three types of problems that can happen after brain injury:

- Physical
- Cognitive
- Emotional

It is impossible to tell early on which specific problems a person will have after brain injury. Recovery may take months. With some severe injuries, improvement may continue over many years as the healthy brain takes over new functions.

What Affects Recovery

Many physical, mental and personality changes can occur after a brain injury. Some of these changes are temporary; others can be long lasting. Each person's recovery is different. Complete recovery to the patient's pre-injury lifestyle may or may not be a realistic goal.

What can affect the degree of recovery:

- The location, type and severity of the brain injury
- The amount of time since the injury
- The length of time in a coma
- The general health before injury
- The person's psychological reaction to the injury
- Pre-injury personality
- Learning style

Common Medical Management

The team works with the patient on a daily basis to promote medical stability. Some of the issues we address are:

Impaired Alertness and Fatigue

Fatigue is common in the early stages after a brain injury. After a brain injury the body needs time to rest, recover and rebuild strength. For some individuals just staying awake, alert and attentive is an accomplishment. A person who is inattentive and drowsy is sometimes accused of being unmotivated. However, the person may not lack motivation. He or she may sincerely be tired. Rehab schedules should include adequate rest periods during the day. The decreased alertness and mental fatigue should gradually lessen as the person recovers.

Muscle Tone

People with brain injury may also experience changes in muscle tone. Muscle tone is the normal resistance to stretch of a healthy muscle. The following terms are related to changes in muscle tone.

Spasticity: Increased tone or contractures causing stiff and awkward movements.

Rigidity: When many muscles are contracting at the same time, making movements difficult.

Flaccidity: When there is no resistance to stretch of a muscle.

Atrophy: A decrease in overall muscle bulk.

Contractures: Muscles and joint capsules and ligaments may shorten permanently and range of motion becomes limited.

Infection

Patients may develop pneumonia due to immobility and/or aspiration. This can be treated with antibiotics, breathing treatments and chest physical therapy.

Nutrition

Many patients are admitted with a feeding tube for nutritional support. The dietitian determines which tube feeding will best meet the needs of the patient based on their height, weight and medical needs.

The medical team monitors the patient's tolerance to the tube feeding by checking residuals, laboratory data and weekly weights. Checking residuals is a way to make certain that the stomach is tolerating the formula.

Residual is the formula that remains in the stomach from the last feeding.

Tube feeding is infused over 24 hours. Once the patient is stable the infusion time is decreased and the rate is increased. This allows time off the feeding for rehabilitation needs. The next step is bolus feedings.

Bolus feeding is formula is placed in a syringe and flows slowly into the feeding tube. This is done a number of times per day based on the patients' needs.

Vital Sign Changes

The brain controls many activities on an unconscious level (i.e., breathing, blood pressure, heart rate, temperature). Your family member may experience difficulty with elevated heart rate, fevers and/or profuse sweating. The blood pressure may be too high, too low or go up and down suddenly. Some symptoms (such as heart rate and temperature) can be treated with medications. Fluids and medications can be given to keep the patient comfortable.

Skin breakdown

Immobility may cause the development of pressure ulcers. Changes in body chemistry may lead to skin problems. These may be treated with medications or creams. It is important that the skin is inspected daily to monitor for the development of skin breakdown. Frequent turning in bed, adequate nutrition, special mattresses and skin care can help in preventing pressure ulcers from developing or progressing.

Constipation

Constipation is common and a bowel program will be established using stool softeners, suppositories or other laxatives as needed. Toileting programs may be initiated to retrain the bladder and bowel when the patient's level of alertness has improved.

Blood clots

Prolonged bed rest and decreased mobility increase your family member's risk of developing blood clots in their legs. Elastic stockings and pneumatic boots may be used to decrease this risk. A patient may receive medications (blood thinners) via a pill or injection.

Neuropathy

Neuropathy is defined as a weakness and/or change in sensation in the arms or the legs. Patients with a brain injury may develop neuropathy due to nerve damage that may have occurred during the initial injury or due to prolonged immobility. Neuropathy may resolve if a cause of nerve compression is identified and relieved. Neuropathy that does not resolve is treated symptomatically (i.e., bracing) to provide support to the affected limb.

Altered sleep/wake cycle

The return of a sleep/wake cycle is a sign of emergence from a comatose state. Normal sleep patterns may be disrupted after a brain injury. Your family member may sleep a lot, have difficulty falling asleep or staying asleep. Over time it will become easier to develop a regular sleep cycle. Disrupted sleep patterns may respond to a routine bedtime, relaxation techniques, a quiet, uninterrupted environment and/or medication.

Hematoma

A hematoma is the formation of a clot. If it occurs in the brain, it may cause more damage. There are three kinds of hematomas: subdural (when a vein bleeds slowly between the skull and brain), epidural (when an artery bleeds quickly between the skull and brain) and intracerebral (when bleeding occurs inside the brain).

Hydrocephalus

Hydrocephalus is an enlargement of the four cavities (called ventricles) inside the brain. Hydrocephalus occurs when the cerebrospinal fluid is prevented from circulating around the brain and spinal cord. This fluid builds up in the ventricles causing them to enlarge. A shunt (small tube) may be placed in the head to drain fluid from the brain.

Seizures

Seizures occur due to a burst of electrical activity in the brain. Symptoms of a seizure depend upon which area of the brain is involved, and may include abnormal twitching or shaking, or loss of consciousness. Treatment includes medications and protecting a patient from injury during the seizure. Seizures often resolve over time.



Early Stages Of Brain Injury Recovery

Severe brain injury causes alterations in consciousness. Consciousness is defined as an individual's awareness of his/her self and environment. The recovery to consciousness can be a gradual process for individuals who have sustained a severe brain injury. It is important to know that these are stages individuals **usually, but not always**, pass through. Recovery can stop at any one of these phases. There is also no definitive timeline to predict how long an individual will remain at any one of these phases.

Coma

The person is unconscious, does not respond to visual stimulation or sounds, and is unable to communicate or show emotional response. Patients in this stage are unable to follow commands, speak or move purposefully.

Vegetative State

The person has sleep-wake cycles, and startles or briefly reacts to visual stimulation or sounds. These patients may make some sounds; cry, smile, or make facial expressions without any known cause; move eyes or 'follow' people and react to loud sounds with a startle.

Minimally Conscious State

The person is partially conscious, knows where sounds and visual stimulation are coming from, responds to commands inconsistently, can possibly vocalize and show emotion. They may use common objects purposefully; speak some understandable words; and respond to other people, things, events by showing emotions, gesturing, or focusing on objects.

* It is important to note that patients in a minimally conscious state do all of these things **inconsistently**, which can make it difficult to determine which state they are in.

Emergence from Minimally Consciousness State

Once a person can communicate, follow instructions, and/or use an object consistently and appropriately, they are no longer in a minimally conscious state.

*It is important to note that it is very common for patients to then experience confusion. This is called the Post Traumatic Confusional State.

The Coma Recovery Scale

The Coma Recovery Scale (CRS) is an assessment used in the DoC Program. It helps determine the patient's level of responsiveness. The CRS helps with treatment planning and tracking progress.

There are six subscales in the CRS. The scoring for each subscale is determined by a patient's capacity to perform tasks. Tasks range from reflexive to purposeful. The CRS is performed twice each week. It can be administered by a physical therapist, occupational therapist, or speech language pathologist. CRS scores range from zero to 23.

The subscales are broken up into the following functional abilities:

Auditory Function

Does the patient respond to verbal commands consistently or repeatedly?
Does the patient orient toward or react to loud noises?

Visual Function

Does the patient orient (with eyes or limbs) toward objects consistently or repeatedly?
Does the patient follow objects with his or her eyes smoothly?
Does the patient search for objects with his or her eyes?
Does the patient blink when presented with a visual threat?

Motor Function

Does the patient display the ability to perform motor functions?
• Attempting to use functional objects purposefully (spoon, comb)
• Other non reflexive movements such as grasping, reaching for a ball
How does the patient react to noxious stimuli?

Oromotor/Verbal Function

Does the patient speak in words, vocalizations, or exhibit reflexive oral movements such as yawning and tongue pumping?

Communication

Does the patient accurately and/or intentionally answer yes or no questions?
• By means of speaking, blinking, hand gestures, or other movements in his or her capacity

Arousal

How much stimulation does the patient require to attend to the entire assessment?

Other Assessment Tools And Scales

There are many different assessment tools and scales used to assess a patient's abilities and limitations during the rehabilitation process. The CRS is used most often in the DoC Program. The following scales may also be used to assess and track progress.

Confusion Assessment Protocol (CAP): Developed to assess a broad range of symptoms of the post-traumatic confusional state, including:

- Arousal, awareness and responsivity
- Cognitive ability for self care skills
- Dependence on others
- Psychosocial adaptability

Limb Movement Protocol: testing consistency and accuracy of the patient's ability to follow simple commands

Functional Communication Measure: This assessment is performed by the Speech Language Pathologists. It is a series of seven point scales to describe different aspects of the patient's functional communication and swallowing abilities.

Agitated Behavior Scale: This assessment is completed by nursing and therapy. Agitation is a normal part of brain injury recovery as the patient progresses.



How To Interact With Your Family Member

Here are some suggestions. We will help you choose some of these tips. Your family member needs a balance of stimulation and rest. We will help you find that balance.

If your family member is in a Coma:

- Stimulate senses by offering:
 - Smells (favorite foods, perfumes, flowers)
 - Sounds (music, voices of special people)
 - Things to look at (family pictures)
 - Things to touch (favorite blanket, stuffed toy, or clothes of different textures)
- Physical touch with your family member is important
- It is important to balance rest periods and periods of stimulation

If your family member is in a Vegetative State:

- Talk to your loved one even though they may not respond or understand. Recall recent life events, family changes, or current events to connect with family member.
- Use kind words and a gentle tone of voice when speaking to your family member. Use short sentences and simple words but speak in an age appropriate way.
- Assume that they can hear you and be careful what you say about them.
- Talk to your family member as you provide care so they are aware of what is happening to them.
- Tell your family member the day, date, time, where they are and what has happened to orient them.
- Limit conversing to one person at a time.
- Balance of stimulation and rest periods continues to be important.

If your family member is in a Minimally Conscious State:

- Limit the number of visitors to 2-3 at a time and for the day.
- Not more than one person should speak at a time.
- Maintain your voice in a calm tone and keep the room quiet and calm.
- Assume that they can hear you and be careful what you say about them.
- Ask your family member to complete simple tasks (squeeze hand, blink eyes) as instructed by therapy, but do not question them.
- Give them extra time to respond. You may see inconsistency in their response- this is normal.
- Ask your family member's therapy team if they have a yes/no communication strategy. If there is one in place, attempt to use this with your family member.
- Balance of stimulation and rest periods continue to be important.

If your family member is *Emerging from Minimally Conscious State*:

- Limit the number of visitors to 2-3 at a time and for the day.
- Not more than one person should speak at a time.
- Maintain your voice in a calm tone and keep the room quiet and calm.
- Assume that they can hear you and be careful what you say about them.
- Keep a calendar of activities visible and cross off days as they pass.
- Tell them often of the day, time, where they are, and what has happened to them.
- Remain cautiously optimistic, but do not overwhelm your family member with high expectations. Set small goals at a time.
- If your family member is unable to complete a simple task, do not argue with them or try to make them do the task.
- Reinforce that they are in a safe place and the people around him/her are there to help.
- Place objects that your family member may need within easy reach.
- Balance of stimulation and rest periods continues to be important.
- Keep a diary of visitors and important milestones.



Impact On Family

Most of the pages in this manual are devoted to what happens to the person with the brain injury. As a family member, you have also been significantly impacted by the brain injury in many ways. Being a part of your family member's recovery has likely been stressful physically, mentally and emotionally for you as well. It may seem like every aspect of your life has changed, which can feel overwhelming. Moving forward, your life will continue to be affected as your family member progresses through the rehabilitation process. The brain injury team members appreciate this and are here to support you. We know that your involvement is crucial in the patient's recovery process and we value your input and suggestions.

Taking Care of Yourself

Each family member copes with stress differently and makes adjustments in their own way. One of the key ways that you can support your family member is by taking care of yourself, physically and emotionally. This means eating well, getting enough sleep and adjusting your priorities to avoid feeling overwhelmed.

Understanding the Grieving Process

Each family member reacts differently to the impact of having a family member with a significant brain injury. Patients recovering from a brain injury act and think differently than they did prior to their injuries. This can be very stressful for family members because it means dealing with uncertainty of what will happen in the future. Family members may experience different stages of grief as they cope with the impact of the brain injury. Family may experience different emotions at different times during the patient's recovery. These may include fear, denial, sadness, anger, guilt, isolation, hope and gratitude. All of these reactions are normal.

Family Dynamics

In addition, family dynamics play a role in how families cope. At times, family conflicts can resurface and this can contribute to the ongoing stress associated with having a family member in the hospital. Sometimes, family members have to move into new roles and responsibilities such as a caretaker role that may be new for them. This adjustment can be challenging. It is important to communicate your concerns with the patient's team and ask questions. The rehabilitation team is available to support family members as they learn about how to best plan for the patient's future.

Suggestions For Coping

What works for one person may not be helpful for another. It may be helpful to think about what has worked in stressful situations in the past. The following suggestions are some ideas which may help you:

- Bring a trusted relative or friend to important meetings. They can be a helpful second set of ears for you.
- Write important information down in a journal or notebook. There is space at the end of this booklet. You can use this to keep track of questions you want to ask the health care team.
- Set up a phone tree or a communication system with friends and family. Name one other person for family and friends to call for information on the patient's progress. Use an internet site such as CarePages, Caring Bridge or Facebook.
- Rotate family visits. When you need to be away from the hospital, someone else may be able to visit.
- When someone offers to help, accept the offer. Keep a running list of chores to delegate and be specific about how someone can help. This is a great way to involve extended family and friends.
- Express your feelings. Discuss how you are feeling with a close family member, a friend or the staff. Realize that there may be emotional highs and lows. Talking can help the stress.
- Be kind to yourself and to others. Realize that you will not all have the same response or be feeling the same emotion at the same time.
- Promote your own health. Eat well, get sleep and exercise, and attend to your responsibilities outside of the hospital. Avoid overuse of alcohol, smoking or food as a way of coping. Find some activities you enjoy and that give you peace.
- Get involved. Become educated about brain injury. Attend therapy. Ask questions!!



Supports and Resources

The Brain Injury Association of America (BIAA) is the country's oldest and largest nationwide brain injury advocacy organization. BIAMA is one section of BIAA. The National Brain Injury Information Center is also associated with the BIAA. The BIAA are dedicated to advocacy, education and research on brain injury to bring hope and healing to the individuals with brain injury, their families and the professionals who work with them.

Brain Injury Association of America
1608 Spring Hill Road, Suite 110
Vienna, VA 22182
Tel: (703) 761-0750
Fax: (703) 761-0755
www.biausa.org

The Brain Injury Association of Massachusetts (BIAMA) is a private, nonprofit organization that serves individuals with brain injury and their families and offers award-winning prevention programs to individuals of all ages. BIAMA provides support services to brain injury survivors and their families, offers programs to prevent brain injuries, educates the public on the risks and impact of brain injury, and advocates for legislation and improved community services. Several support groups can be found throughout the state including Boston, Braintree, Framingham and Woburn.

Brain Injury Association of Massachusetts
30 Lyman Street, Suite 10
Westborough, MA 01581
Tel: (508) 475-0032
Toll-Free: (800) 242-0030
TTY: (508) 475-0042
Email: biama@biama.org
www.biama.org

The Massachusetts Rehabilitation Commission is responsible for Community Services and eligibility determination for the Social Security Disability Insurance (SSDI) and the Supplemental Security Income (SSI) federal benefits programs. The Statewide Head Injury Program (SHIP) is a division of the Massachusetts Rehabilitation Commission that offers many resources and services for Massachusetts residents who have sustained an externally caused traumatic brain injury. When you visit the mass.gov website, search for head injury.

The Massachusetts Rehabilitation Commission
Statewide Head Injury Program (SHIP)
Administrative Offices
27 Wormwood Street
Boston, MA 02210-1616
Tel: (617) 204-3852
www.mass.gov

BrainLine is a national multimedia project offering information and resources about preventing, treating, and living with TBI. BrainLine includes a series of webcasts, an electronic newsletter, and an extensive outreach campaign in partnership with national organizations concerned about traumatic brain injury. BrainLine serves anyone whose life has been affected by TBI. That includes people with brain injury, their families, professionals in the field, and anyone else in a position to help prevent or ameliorate the toll of TBI.

National Brain Injury Resources
2775 South Quincy Street
Arlington, VA 22206
Tel: (703) 998.2020
E-mail: info@BrainLine.org
www.brainline.org

The Brain Trauma Foundation (BTF) is focused on developing best practices guidelines, conducting clinical research, and educating medical professionals, patients and their caregivers. BTF is dedicated to increasing awareness and understanding of brain injury and treating the immediate and ongoing difficulties associated.

Brain Trauma Foundation
7 World Trade Center 250 Greenwich Street
34th Floor
New York, NY 10017
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www.braintrauma.org
Tel: (212) 772-0608
Fax: (212) 772-0357

The National Rehabilitation Information Center (NARIC) website has easy to find information on organizations, agencies, reports, internet resources and research projects.

National Rehabilitation Information Center (NARIC)
8201 Corporate Drive
Suite 600
Landover, MD 20785
E-mail: naricinfo@heitechservices.com
www.naric.com
Tel: (301) 459-5900 or (301) 459-5984
TTY: 800-346-2742
Fax: (301) 562-2401

The Family Caregiver Alliance is a national organization serving those who are caregivers for a variety of different people with a variety of different diagnoses. They have a variety of information such as publications, policy, research, newsletters, groups and advice.

Family Caregiver Alliance/ National Center on Caregiving
180 Montgomery Street
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BABIS (Boston Acquired Brain Injury Support Group) meets monthly at SRH in Charlestown. BABIS was started in January, 2001 by a group of professionals, survivors and family members to provide support, socialization, and education about ongoing challenges for brain injury survivors/families and strategies to better cope. The group averages 50-60 attendees per month. Speakers are chosen with expertise in various areas of brain injury recovery, including talks by survivors themselves about adapting to changes following brain injury. Meeting at the same time is the facilitated Family/Caregiver support group which allows family members the opportunity for their own discussion.

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Tracheostomy And Suctioning

Airways

The airways are pipes that carry oxygen-rich air to the lungs. They also carry carbon dioxide, a waste gas, out of the lungs.

The airways include:

- Nose and linked air passages (nasal cavities)
- Mouth
- Larynx (voice box)
- Trachea (windpipe)
- Tubes called bronchial tubes or bronchi and their branches in the lungs

Air first enters the body through the nose and mouth. The air then travels through the larynx and down your trachea. The trachea splits into two bronchi that enter the lungs.

Tracheostomy

If enough air is not getting to the lungs, a person cannot breathe without help, or is having problems with mucus or other secretions getting into the trachea because of difficulty swallowing, a tracheostomy is sometimes performed.

A tracheostomy is a surgically made hole that goes through the front of a patient's neck and into his/her trachea, or windpipe. The hole is made to help the patient breathe. This procedure is usually done in a hospital operating room.

A tracheostomy is usually temporary, although a patient could have one long term. The amount of time a patient will have a tracheostomy depends on the condition that caused the need for it and his/her overall health.

Tracheostomy Management

While in the hospital, the patient will work with a team of professionals who are trained to help manage tracheostomies.

Suctioning is one part of tracheostomy management. Suctioning can be performed in the mouth or through the tracheostomy tube and is a way to remove mucus and secretions. Suctioning is usually performed by a trained member such as a respiratory therapist, nurse or rehab staff (physical therapist, occupational therapist, speech-language pathologist).

Weaning from the Ventilator and Tracheostomy

As a patient grows stronger and medical issues begin to resolve, a respiratory therapist and pulmonologist will monitor the patient's ability to breathe on his or her own. Once the patient shows he or she can breathe safely off the ventilator, the respiratory therapist may trial a speaking valve and then cap which covers the tracheostomy tube and allows the patient to breathe through his or her mouth. If the patient can consistently tolerate a trach cap, the pulmonologist and/or respiratory therapist may take out the trach tube (decannulation), allowing the tracheostomy hole, (stoma) to close. Weaning from the ventilator and tracheostomy is a process that takes time and the amount of time depends on many factors such as the health of the patient and initial reason for the tracheostomy.

Swallowing

A **swallowing disorder**, also called **dysphagia**, is defined as a difficulty moving food from mouth to stomach but can also include decreased cognitive awareness, visual recognition of food, and all of the responses to the smell and presence of food such as increased saliva production. Difficulty swallowing can occur at different stages of the swallowing process:

- **Oral phase** –sucking, chewing, and moving food or liquid into the throat
- **Pharyngeal phase** –starting the swallow reflex, squeezing food down the throat, and closing off the airway to prevent food or liquid from entering the airway (**aspiration**) or to prevent choking.
- **Esophageal phase** –relaxing and tightening the openings at the top and bottom of the esophagus and squeezing the food through the esophagus into the stomach.

Signs and Symptoms

Common signs and symptoms of dysphagia include the inability to recognize food, difficulty placing and holding food in the mouth, coughing before, during, or after a swallow, difficulty breathing, increased congestion, or a wet/gurgly sounding voice after a swallow, extra effort or time needed to chew and swallow, or recurring pneumonia.

Diagnosis

Dysphagia is diagnosed by a speech language pathologist (SLP). A swallowing evaluation is usually not completed until respiratory function is stable and the patient is awake enough to participate. Once it is considered safe, the SLP will do a bedside swallow evaluation to assess the strength and movement of the muscles involved in swallowing and observe posture and behavior. If appropriate, the SLP may also use small amounts of liquid or food to assess swallow function. Depending on how the patient does at bedside, the SLP may recommend additional testing such as a modified barium swallow (MBS) which involves eating and/or drinking food and liquid with barium in it while the swallowing process is viewed on an x-ray.

Treatment

Treatment depends on the cause, symptoms, and type of swallowing problem. An SLP may recommend specific swallowing treatment, positions or strategies to help the patient swallow more effectively, or specific food and liquid textures that are easier and safer to swallow. The recommended frequency and duration of treatment can vary significantly and in some cases, the patient may need more time to heal before direct swallow therapy can be safe and effective.

Prognosis

Prognosis for recovery from dysphagia is very difficult to predict and depends on many variables such as the cause, symptoms, severity, and type of swallowing problem. While in some cases, the patient may eventually be able to return to a normal diet, others may need to be on modified consistencies such as thicker liquids or softer solids to support safe swallowing. Unfortunately, some patients may never reach a point of recovery where they are able to resume eating by mouth and these patients will likely rely on alternate means of nutrition and hydration such as a feeding tube.

NOTES