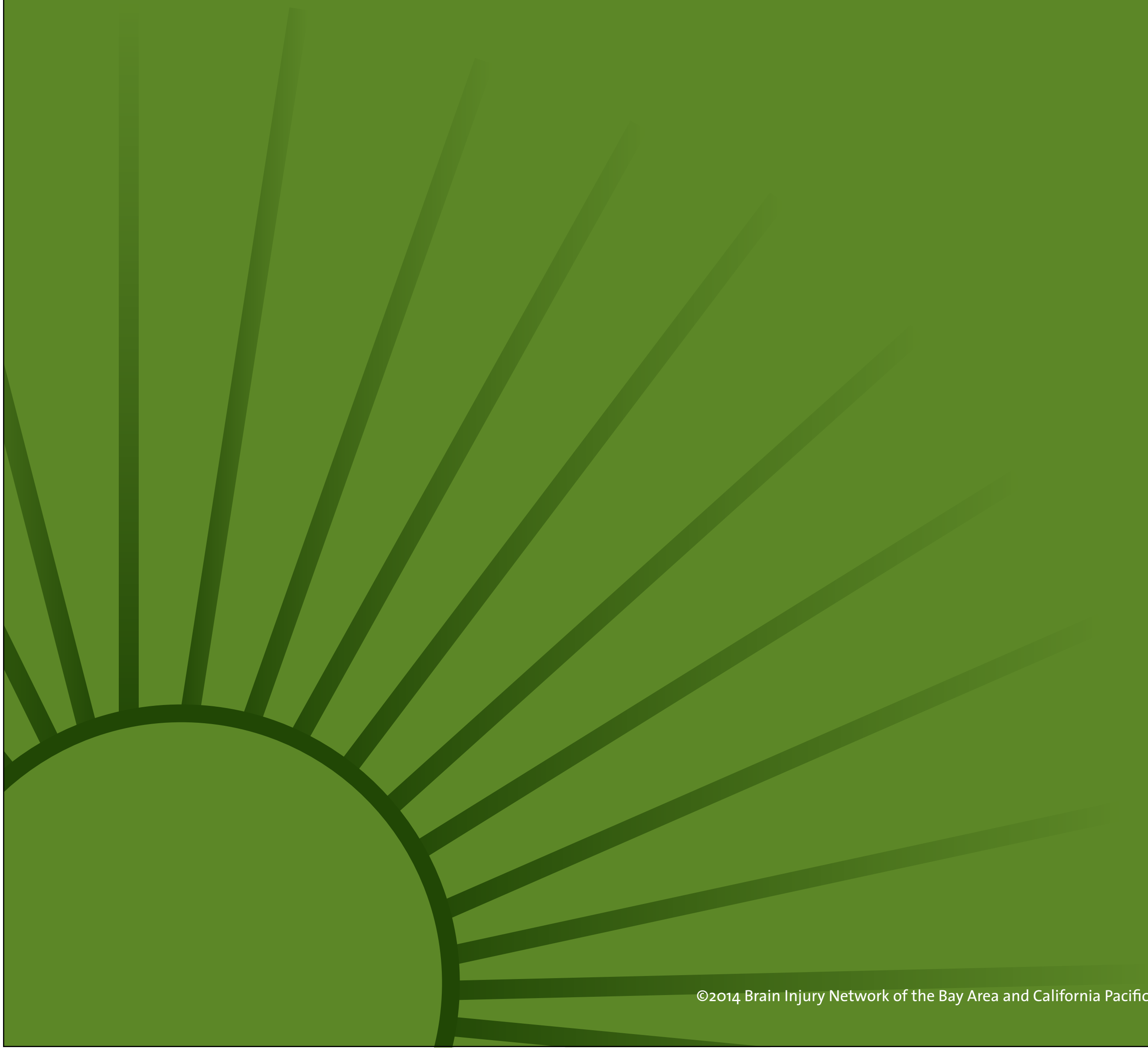
Brain Injury Information Handbook

A Guide for Patients and Families From Hospital to Home

California Pacific Regional Rehabilitation Center
Brain Injury Network of the Bay Area



Introduction

I'll begin by commending you for opening this guide. Recognizing that this process is one you will need help with is an important first step. California Pacific Regional Rehabilitation Center and the CPMC Foundation were eager to provide a resource that can help with this process.

Knowledge and information provide a relative amount of control to a seemingly out of control situation. It is our hope that the information in this handbook empowers you to ask more questions and purposefully seek the answers and care you and your loved one deserve.

Respectfully,
Scott Rome, M.D.
Medical Director, California Pacific Regional Rehabilitation Center
Chief, Division of Physical Medicine and Rehabilitation
California Pacific Medical Center
San Francisco, California

> I am glad this handbook has found its way to you. It is the collaborative effort of a team that genuinely cares about your experience and hopes to provide some guidance as you navigate the path of brain injury rehabilitation.
>
> *–Patricia Gill*

This handbook was designed to provide information and answer questions, many of which you didn't even know you needed to ask. It is divided into distinct sections that are relative to a somewhat predictable progression that follows a brain injury. The information ranges from what to expect in the intensive care unit (ICU), to how to talk with insurance companies, to what questions to ask your team when discharged home. Personal case studies are included throughout to highlight strategies that have worked for others whose experience may resonate with you.

While this handbook is full of information, it is not exhaustive. And there are holes in the continuum of brain injury recovery. In some regions, these holes include a lack of community organizations or support groups for the brain injured population. Universally, there is a lack of housing specifically designed for this population. And funding is always an issue. We do not have all the answers, but they're out there. They might not look like what you would have thought they would or be in a place you would expect but they are out there. We know this because we have witnessed the creative and resourceful efforts of many survivors and their caregivers over the years.

We hope the guide empowers you to ask questions and not accept "I don't know" as an answer. The real-life examples included are not only inspiring, but are also examples of how others have plugged these holes.

I am grateful to California Pacific Regional Rehabilitation Center and the volunteer team that partnered with BINBA to create this guide. Thank You to everyone who has contributed.

It is our hope that the book you hold in your hands becomes a helpful tool that you are able to refer to as a means of attaining information and providing some sense of comfort in increased knowledge.

Warmly,
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You can find this guide and additional information at www.binba.org

Acknowledgements

This guide is the collaborative effort of many and reflects what can be accomplished when a group comes together with a common goal. Survivors, family members, caregivers, and brain injury professionals volunteered their time, expertise, experience, and insight to help pave a smoother road for those who find themselves holding this book. The strength and wisdom of each contributor is profound and to each we are grateful.

This guide was funded by a generous grant from the CPMC Foundation and California Pacific Regional Rehabilitation Center at CPMC. Thank you.

How To Use This Guide

This guide is intended to provide as a reference that will help you access information in a manner relative to your current needs. These needs may change rapidly, though often in a somewhat predictable sequence.

Hopefully, this guide will provide a framework for gathering relevant information, help you to formulate questions and identify areas that need attention. It is not intended to replace professionals or to serve as the only means of attaining information. It is not a comprehensive manual, but an introduction to issues that may cross your path as you navigate through the process of brain injury recovery.

Recovery from a brain injury involves the efforts of a community. In some cases this community is one you didn't know existed.

The guide is divided into general sections that are initially relevant to levels of medical need and the probable issues associated with that level. Further into the guide, the information is directed toward the needs of survivors and caregivers after they leave the hospital setting, including a section with resources.

It must be recognized that no two courses of recovery follow the same path. For this reason, when using this guide, it is important to take notes, underline and jot down questions as they arise.

Hopefully, there is some comfort in knowing the information in your hands was compiled by people who have been in your same place. Sat in that same chair. Watched the same monitors. The intention of this guide is to fill in the gaps in your understanding and provide useful information so you can more easily navigate this unfamiliar terrain. And hopefully with knowledge will come some sense of control.

The information and resources listed here are not intended to be an endorsement, nor are the listings all-inclusive. While we have tried to check all resources as thoroughly as possible, we cannot guarantee the accuracy of all information. Additionally, there may be omissions that are unintended. While it is not an exhaustive list, there are many helpful resources listed that can help point you in the right direction to find the service you need.

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Chapter II. Overview Of Brain Injury

What's in this section...

This section will provide a working definition of brain injury, as well as a look at the general factors considered when determining the prognosis for recovery following a brain injury. You'll also find a description of the different phases a brain injured individual might progress through and how to interact with your loved one during each stage.

Hopefully, as your understanding of brain injury increases, you may develop some sense of control of the situation.

ACQUIRED BRAIN INJURY: DEFINITION

We take for granted the role our brain plays in our lives. We move through our days facing minor irritations, finding times when we are not as sharp as we would like, maybe having some moments of forgetfulness. We notice that when we are tired or stressed, things are not as easy as when we are rested and focused. *But what we generally do not think about is how the brain is responsible for our every action, emotion, and thought.*

A brain injury can affect how a person feels, thinks, acts, and relates to others. The important role our brain plays in all areas of our functioning, and our lives, comes into sharp relief when there is an injury to the brain.

Brain injury is a significant public health problem. These injuries not only affect the individual and his family, they also take a toll on our economy and our society.

Brain injuries are classified into two different categories.

Acquired Brain Injury

All forms of brain injury that occur after birth, regardless of the cause, are termed Acquired Brain Injury (ABI). Trauma, stroke, aneurysm, loss of oxygen to the brain (caused by heart attack, near drowning, suffocation, etc.), infectious disease and toxic exposure are some of the causes of ABI.

Traumatic Brain Injury

A Traumatic Brain Injury (TBI) is a form of acquired brain injury that results from an external blow, penetration or jolt to brain. The severity of TBI ranges from mild to severe. Common causes of TBI are falls, car accidents, assaults, gunshot wounds and sports related impacts. A closed head injury is one that does not involve damage to the skull. An open head injury (also called a penetrating head injury) is when the skull is breached or damaged. Concussion is a form of traumatic brain injury, though symptoms typically resolve often after a period of time. (For more information on concussion see *www.concussionmarin.org*.)

Statistics

Acquired brain injury is a significant public health problem. These injuries not only affect the individual and his family, they also take a toll on our economy and our society. Here are just a few statistics:

- An estimated 1.7 million children and adults in the U.S. sustain a traumatic brain injury (TBI) and another 795,000 individuals sustain an acquired brain injury (ABI) from other causes each year.
- 5.3 million Americans live with a long-term disability as a result of TBI.
- The annual cost of TBI to society exceeds $76.5 billion.
- The annual cost of stroke in the United States was $53.9 billion in 2010.
- 75% of traumatic brain injuries are classified as “mild”.
- Children ages zero to four-years-old, older adolescents aged 15 to 19 years, and adults aged 65 years and older are most likely to sustain a TBI.
- Males are more likely, at any age, to sustain a TBI.
- Falls are the leading cause of TBI. Rates are highest for children aged zero to four-years-old, and for adults aged 75 years and older.
- A stroke happens every 40 seconds in the US.
- An estimated 1.1 million living in the US have a disability due to a stroke.

**Sources: Brain Injury Association of America; U.S. Department of Health and Human Services; Texas Health and Human Services Commission.*

GLASGOW COMA SCALE

The Glasgow Coma Scale (GCS) is a quick, standardized tool used to assess the degree of consciousness in the brain injured population. The score is the sum of values assigned to the patient's eye opening, verbal response and motor ability.

Eye Opening

- Spontaneous: open with blinking *4 points*
- Opens eyes to speech *3 points*
- Opens eyes to pain only *2 points*
- No response *0 points*

Verbal Response

- Oriented to person, place and time *5 points*
- Talks but confused (able to answer questions) *4 points*
- Uses inappropriate words *3 points*
- Incomprehensible speech *2 points*
- No response *0 points*

Motor Response

- Obeys commands for movement *6 points*
- Purposeful movement to painful stimuli *5 points*
- Withdraws in response to pain *4 points*
- Flexes extremities in response to pain *3 points*
- Extends extremities in response to pain *2 points*
- No response *0 points*

Reference: Teasdale G., Jennett, B. Assessment of coma and impaired consciousness. A practical scale. Lancet 1974, 2:81-84.

PROGNOSTIC FACTORS

There are many theories and formulas used by physicians and other health professionals to predict the long-term outcomes following a brain injury. The truth is no one knows exactly what that outcome will be, or how long a recovery will take. And for every rule, there is an exception. Each person is an individual and will progress at his or her own rate, in his or her own way. Often, patience and acceptance are as important as the prognosis itself.

Keeping this in mind, here are the factors that professionals will use to help you predict what the long-term future holds:

- The type, location and extent of brain injury.
- The Glasgow Coma Scale (GCS) score at the time of injury. (See side bar.)
- The duration of coma.
- The survivor's age at time of injury.
- A history of substance abuse, including the extent of the abuse and whether the individual was intoxicated at time of injury.
- The level of the survivor's functional ability before the injury, including levels of achievement (professional and academic), intelligence level, presence of learning disabilities and the impact of any previous brain injuries.
- Overall health at the time of the injury. (pre-existing medical conditions? Diabetes, previous stroke, dementia, etc.) and any medical complications that occurred in conjunction with or after the injury (internal organ injury, heart attack, etc.).
- The survivor's level of motivation, both before and after the injury.
- The individual's level of insight and awareness; if a brain-injured person is unaware of his impaired abilities, then his safety, willingness to change, and ability to learn compensatory strategies will be compromised.
- The survivor's perception of how much control he or she has over the recovery process.
- Socio-economic status.
- Access to health care, including at the emergency level and during long-term rehabilitation.
- Personality traits and coping skills before the injury.
- Family involvement and support.

Generally, brain injury is classified as:

Severe:	GCS < 9 points
Moderate:	GCS 9-12 points
Mild:	GCS > 13 points

Rancho Los Amigos Levels

Rancho Los Amigos (RLA) Levels of Cognitive Functioning Scale

The Rancho Los Amigos Levels of Cognitive Functioning Scale (Hagan et al, 1972) is an evaluation tool that is widely used by rehabilitation teams to assess individuals after a brain injury. The Scale's eight levels, which outline predictable patterns of recovery, describe behaviors that typically emerge after a brain injury. They help the treatment team and family members determine the most effective way to interact with the patient, based on his or her current level of functioning. When looking at this scale, you should keep in mind that each brain-injured person will move through the levels at a unique pace. The rate at which each individual progresses depends upon the type and severity of injury. Also, some brain-injured patients move through the levels sequentially, while others may skip stages or advance to a certain level and not move beyond it.

Level I: No Response

A person at this level is in a deep coma and does not respond to sights, sounds, touch or movement.

Level II: Generalized Response

The patient is more awake and begins to *inconsistently* respond to sounds, sights, touch or movement. He responds in the same way to everything that he sees, hears or feels *(generalized response),* and these responses may include chewing, grinding teeth, sweating, breathing faster, moaning, random movements or increased blood pressure.

Level III: Localized Response

At this level, the patient begins to respond more purposefully to what he sees, hears or feels. For example, he may turn toward a sound, withdraw from pain, or attempt to watch a person move around a room. He may begin to recognize family members and friends, smile and be able to follow simple directions such as "Look at me." He may start to answer basic personal "yes" or "no" questions.

Suggestions For Interacting With An Individual At RLA I, II, III

- Speak in a normal tone of voice.
- Explain what you are doing, as you are doing it. Request that the staff interacting with the patient does the same.
- Make requests of the patient simple and direct. Allow adequate time to respond before asking again. If the patient does not answer or follow the command, when possible, do it for him.
- Keep the room calm.
- Read to him, listen to music, look at photos of family/friends and talk about them, watch TV programs of interest.
- Tell him who you are.
- Tell him where he is, why he is there/what happened and that he is safe. You can do this frequently.

Level IV: Confused and Agitated

At this point, the patient may be very confused and frightened and may not understand what is happening around, or to, him. As a result, he may seem to overreact to what he sees, hears or feels. Behaviors such as agitation (restlessness, pulling at tubes and IV lines) or combativeness (striking out, or attempting to hit, spit or bite) may emerge during this stage. These behaviors are often related to some sort of physical discomfort or overstimulation. Overstimulation occurs when a brain injured individual becomes unable to process and filter out information that he is subjected to. For example, he may be extremely sensitive to noise and light and become restless or agitated when the TV is on and people are talking in the room. Or when someone tries to feed him, move him, change his clothing, help with toileting or administer medication, he may react by striking out, attempting to bite or spit. His communication could be very limited. He may not fully understand what is said to him or be able to express his needs. This can cause frustration and possibly reactive behavior. Most likely he will have limited short-term memory. He may not remember where he is, why he is there or who all the unfamiliar people are that are doing personal care.

Suggestions For Interacting With An Individual At RLA IV

- Reassure him that he is safe.
- Keep the room quiet, calm.
- Dim the lights. Keep the door closed. Draw curtains.
- If he becomes agitated, talking, stroking and restraining may increase the agitated behavior. Sometimes the best thing to do is assure he is safe (cannot fall out of bed or injure himself accidentally) and leave him alone or sit quietly outside of his view. If you leave the room, advise the staff that you are no longer at the bedside.
- Explain what you are doing, as you are doing it. Request that the staff interacting with the patient does the same.
- Limit visitors and length of visits.
- Reorient him to place, time (month and time of day), and circumstance (why he is hospitalized and what happened.) You can do this frequently.
- Don't ask questions you don't know the answer to so you can prompt him if he does not recall immediately. ("What did you have for lunch?" "I don't know." "Did you have a hamburger or spaghetti?") Correct incorrect responses.
- Read to him, listen to music, look at photos of family/friends and talk about them, watch TV programs of interest. Discontinue if he starts to become agitated.
- Pay attention to what is going on in the room when the patient becomes agitated. Controlling the environment is the first line of defense in managing behaviors

Level V: Confused and Inappropriate

By this stage, the patient will be able to pay attention for a few minutes at a time, yet she remains confused and disoriented and has difficulty making sense of what is happening around her. She may have a hard time starting and completing simple tasks. She may get stuck at one step of the process or repeat the same step over and over (this is called *perseveration*). She may have reduced physical or mental energy and become easily overloaded, overstimulated or restless when tired or when expectations are too high. Her short-term memory will probably still be impaired and she may try to compensate with *confabulation,* or making things up, to fill the gaps in memory. You can expect her behavior to be impulsive, and she may act before thinking or planning.

Suggestions For Interacting With An Individual At RLA V

- Reorient to time, date, place and reason for hospitalization. Patients at this level of functioning are becoming more aware but may not understand the purpose of therapies and treatments.
- Explain what you are doing, as you are doing it. Request that the staff interacting with the patient does the same.
- Allow for rest breaks.
- Know the answer to the questions you ask so you can prompt him if he does not recall immediately. ("What did you have for lunch?" "I don't know." "Did you have a hamburger or spaghetti?") Correct incorrect responses.
- Help him complete tasks by giving prompts rather than doing for him. (i.e.; hand him the fork, rather than feeding him. Give him the socks, rather than putting them on for him.)
- Support and reinforce the strategies taught in therapy. This consistency will make these strategies part of his whole day, not just during therapy sessions. This is called "generalization" and is the goal of rehabilitation.

Level VI: Confused and Appropriate

The patient is less confused by now but still has significant short-term memory problems, especially when it comes to details of events and newly-learned information. He is better able to pay attention but remains sensitive to distractions. He can likely follow a schedule, with some assistance, and feed himself and dress on his own. He will probably continue to act impulsively, without thinking first, and may experience difficulty with changes in routine due to a lack of mental flexibility. His insight is emerging though he is likely more aware of his physical problems than with those of his thinking.

Suggestions For Interacting With An Individual At RLA VI

- **Support and reinforce the strategies taught in therapy.** This consistency will make these strategies part of his whole day, not just during therapy sessions. This is called "generalization" and is the goal of rehabilitation. This is vitally important at this stage as he may not fully understand why he is in therapy (lack of awareness).
- Information, instructions, plans, events that have occurred will need to be repeated. He will need cues or reminders to use his memory book.
- He may need help initiating, or starting, tasks. He may also need help continuing, or staying focused on that task, once he starts.

Level VII: Automatic and Appropriate

Though improving, the patient will still have trouble paying attention in distracting or stressful situations. She may have problems planning and executing an activity, even though she'll be better able to evaluate her own performance. She may be rigid in her thinking, and have difficulty finding alternative solutions to problems or seeing another person's point of view. Because she continues to have poor insight and awareness, she may not realize that her thinking and memory are still impaired, and may attempt to return to school or work prematurely. She'll continue to need supervision when out and about because her judgment is impaired—especially when it comes to personal safety. She may exhibit social behavior that is awkward and unrestrained. By now, however, she will likely be better able to use compensatory strategies, especially when it comes to filling in gaps in short-term memory.

Level VIII: Purposeful and Appropriate

When an individual reaches this phase, he probably realizes that he has difficulty with his thinking and memory, and may try to find ways to compensate. He will not always be successful. His attempts may be disorganized (Post Its all over, notes in his pockets, etc.). He might be more flexible in his thinking, and may be ready for driving and job training evaluations, though certain accommodations will likely still be necessary. He will be better able to pay attention for longer periods, but may still become overstimulated during difficult or stressful times, or in the case of emergencies. You can expect him to show poor judgment in new situations, and he will most likely need some guidance in making complex or important decisions. Also, as he comes to terms with the changes in his life as a result of the brain injury, he may experience depression.

Suggestions For Interacting With An Individual At RLA VII And VIII

- Encourage continued participation in therapies. He may feel "normal" and have difficulty understanding the purpose of continued therapy.
- When a situation arises where he has problems, help him figure out how to avoid the problem next time. Be careful not to gloss over it. These situations provide excellent opportunities for **real time learning**. An actual problem with real consequences is much more meaningful than a discussion about *the possibility of the same consequences.*
- Discourage the use of drugs and alcohol. Repeat injuries are frequently directly related to their use.
- Help him identify situations that create stress, anger or frustration. Talk about how to manage (or avoid if possible) these situations. Sometimes it is as simple as changing the time of a task, making sure outside noise is eliminated or that he is not hungry, etc.
- Be careful when joking or teasing. The subtleties of comments intended to be funny may be misunderstood.
- Remember he is an adult and his opinions matter.
- Becoming involved in support groups (both for the survivor AND the caregiver) is important and worthwhile.
- Remember and remind that recovery from a brain injury is a lifelong process. Improvements may continue over many years.

**An additional resource guide, provided by Ranchos los Amigos, can be found at the following website: Rancho.org/research/bi_cognition.pdf*

Notes

Chapter III. Advocacy

What's in this section...

This section provides a description of the rights of the patient, as well as those of the caregiver. Understanding your rights helps you advocate more effectively.

ADVOCATING FOLLOWING BRAIN INJURY

An advocate is someone who supports and acts in the best interest of another who may, or may not, be able to do so himself.

Advocating takes many forms. Creating a comfortable and familiar hospital environment and delegating responsibilities to others outside the hospital are but a few ways to support your loved one.

Patient Bill of Rights

During the hospital and rehabilitation phase:

You Have the Right to:

- see each facility's "Patient Bill of Rights" upon request.
- privacy.
- a safe, clean and quiet environment.
- considerate and respectful care from your doctors and health care team.
- healthcare that does not discriminate against you based on your race, ethnicity, national origin, religion, sex, age, mental or physical disability, sexual orientation, genetic information, or ability to pay.
- be informed of, understand, and participate in as much of your treatment plan as your capabilities permit.
- continue asking questions about medical procedures, treatment options and rehabilitation plans until you **fully understand the answers**.
- ask questions about any medical terminology that you do not understand.
- refuse any test or treatment, even if it means you might have a bad health outcome as a result.
- you have the legal right to choose who can speak for you if you cannot make your own decisions.
- appeal medical decisions. If you are not satisfied with the decision that a provider has made in terms of your care, you have the right and responsibility to appeal that decision.
- **speak to representatives at your health insurance provider WHENEVER and about WHATEVER you want.** Facilities and hospitals cannot discourage you from speaking to your insurance company about services you think may be appropriate or necessary to your care. Asking questions of your insurance provider about programs, treatments, procedures and other facilities **WILL NOT** compromise your coverage.
- speak up for yourself. Remember that you and your family are your own best advocates.

Caregiver Bill of Rights

During the hospital and rehabilitation phase:

You Have the Right to:

- care for yourself. The better you care of yourself, the better you will be able to care for your loved one.
- seek help from others even if your loved one objects.
- clarify and state the limits of your strength and endurance.
- feel angry, overwhelmed, and anxious. And you have the right to ask family, friends, social workers and chaplains to listen to you without judgment.
- reject your loved one's attempts to manipulate you through guilt or anger. In turn, you have the responsibility to communicate clearly, with as little blame and judgment as humanly possible.
- be treated considerately by the medical team and by the injured person you are caring for.
- receive affection, forgiveness and acceptance during this difficult time, and you need to offer that in return.
- take pride in what you are doing, and to recognize and appreciate your own dedication, courage and hard work.
- a life that will sustain you.

CREATING THE BEST HOSPITAL ENVIRONMENT

Creating a hospital room that feels familiar and welcoming can make a difference for the patient, the family and the caregivers who come in and out. Below are suggestions for making a hospital experience more comfortable.

- Create a picture wall. Include photos (or copies of photos) of the patient, family, friends and pets. Include photographs of vacations, family reunions and other events that have created the mosaic of her life. Label people, pets, places and events. These photos will also serve as an orientation tool that will be used again and again by staff and visitors.
- Hang a large, easy to read calendar in the room. Mark important dates, appointments, holidays, birthdays, etc. Incorporate a review of the calendar into his daily routine. Cross off each passing day (orientation) and review upcoming events (prospective memory). Decorate the room for seasons or holidays.
- Provide the patient with her own clothing. This will make her feel better, allow her a bit of control and the opportunity to express herself. (In the ICU and acute hospital, patients will not be able to wear clothes other than hospital gowns because of medical necessity.)
- Assure that there is a comfortable place for visitors to sit so visiting is a more welcome proposition.
- Ask the hospital if pets or therapy dogs can visit. Often a patient that has trouble responding to people will respond if an animal is present.
- Contact your local brain injury association and ask if they have survivors/volunteers that are able to visit in the hospital to share their stories. It can be helpful to speak with others who have experienced similar issues and gotten through it.
- Bring in large piece puzzles and playing cards if the patient is able to manipulate these items.
- Brightly colored balloons can be placed in the room for visual stimulation. Move them around to different locations for tracking and visual stimulation.
- Place a bowl of candy on the bedside table for the nurses-it gives them something to look forward to when answering the call bell or making routine visits. Anything you can do to show the staff you appreciate them is a good idea.
- Bring in photo albums. Reviewing these with the patient offers something to talk about and can provide a meaningful therapeutic interaction (naming, recalling, orientation, etc.)
- Bring in the daily newspaper. Read (or summarize) a story that is of interest to the patient. Ask questions about the story (and provide answers if necessary.) Share the photos associated with the stories.
- Use television sparingly. Watching a TV program or event can be a good activity, but having the TV on all the time is not a good idea. If he is not engaged with the show, is agitated or restless, turn the TV off. The TV should not be left on if the patient is unsupervised.
- Bring in a radio or portable CD player. As with the television, listening to favorite or familiar music is a good activity, unless it creates confusion and/or agitation. Music should not be left on if the patient is unsupervised.
- Occasionally bring a basket of fruit, cookies or muffins to the nurses' station. You may not have time to manage this, but it is a nice task for a friend who asks what they can do to help and is greatly appreciated by the staff.

Personalizing the Hospital Experience

CASE STUDY

Before her injury Lisa was an energetic, athletic mother of two girls. She worked long hours helping her husband run their construction company; ran for exercise everyday; and studied dance four days a week. So it came as a complete shock in 2009 when, at the age of 48, she suffered a complete cardiac arrest that resulted in a brain injury from oxygen deprivation.

Lisa spent days in a coma. Her family spent days at her bedside. By and by, Lisa slowly began to emerge and "wake up." And even though the end point was uncertain, her family advocated that she be put on a rehabilitative path. The path was marked by ups and downs. And her family learned a lot along the way. For example, they found it beneficial to build relationships with the staff by sharing information about Lisa before her injury. Staff members discovered they had things in common with Lisa that they otherwise never could have known. This gave those caring for Lisa a personal connection to her. The family left thank you notes and treats for Lisa's team of caregivers to show their appreciation. They knew treating the hospital personnel with kindness, respect and thoughtful gestures would benefit everyone.

Mara, Lisa's daughter, covered her mother's room with pictures of Lisa before her injury. She included photographs of her with her family, on vacation, being silly. "And every single person who went into that room," says Mara, "said, 'Oh this is your mom.'" It was a reminder of who the person in the bed was, especially since Lisa could not communicate for herself. Eventually these pictures were used to help reorient Lisa to herself and provided meaningful topics to talk about.

Her family made a point from the very beginning of respectfully asking questions—a lot of them. "If my father didn't understand an answer, he said 'Can you explain that? I want to know what it means.' It's rare that you'll find a doctor that really explains everything to you. You need to ask questions." When the family understands what is going on, it makes it easier for them AND the staff. As Lisa became more aware, her family was able to reassure her and describe the situation in appropriate detail. They could answer Lisa's questions in a way she could understand.

> *They knew treating the hospital personnel with kindness, respect and thoughtful gestures would benefit everyone.*

More than anything though, the family and Lisa's many friends, were there, both in the ICU and later in the hospital where she got her rehab. Lisa was never alone. This too, was reassuring and calming.

As for now, Lisa's life is different. She is partially blind, she cannot drive and even going out for a walk is a challenge. She is profoundly grateful to the many caregivers that helped "give her a second chance" to "be with her family and to tell them how much she loves them."

When a serious injury occurs, you may be focused on matters at the hospital and not on matters at home. But the issues at home still require attention. Your friends and family will ask how they can help. And even though you are overwhelmed with things that need to be done, you may not be able to think of what you need. Below are some common tasks that you may need help with. A worksheet to help with these assignments follows.

MANAGING AND DELEGATING RESPONSIBILITIES OUTSIDE THE HOSPITAL

- Ask a friend or family member to act as the **"General Manager"** (GM). This will be someone who is responsible, organized and has enough time. She will be the one who oversees all the tasks outside the hospital. She can help set up and maintain on-line sites like *caringbridge.org* or *carepages.com*, and coordinate visitors, meals, household chores, etc. Or she can delegate these tasks to others who want to help. You can leave an outgoing message on your phone with the GM's phone number so you don't have to return calls, if you don't want to.
- Managing visitors may be necessary if there are many concerned friends/family who want to come to the hospital. There may be people you don't want to visit. The GM can act as a gatekeeper and regulate visits (frequency and length) according to your wishes, or as prescribed by the hospital staff.
- The GM can also coordinate/manage the amount of food brought to your home. She can set up an online site, such as *takethemameal.com,* so you don't end up with 17 lasagnas in Pyrex dishes that will need to be returned.
- It is often helpful to have take out meals brought directly to you in the hospital if you are spending long hours at the bedside.
- If you have other children, you will need help arranging their schedules and carpools. A close friend or family member that the children feel comfortable with is the best choice.
- Consider having this person move in to your home. Children can be sensitive to change and having one person there for the day to day is helpful if you will be away at the hospital for extended periods of time.
- Pets will need to be fed and exercised. It might be easiest if a friend takes them to their home while you are away.
- Friends may pitch in to hire a housekeeping service or volunteer to clean your home (change sheets, clean out refrigerator, etc.) periodically.
- Someone will need to collect newspapers and gather mail. Ask the person bringing in the mail to recycle all non-essential material, like fliers, catalogs or mail addressed to "resident." They may bring mail to you and take responsibility for making sure your bills are paid while you are away.
- If there are family members or friends who are not computer-savvy, ask someone to record an outgoing message on your phone each morning that offers an update. This way you won't have to return phone calls, unless you want to.
- It may be helpful for you to be relieved of your bedside duties during the acute phase. Ask a friend to sit at your loved one's bedside so you can sleep, take a walk or just get outside for a bit.

It Takes a Village

CASE STUDY

If there is one thing Gunnar's family learned after his brain injury in 2010, it's that it takes a village to get through it.

Gunnar, a pitcher on his high school's baseball team, was 16-years-old when he was hit in the head by a line drive travelling more than 100 miles an hour. His father, Bjorn, sat in the stands and watched his son collapse on the field. His mother, Lisa, was at the hospital when they reached the emergency room. Gunnar was talking when he arrived at the hospital and they all expected to spend one night for observation, maybe two, before going home and back to their busy lives. What they didn't realize was that Gunnar's injuries were so severe that it would be months before they would sleep in their own beds, or even feel that they could take a breath.

Lisa had always been a take charge woman, a self described "control freak" who says, "it was easier to do something myself than explain to somebody else how to do it." But once the seriousness of Gunnar's injury was clear, she resigned control of all her day to day duties so she could focus on her son. She, for the first time in her life, accepted help without hesitation.

One of Lisa's close friends, Molie, quickly became their "point person." Molie set up schedules for meals, visitors, housecleaning. She helped limit the overwhelming flow of well-wishers to the hospital and managed their home while they were away.

> *They also celebrate and are grateful to the community that held them up during the long, and ongoing, process of brain injury recovery.*

Another friend took their dog Fletch and kept him for months while they were taking care of Gunnar. Knowing Fletch was fed, walked and cared for was one less thing to think about. A friend of Bjorn's mowed the lawn and tended the yard while others helped out with a range of tasks to support Lisa and Bjorn's ability to focus on Gunnar's treatment.

Friends organized a vigil and hundreds of people from the community came. They gathered in the park across the street from the hospital. As the crowd stood out there with lighted candles, the family felt the community sharing some of what they were feeling so intensely. To this day they believe the vigil helped in Gunnar's recovery. They will never know, but what they know for certain is how powerful this gesture was in getting them through a nearly impossible experience.

"Lisa and I are pretty organized and resourceful," says Bjorn, "but you're in just so far over your head that, without people helping you and guiding you, you would lose it."

Gunnar made incredible improvements and, though he still struggles and deals with residual deficits, he is thriving. Lisa and Bjorn obviously celebrate and marvel at the strength of their son. They also celebrate and are grateful to the community that held them up during the long, and ongoing, process of brain injury recovery.

WORKSHEET FOR MANAGING RESPONSIBILITIES OUTSIDE THE HOSPITAL

TASK	WHEN	WHO	PHONE #	NOTES
General Manager (organizes, assigns/coordinates tasks)	daily			
Maintaining website (caringbridge.org, carepages.com,etc.)	daily, or as needed			
Scheduling visitors	daily, or as needed			
Preparing/delivering meals to family, organizing meal delivery (takethemameal.com)	daily, or as needed			
Childcare	daily, or as needed			
Pet care	daily, or as needed			
Household chores (laundry, housecleaning, etc.)	as needed			
Yard maintenance	as needed			
Mail (separating bills and personal correspondence from catalogs and junk mail)	daily, or as needed			
Newspapers	daily			
Respite for family, bedside duty	daily, or as needed			
Banking	as needed			
Bill paying	as needed			

Chapter IV.

The Acute Phase:
From the ER to the Medical Floors

What's in this section...

As you move from the Emergency Room to the ICU and then to a medical floor, your needs and questions will change. You'll have questions about the multiple specialists and physicians your loved one will be seeing. You'll have questions about insurance and social service programs. You'll need to organize the information that is being generated regarding your loved one's care. You and your family may be challenged by grief and its associated stages. And you'll need to start preparing for the next step. Where do we go after we leave the hospital?

This section will help address these issues and answer some of these questions.

THE EMERGENCY DEPARTMENT: WHAT JUST HAPPENED?

Things move quickly in the emergency room (ER). The priority is to provide the necessary medical attention in the quickest manner, often to save a life. As a result, it feels overwhelming and staff may not have time to explain what is going on. When an individual arrives in the emergency room with a suspected brain injury, he'll be seen by a response team that is made up of a number of different professionals.

Emergency medicine physicians, neurologists, neurosurgeons, radiologists, cardiologists, critical care physicians, trauma surgeons, nurses, respiratory therapists, registration staff, chaplains, social workers, paramedics and law enforcement personnel may all be in the emergency room tending to one patient. The medical staff will need to monitor patients. This necessitates open viewing areas. For this reason, family members may not have been allowed in the treatment areas. Not only because sometimes there isn't physical space for them, but also to protect other patients' privacy as much as possible.

You need to know...

The purpose of an Intensive Care Unit is to prevent life threatening complications of an illness or injury and to establish medical stability. This is the single focus of these complex settings.

It can be difficult to tell who is in charge, especially when there are numerous physicians attending the patient. Everyone admitted to the emergency room will be seen by an emergency medicine physician and this doctor is in charge while the patient is in the ER. Specialty physicians may be called in by the emergency medicine doctor. Patients with a brain injury are often seen by a neurosurgeon, a neurologist, a trauma physician/surgeon and/or a critical care doctor while still in the emergency department. If admitted to the hospital from the emergency room, one of these "specialist" doctors will take over and become the "attending" physician. The patient may see all of the specialists after leaving the ER but the emergency medicine physician will no longer be involved.

THE ICU: WHAT TO EXPECT

After the emergency room, the brain injured patient will most likely be admitted to the intensive care unit (ICU.) The ICU cares for patients who need around the clock intensive medical attention, and as a result, operates in a different manner than an ordinary hospital unit.

Restricted Visitation

You'll find that you cannot just walk into the ICU. There is usually a phone outside the unit for you to announce your arrival and ask if you can come on to the unit. Why? Because, like the ER, patients in the ICU need constant medical attention and the medical staff often complete complex (or sterile) medical procedures at the bedside. The nursing staff and physicians want to ensure that patients are not in the midst of a procedure and are stable enough to receive visitors before allowing them in. In addition, because patients in the ICU require constant monitoring and observation, the rooms have glass doors and are often open to the nurses station. In order to protect the privacy of all patients in the ICU, visitation may be restricted for reasons unrelated to your patient.

Visiting Hours

Visiting hours vary from hospital to hospital. Some allow family members to stay 24 hours a day, while others have restricted times. There are several times during the day when visitors are never allowed on the unit: when nurses are conducting their patient report at change of shift. This is to ensure privacy of all the patients on the unit.

Physicians

Patients in the ICU require high-level monitoring and medical care. Typically there are a number of doctors involved in a patient's treatment. These may include an intensive care physician (intensivist), trauma surgeon, neurosurgeon, hospitalist (specialized hospital-based internal medicine physician), neurologist, orthopedic surgeon, plastic surgeon, and primary care physician. Because you may be encountering so many doctors, and receiving so much information, you will want to keep notes. (See the section on making a Medical Binder.) Therefore, do not be afraid to ask questions, even if the question is as simple as, "Which doctor are you and why are you seeing the patient?"

Monitors

When in the ICU, doctors and nurses are gathering information to understand and treat a patient's injury as effectively and safely as possible. For this reason, patients are attached to many different monitors. There are monitors that keep track of heart rate, the amount of oxygen in the blood, blood pressure, intracranial pressure (ICP), medications and respiration rate, to name a few. These monitors are programmed to alarm, and the medical staff is able to recognize the meaning of these alarms and respond accordingly. **It is important not to touch the monitors or silence an alarm, even if the staff has told you a particular alarm is not significant.** (Some alarms are very sensitive and sound with even slight movement. The staff will silence alarms or adjust setting as directed by the physicians. Vital information can be lost if monitors are inappropriately adjusted.)

You need to know...

It is important not to touch the monitors or silence alarms. Even if you have seen the staff do so many times. Or even if they have told you the alarm is not significant. Vital information can be lost if alarms and monitors are accidentally or inappropriately adjusted.

The Healing Process

After a brain injury, it may be difficult to recognize the healing that is taking place. It may seem as if there is no change in the patient from day to day. In some cases, the physicians may need to medicate the patient into a sedated state (medically induced coma) to facilitate healing. Sometimes, it seems the patient is sleeping a lot. Rest and quiet are necessary to healing and the doctors will help regulate this. All the while, the medical staff will use a variety of methods to assess the brain, including CT scans, MRI scans, blood tests, ICP monitoring and EEGs. These tools allow the doctors and nurses to "look inside" the head and provide adjustments to care as needed.

Delayed Injuries

When the patient arrives in the ICU, the first priority is continued care for life threatening injuries or conditions. Over time, however, it may become apparent that there are other, less critical injuries that may not have been identified. This is especially true when a patient becomes more alert and begins to move or communicate to the staff what she is feeling. For example, if a patient is lying still in bed, she may not notice that her ankle hurts. If there is no obvious injury, an x-ray of the ankle may not have been performed. When she stands, an injury (and pain) becomes obvious. It is important that you report any complaints the patient makes, either verbally or non-verbally (she grimaces when you roll her, or winces when you squeeze her hand) so investigation and necessary treatment can be implemented.

Nutrition in the ICU

In order to heal, it is critical that a seriously injured person be well nourished. Dieticians are an important part of the ICU team and work with the physicians to ensure that nutritional needs are met. The doctor determines when it is

You need to know...

It is important to note that swallowing problems are not always obvious, which is why a trained specialist must evaluate for the disorder. Just because a patient doesn't cough or look distressed when swallowing, does not mean there isn't a problem. Feeding or allowing someone to eat/drink when the team has advised that its not safe to do so puts the patient at risk for unnecessary complications.

necessary to initiate feeding and whether it will be oral (by mouth) or non-oral (by feeding tube). There are many factors the doctor must consider before initiating nutrition. Fluids (hydration) are frequently administered intravenously (IV) early on, but "food" might be held off, depending on the physician assessment.

Once the doctor determines that it is safe for a patient to try oral food, the patient will be seen by a speech pathologist, who is trained to assess for swallowing problems (dysphagia) or aspiration (when food or liquid enters the respiratory tract.) Swallowing problems can be serious and lead to medical issues that can prolong recovery.

Introduction of Rehabilitative Efforts

The physician may initiate physical therapy, occupational therapy and speech/language pathology while the patient is still in the ICU. These trained specialists will evaluate the patient and develop a plan of treatment (including goals) that are specific to the patient's level of function at that time. Early on, the physical therapist may see a patient to move his limbs and keep muscles and joints loose. The occupational therapist may develop splints and positioning techniques to keep the hands healthy. The speech pathologist may assess swallowing ability and/or perform evaluations to determine what and how much an individual is processing/understanding.

The Medical Floor: What to Expect

Eventually, the brain-injured patient will become medically stabilized and will not need the intense medical care provided by the ICU. He may be moved to one of the regular floors of the hospital. What can you expect then?

Being moved out of the ICU is usually a good sign. It means the patient requires less medical attention and is moving toward stability.

Less Medical Attention

Patients who are moved to less acute areas of the hospital have fewer specialized needs and therefore require less attention. Unlike the ICU, where each nurse is assigned only one or two patients at a time, your nurse will now care for several patients. The nurses will check vital signs less frequently and there will be fewer monitors.

Different, and Fewer, Doctors

Once the patient is on a regular hospital floor (medical or surgical unit), he or she will not need as many specialty physicians. As each particular specialist is no longer needed, he will sign off to the attending physician. The attending physician is the doctor in charge. Even after a specialist has left the case, or signed off, you may still have questions for him or her; if so, your nurse can provide you with the information you need or put you in touch with the doctor.

You need to know...

The more alert and aware a patient becomes, the more likely she is to become agitated, restless or even combative. She may try to pull out tubes and lines. This is actually considered a good sign. When the patient was in the early stages of recovery, she may not have been aware of the tubes or IV lines. She doesn't understand why she needs them, only that she wants them out. This is a difficult phase to manage but is a positive indication of improving awareness.

Delayed Injuries and New Behaviors

The further you or your loved one gets into recovery, the more minor injuries you may discover. As the patient becomes more mobile and aware of her body, the more able she may be to report discomfort. Also, the more alert and aware a patient becomes (Refer to page 10, **Rancho Levels**), the more likely she is to become agitated, restless or even combative. She may try to pull out tubes and lines. This is actually considered a good sign, even though it may involve highly emotional or anxious behavior. When the patient was in the early stages of recovery, she may not have been aware of the tube in her nose. Now she is. She may not remember why the tube is there despite frequent reminders, but she knows she wants it out. She may not understand that she is in the hospital or that she had a brain injury. So when a nurse is doing a procedure or asking her questions, she may react inappropriately.

Rehabilitative Efforts

By the time a patient moves to the floor (out of the ICU), rehabilitative therapies will likely be underway. The goals of the therapies will vary, but it is important that they are in place. The information documented by the physical, occupational and speech pathologist is helpful in determining what the next step in the rehabilitation process will be.

INSURANCE

Working with insurance companies can be a daunting task. Accessing the information you need can seem overwhelming. Knowing who to ask for help is the first step to take. In the acute hospital your point person will be your case manager or social worker. Sometimes a social worker is not assigned to your case and you may need to ask for one.

There are two types of insurance: government issued and private. Government issued insurance coverage would include policies for government employees, military personnel and their families, Medicare and Medicaid/MediCal. Private insurance is the coverage purchased by an individual or his employer.

Insurance plans vary widely. To best understand your policy, you will start by contacting the insurance company directly. Ask to speak to the case manager at the insurance company who is handling your case. Ask if a *catastrophic case manager* can be assigned.

Medicare recipients can contact Medicare at 800-MEDICARE or access their website at *http://www.medicare.gov*

You can speak to your insurance company whenever, and about whatever, you need to understand. Asking questions about services, programs, facilities or treatments you think may benefit your loved one <u>will</u> <u>not</u> compromise his coverage. Hospitals and other facilities <u>cannot</u> attempt to limit contact with your insurance carrier, nor should they be the only party speaking to the insurance company on your behalf. <u>It is your responsibility to understand your coverage</u>. So ask questions.

What Happens if Insurance Won't Pay?

When insurance won't pay you have several options. You can:

- Fight insurance denials by submitting an appeal. Submitting letters of medical necessity written by involved physicians may be helpful in reversing a denial of services.
- Utilize a *patient advocate* or *patient representative* to help with issues involving access to care and coverage of services. California Office of the Patient Advocate can be accessed at www.opa.gov. Patient advocates can be hired privately or case management assistance can be accessed for free through Patient Advocate Foundation at *www.patientadvocate.org*
- *Medical billing* advocates can be hired privately to help negotiate with your insurer to appeal coverage denials, negotiate lower fees with care providers or find errors in bills. Some hospitals and clinics have medical billing specialists on staff.
- The benefits department of the employer that purchased the policy can be helpful in obtaining information and putting pressure on the insurance company.
- If insurance continues to deny payment after an appeal, you may be required to pay a claim if you pursue the services denied. Ask the hospital if there are modifications that can be made to the amount billed. The amount billed to an individual who is paying privately is often MORE than what the insurance provider would have paid. Request that you be billed what your insurance would have paid if the service was covered.

How to Talk to Your insurance Company

When speaking with your insurance company;

1 Have the policy number and patient's birthdate handy. They will ask for it every time. They may also give you a reference or tracking number that will make pulling up records faster.

2 Document every phone call. Date, time and who you spoke to. Write down information as you receive it and **read it back to ensure you understood.**

3 When dealing with insurance companies, it is most effective if you are calm and informed. Remember the person who answers the phone may not have the information you need. BUT you need her to help you to get to the person who does. Be respectful and kindly persistent.

4 When filling out forms for insurance companies, make sure it is complete. Forms that are incomplete may not be processed and will delay decision making.

You need to know...

The best way to learn about the social service programs available to you or your loved one is by asking questions. Ask case managers, other family members, friends, therapists, chaplains. Often the social worker in the hospital is your best connection to these services. Local or State Brain Injury Associations are also good resources when looking for social service programs. There are often services unique to your area that are little known, so ask questions...

Social Service Programs

The case manager, social worker and/or representatives from patient financial services will help you initiate the process of applying for the social services that may be available to you. These services may include:

- **Medicaid/Medi-Cal:** This health insurance program is funded by federal and state governments and is available to individuals based on financial need.
- **Supplemental Security Insurance (SSI):** SSI is a federally funded income supplement program that pays benefits based on need or lack of resources. Additional information regarding SSI is available at *www.ssa.gov/pgm/ssi.htm*
- **In Home Support Services (IHSS):** IHSS is a program that helps to pay for services so a disabled individual can stay safely in his home. An individual may be eligible for IHSS if he/she is currently receiving SSI, he/she meets the eligibility criteria for SSI but is not receiving SSI or if he/she is a Medi-Cal recipient who meets SSI criteria. Additional information regarding IHSS can be found at *www.cdss.ca.gov/agedblinddisabled/pg1296.htm*
- **Social Security Disability Insurance (SSDI):** SSDI pays benefits to the injured individual if they are covered. Being covered means you have been employed long enough and have paid Social Security taxes. Social Security Disability Insurance pays benefits to individuals if the disabling condition is expected to last at least one year. Unlike SSI, SSDI is not based on need or lack of resources. It can take a long time to process a SSDI application (3-5 months). Additional information is available at *www.ssa.gov/pgm/disability.htm*

Remember the person who answers the phone at your insurance provider may not have the information you need. BUT you need her to help you to get to the person who does. Be kindly persistent and respectful.

MEDICAL INFORMATION BINDER

When an injury involves hospitalization, there is a staggering amount of paper involved, from test results and reports to medication prescriptions. Creating a Medical Information Binder will help you to keep all of this material organized and accessible. This binder will become your "go to" resource for keeping track of doctors, medications and dosages, test results, consultation reports and necessary follow up plans. It can be the binder of information that you keep with you now and carry with you to all appointments after discharge from the hospital.

If you do not have time to create such a binder, or feel overwhelmed at the prospect, ask a trusted friend or family member to do it for you. If you designate a person to help you, you will need to contact the Medical Records department of the hospital or treatment facility where the patient is receiving care and give permission for your friend or family member to obtain your records.

Keep extra room in each section for writing additional notes. If you have a place where you can scribble questions/concerns down, you'll have a much better chance of remembering them later.

Also, be sure to purchase a binder that includes sleeves or pockets that will hold copies of disks; most copies of CT, MRI and EEG results will be given to you on a disk. It would also be a good idea to invest in a 3-hole punch, so that you can punch each report and slip it into the binder.

Binder Cover

Jane Doe	DOB: 11/28/1960

1st Section: A chronological history of events, beginning with the injury

8/29/2009	Anoxic Brain Injury	County General Hospital
9/12/2009	Discharge	
9/12/2009	Rehab	Lake Rehabilitation Hospital
11/10/2009	Discharge	
5/10/2010	Seizure	County General Hospital
5/11/2010	Discharge	
2/19/2011	Chest Pain	Redwoods Forest Hospital
2/20/2011	Discharge	
2/20/2011	Transfer Care	Plains Hospital
2/21/2011	Discharge	

Keep adding to the list every time the patient is admitted to the hospital.

Personal Section

This section should include:

- The patient's name, address, date of birth, telephone number, alternate telephone number, and e-mail address.
- An emergency contact. It's a good idea to include more than one emergency contact. This would be a family member or close friend.
- Your pharmacy's name, address, telephone number and fax number.
- A copy of the patient's Advanced Health Care Directive Form, if he or she has one.
- A list of the patient's medical disabilities and allergies, including allergies to any medications.
- A copy (front and back) of the patient's insurance cards. Update these if policies change or you get a new card.

List of Medications

Keep track of all the medications that the brain-injured person needs to take. There can be a number of them, so it's crucial to list when it was prescribed, the dosage, frequency and purpose of the medication. Add to and modify the list as necessary. Medications that are no longer being used should be crossed off the list.

Date prescribed	Drug name	Dosage	Purpose
1/2/11	Diltiazem HCI	120 mg. by mouth— 2 capsules, 24-hour sustained Release/2 x per day	Hypertension
2/3/12	Levetiracetam	1000 mg. by mouth— 1 tablet every 12 hours	Seizures
3/4/13	Lipitor	20 mg. by mouth— 1 x per day	High cholesterol

Physician Contact List

List all the patient's doctors, his or her specialization, and telephone number, as in the example below:

Nancy Jones, MD 555-XXXX	Physiatry	Lake Rehabilitation Hospital
Thomas Bloch, MD 555-XXXX	Cardiologist	Forest Cardiology Associates
Samantha Yee, MD 555-XXXX	Internist	Private Practice

Records of Tests

List the dates of all CTs, MRIs, EEGs, EKGs, etc.

*CT head	8/31/2009
*CT abdomen	5/10/2009
Angiogram	2/20/2011
EKG	10/21/2009

X-rays, CT scans and MRIs will have a written report that describes the study. If you request copies of these tests from the hospital, you should ask for the written report and a copy of the films on a CD. These disks should be kept in the binder. Sometimes a physician will want to look at the actual "pictures" and you will need to provide the CD. You can put an asterisk (*) next to the tests for which you have a disk.

Hospitalization Section

This will be the real "guts" of the Medical Information Binder. Signify the beginning of this section by using a Divider Tab marked with the dates of the hospitalization, so you can find it easily.

In this section, you will include documentation pertaining to this particular injury. Put it in chronological order as this will help greatly in mapping the progress of the patient.

The hospitalization section may end up being very thick, with many pages of information. Under each different hospital stay, you will want to include the following documentation and paperwork:

Emergency Dept. Admit Report
History and Physical Report
Consultation Reports
EEG, x-ray, EKG, ECHO, CT and MRI reports
Operative Reports
PT/OT and Speech Pathology evaluations and notes
Discharge or Transfer Summaries

There will be many nursing reports generated and daily progress notes from multiple physicians. To collect each would be unwieldy. Reports and consultations (listed above) will provide a summary of critical information. Copying an entire medical record is not usually necessary. File reports chronologically with the newest documents going in front.

Additional Sections

You can add a section for each different phase (acute rehabilitation, outpatient therapies, etc.).

Physician Appointments (Outpatient Office Visits)

Include in this section notes on physician office visits and assessments. If the patient sees many different physicians on a regular basis, you may want to create sections for each physician. Document what is recommended for follow up and if changes are made to medications/prescriptions. If changes are made to medication and/or dosages, it is a good idea to make those notes while still in the office.

Notes

When Life Gives You Lemons...

CASE STUDY

Carol H.W. is a believer in the transformative power of unexpected catastrophic life events. She looks upon the stroke she had at age 38 as one of life's greatest teachers.

Before the stroke, Carol was newly married and had just finished a graduate degree in psychotherapy. Brimming with ambition, she was hoping to start a family and build a thriving private practice. But despite her plans, one summer afternoon in 1985, she suffered a stroke while attending a party with friends. She woke up in the hospital, where doctors told her she would be fine in about six months. Like many stroke survivors, she was not.

Due to ataxia, she could not control the movements of her legs. After months of therapy, she progressed from a wheelchair to walker to four-point cane. Eventually she was able to walk for fitness. But it took almost three years. Her cognition, was initially altered. "My thoughts were slow, my speech was slow," says Carol. "78 rpm, at best."

Over time, she discovered that doing things slowly, one task at a time, was not a limitation. It was self-care. After her stroke, she began reading Buddhist literature, meditating and attending Buddhist retreats. "And guess what?" she says. "They teach people to pay to attention to your thoughts and see if you can be aware of them enough to identify patterns; to focus on your breath and notice the space between them. That made me laugh. I remember thinking, *Space between your thoughts? Guess my stroke took me on my first meditation retreat!*"

The stroke also made her a wiser, more compassionate therapist. And it led her to her life's work, helping other stroke survivors. It was a journey that started when she herself was in rehabilitation, sitting after dinner with other stroke patients, thinking to herself, *"Nobody is listening to our stories."*

Eventually she became co-facilitator of the Stroke Club in San Francisco, and a member of the American Heart Association's Stroke Committee—the first stroke survivor to do so.

If you weren't really good at patience beforehand, this is like getting a PhD course in it.

When she and her husband moved from San Francisco to Marin, she got a job at the community college teaching a weekly class and psychosocial support group for stroke survivors. Later she opened a private practice, which included supervising graduate students, working with individuals and couples, and leading a group for stroke survivors. This is how she earns her living today.

In her work, Carol fosters an environment of patience. "I tell people," she says, "'If you weren't really good at patience beforehand, this is like getting a PhD course in it."

It's a practice that she extends not only toward her clients, but also toward herself. The stroke taught her a slower, more spiritual way of life, both personally and professionally. "It opened me to the value of love and connection as opposed to achievement," she says. "And in the end, that's all that really matters."

Stages of Grief

Grief often follows trauma or loss. If your life, or the life of a loved one, has been changed as the result of a brain injury, you will almost certainly go through a grieving process for what is lost or altered.

Grief is not a single emotion, but a constellation of several phases. As defined by Elizabeth Kubler-Ross, there are Five Stages of Grief that most people experience after a loss. You may not experience all of these stages, and you may not move through them in order. Everyone grieves in their own way, in their own time.

It is important to note that families or friendships may come into conflict because individuals are at different stages of their process at the same time. You may be feeling depression, while others may be in denial or anger. You may come to acceptance while others are immobilized by depression. This can create tension, misunderstandings, inconsistencies in "what is best" for the patient and how to manage life situations. It is important to recognize this and seek help from professionals that will be able to negotiate and assist with problem solving (social worker, case manager, chaplain, psychologist.)

The process of grieving is normal and does not have to harm relationships with the people you love. As you grieve, it may be wise to seek the help of a professional, such as a therapist or social worker, to help you understand and accept the many feelings created by loss or an unexpected life change.

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1 Denial: This is usually the first stage of the grief process. Denial can be conscious. ("This cannot be happening to me.") Or denial can be an unconscious refusal to accept facts or make appropriate decisions. ("Everything is fine. If I could just go home, all will be back to normal.")

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2 Anger: Anger often results from the pain of loss AND is a necessary stage of healing. We can be angry at many different things: the person who caused the injury, the doctors, therapists, our loved ones, ourselves, sometimes even the injured person himself.

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3 Bargaining: This is the stage when we make bargains with ourselves, others, perhaps God, to be spared the pain that accompanies the loss. It's not uncommon at this stage to say "I will do anything if only you will make my loved one well again."

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4 Depression: As the reality of the situation starts to sink in, you may feel profound sadness, and may feel immobilized by this. It's normal to feel sad when a loss or traumatic life-changing event has occurred. However, if depression persists, professional help may be necessary to help one move through this phase to that of acceptance.

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5 Acceptance: Acceptance is when you have learned to live with what has happened. You may not like it, but you are able to move forward.

Sources: Elizabeth Kubler-Ross Foundation (ekrfoundation.org); David Kessler (grief.com)

PREPARING FOR THE NEXT STEP: THE POST ACUTE PHASE

The discussion about where an individual will go when he no longer needs to be in the acute hospital often begins soon after the patient becomes "medically stable". Once the doctors have completed all the testing, interventions and surgery necessary to stabilize a patient AND the patient is tolerating the medications prescribed and procedures that have been performed (feeding tube, tracheotomy tube, stable/improving brain scans, stable lab results), he no longer needs to be in a hospital that can only address these needs. This can be an unsettling time because it involves change.

Sometimes an individual spends weeks in the ICU. The patient and the family become familiar with the schedule on the unit, they know the staff, and leaving that familiar environment can be frightening and often seems too soon. It is hard to imagine that your loved one, who still is so far from herself, could be on a unit that is not an ICU. But because an ICU functions specifically to provide the highest possible level of care to individuals, the patient is not learning/relearning to do for herself. It is time for the next step. This next step often happens in what is called a post acute setting. There are many possible post acute options and your team of caregivers in the ICU or the step down unit (MDs, nurses, therapists and case manager) will determine which is the most appropriate for you or your loved one.

Acute Rehabilitation Facilities

Acute Rehabilitation is the provision of highly specialized, interdisciplinary services (Physical Therapy, Occupational Therapy, Speech Pathology, Neuropsychology, Physiatry, and Rehabilitation Nursing) performed in an acute care hospital. Any acutely hospitalized individual who has a new disability from injury or disease (or an exacerbation of an existing one) may be appropriate for inpatient acute rehabilitation.

Acute rehabilitation is the most intensive and specialized approach to brain injury rehabilitation available and should be provided by a CARF accredited program (Commission on Accreditation of Rehabilitation Facilities *www.CARF.org*)
To be appropriate for admission to acute rehabilitation, patients must be able to tolerate a minimum of 3 hours of therapy/day. And when patients are admitted to inpatient acute rehabilitation, the understanding is that the next stop is the community, usually home. It is incumbent on the rehabilitation facility to complete comprehensive training with the family and/or caregiver to ensure a safe transition from the hospital setting to the community. Sometimes, however, the patient needs to start in a less intensive setting (see below) before advancing to this level of care.

Long Term Acute Care Hospitals

A long term acute care hospital (LTAC) is a specialty hospital that cares for medically complex patients who need to be in a hospital but do not require the intensity of an acute hospital. Patients on long term antibiotics, patients on dialysis, who are slow to recover from an injury, patients with slow to heal wounds, or have long term ventilator dependence may be referred to an LTAC. The brain injured patient may initiate his post acute hospitalization in an LTAC as he progresses toward entry into an inpatient acute rehabilitation facility. Patients will receive some general rehabilitation (PT, OT and speech) when appropriate. LTAC hospitalization is a spring board for inpatient acute rehabilitation, not a substitute. LTACs are not set up for the comprehensive, integrated, specialized brain injury rehabilitation and cannot address the community based needs these individuals will have after discharge. Once an individual is functioning at a Rancho Los Amigos Level IV (see page 11) he should be transferred to an acute rehabilitation facility with a brain injury specialty program.

Subacute Care Facilities

Typically located on units within an acute hospital or skilled nursing facility (SNF). Patients admitted to subacute hospitals do not require hospital acute care, but require more intensive, skilled nursing care than can be provided in a skilled nursing facility. Patients admitted to a subacute level of care may have chronic complex, skilled nursing needs (ventilator dependence, tracheostomy, dialysis, ileostomy, etc.) They will receive some general rehabilitation (PT, OT and speech) when appropriate. Similar to an LTAC, a subacute level of care may be an appropriate setting for the brain injured patient to initiate his rehabilitation process, but it is not/cannot substitute for inpatient acute rehabilitation. Once an individual is functioning at a Rancho Los Amigos Level IV (see page 11) he should be transferred to an acute rehabilitation facility with a brain injury specialty program.

Skilled Nursing Facilities (SNF)

An establishment that houses chronically ill, or slow to recover individuals, that do not require the services of an acute hospital, nor the intensive, specialized services of an LTAC or sub-acute center. SNFs provide long-term nursing care, rehabilitation, and other services. Also called long-term care facility, or nursing home, a SNF may be an appropriate setting for the brain injured patient to initiate his rehabilitation process as he progresses toward inpatient acute rehabilitation. Again, skilled nursing facilities are not/cannot substitute for inpatient acute rehabilitation. Once an individual is functioning at a Rancho Los Amigos Level IV (see page 11) he should be transferred to an acute rehabilitation facility with a brain injury specialty program.

Post Acute/Transitional Living Centers

These settings include outpatient or day treatment program, residential (non-medical) transitional rehabilitation or home based programs. Most frequently the brain injured individual is referred to these settings after completing inpatient acute rehabilitation.

Questions for Interviewing Inpatient Acute Rehabilitation Facilities

1. Does your facility have a Brain Injury Specialty Program?

2. How is that defined?

3. Is your Brain Injury Specialty Program CARF accredited? (CARF: Commission on Accreditation of Rehabilitation Facilities sets quality standards for rehab programs. A list of CARF accredited programs can be obtained by calling CARF at 866-888-1122.)

4. If the program is not CARF accredited, why not?

5. When can I see your facility?

6. What are your outcomes for the brain injured population treated at your facility? How are they measured and tracked?

7. Can I see them?

8. What is the average length of stay? Who decides this?

9. How does your program address behavior management? Physical restraints? Medications?

10. If my loved one needs a sitter for safety, do you provide this? Who pays for it?

11. If my loved one needs a medical procedure (CT scan, surgery, acute medical attention, etc.) can this be provided on site or will he need to be transported to another facility?

12. Can I stay with my loved one in his room? 24 hours/day if I choose?

(continued on next page)

13. *Will my loved one have roommates? How many?*

14. *How does your staff maintain current education and training? Is this required?*

15. *Will my loved one be treated by the same team of therapists throughout his course of rehab?*

16. *What is the staff turnover like?*

17. *Do you have peer support programs?*

18. *Do you provide a home safety evaluation before discharge?*

19. *Do you provide community reintegration?*

20. *What about vocational rehabilitation?*

21. *How do you teach family/caregivers to prepare for the transition home?*

22. *Is there a transitional apartment setting/home orientation suite on your unit where my loved one can "practice" newly learned skills in a home-like setting before discharge?*

23. *What kinds of programs are available at your facility after the inpatient acute rehabilitation program is completed? Day treatment programs? Outpatient programs?*

24. *Does your program have substance abuse counseling (if appropriate)?*

25. *How much of the cost will insurance cover? Are there any costs not covered by insurance?*

Notes

Chapter V.

The Post Acute Phase:
Beginning the Rehabilitation Process

What's in this section...

This is the phase where you will be re-learning old skills, learning new skills and preparing for the next step...home.

This section provides information about some of the new team members that may be introduced when you enter the Post Acute Setting.

It also provides a list of questions you will want answered before you leave the inpatient setting.

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POST ACUTE CARE PHASE—WHAT TO EXPECT

Ultimately, the goal for an individual who sustained a brain injury is to return to the community (hopefully home), as safely, quickly and with the greatest level of independence as possible. In many cases, this is achieved by participation in a brain injury specialty program at an acute rehabilitation facility. But if the individual is not ready for an intensive acute rehabilitation program and does not need to be seen daily by a doctor, he may be moved to a skilled nursing facility (SNF) until he is ready for the next level. If a patient has complex medical needs that need to be addressed first, he may go to a long term acute care hospital (LTAC) or subacute setting before going on to acute rehabilitation. Sometimes patients go straight home or to a transitional living center. These are all various *Post Acute Facilities*.

Transitions to post acute facilities are made with close consideration of a patient's medical needs and current level of functional ability. It is important to recognize that each setting has a purpose in the continuum, or process, of rehabilitation. Leaving a familiar setting can be hard, but it is a necessary part of the process.

No matter which setting is the next step in the rehabilitation process, there will be changes. One of the most obvious differences that you will note in most post acute settings is the nurse to patient ratio. With the exception of acute rehabilitation facilities, there are usually fewer nurses in these settings than in the acute hospital. And in skilled nursing and transitional living centers, patients are seen occasionally by physicians, or certainly much less frequently than in the hospital.

Depending on a patient's level of function, you may also note that the patient is now expected to do more for himself. For example, an individual who was fed in the hospital may be encouraged to feed himself, often as a part of therapy. A urinary catheter may be removed and the patient put on a toileting schedule. These efforts are to increase the patient's "functional ability" and are directed toward increasing his ability to care for himself.

Allowing time to adjust to the newness of a setting may be challenging at first. Continuing to support and advocate for your loved one while allowing the process to move forward is a fine balance. The first step in this process is often simply recognizing the sometimes uncomfortable nature of change.

THE REHABILITATION TEAM: NEW TEAM MEMBERS

When recovering from a brain injury, you or your loved one will be cared for by a team of highly-trained specialists. These will most likely include the following people:

Physiatrist

A physiatrist is a physician (M.D.) who specializes in the treatment of disabling disorders or injuries. A physiatrist is also called a Physical Medicine and Rehabilitation Physician. Some physiatrists are further specialized in the area of traumatic brain injury. His or her job is to both diagnose and treat any disability resulting from an injury, and develop a comprehensive program to help put the pieces of the injured person's life back together. The physiatrist directs the comprehensive rehabilitation team, prescribes and oversees all treatments/therapies and prescribes and monitors the use of specific medications and other interventions. Your physiatrist coordinates the patient's care with other physician specialists and is considered the "leader" (or attending physician) relative to the program.

Rehabilitation Nurse/Certified Rehabilitation Registered Nurse (CRRN)

Your rehabilitation nurses will provide much of the direct care during the inpatient rehabilitation stage. He or she will perform the tasks needed to help the brain-injured person restore and maintain function, while preventing any new complications or further deterioration. Unlike a traditional nurse, a rehabilitation nurse does not just provide care to the patient, but also reinforces any strategies taught in therapies. He or she thereby *helps the brain-injured person re-learn to help himself.* The rehabilitation nurse will also coordinate the daily schedule, as well as provide education and support to the patient and the family.

Physical Therapist

Physical therapists (PT) assist patients in regaining physical function and mobility after an injury. They assess the patient for changes in strength, range of motion, coordination and sensation following an injury. Then they will determine how these factors impact the patient's ability to move. The PT will work with the patient in restoring his ability to get around within the environment of the hospital and eventually the community. The physical therapist will also assess whether a patient needs an orthotic (braces and other supports) or other assistive devices (like a walker, cane or wheelchair) to achieve maximum mobility and safety.

Occupational Therapist

An occupational therapist (OT) helps a brain-injured person re-learn the tasks needed to function in their everyday lives. These activities, also known as Activities of Daily Living or "ADLs", include dressing, grooming, toileting, bathing, eating, cooking, paying bills, using a computer, cooking and home management. An occupational therapist might use physical exercises to increase a patient's strength and dexterity necessary to performing these activities, or they may use functional, "real life" activities that improve decision-making, problem-solving, perceptual skills, memory and sequencing. The occupational therapist will evaluate the home environment, the patient's work-related activities and help improve his or her ability to engage in community life again.

Speech-Language Pathologist

The speech-language pathologist (SLP) will assess, diagnose and treat speech, language and/or cognitive (thinking) disorders related to the brain injury. The SLP also oversees swallowing disorders. He/she will make recommendations for food textures, liquid thickness and safe swallowing practices. He/she will help develop and teach how to effectively use techniques and strategies that assist with memory, planning and sequencing difficulties. The speech-language pathologist works closely with the treatment team to help manage and improve issues of cognition, language and swallowing as they relate to safety and the ability to function effectively and independently in the community.

Neuropsychologist

A neuropsychologist is a clinical psychologist (Ph.D.) who specializes in the relationship between the brain and behavior. He or she will assess cognitive and behavioral issues that have resulted from the brain injury and then design an effective treatment program. Problems resulting from a brain injury may include difficulty relating to other people or adjusting to a new disability. Your neuropsychologist will also lead the rehabilitation team in determining which interventions are necessary to manage behavioral problems, such as agitation or inappropriateness.

Recreation or Activities Therapist

A recreation or activities therapist will plan, direct and coordinate the recreation programs that accompany rehabilitation from a brain injury. These activities may include arts and crafts, drama, music, dance, sports, games and field trips. They are specifically designed to help the patient reconnect with avocational (non-work) interests, while encouraging social interaction with others, a key step towards reintegration into the community.

Case Manager

The case manager acts as the point-person between the health-care team and the patient's family. He or she works directly with insurance providers during inpatient hospitalization and when preparing for discharge from the hospital. He/she is responsible for discharge planning and overseeing matters such as outpatient therapies, transportation, follow-up medical appointments and medical equipment. They can provide lists and ideas for locating or finding accessible housing and attendant care. They cannot, however, choose attendants or housing situations for you. He or she will help the family determine how best they can meet the patient's needs, including review of insurance benefits and available assistance programs. In addition, your case manager will provide counseling and support while hospitalized and is a valuable resource after discharge.

Social Worker

The social worker acts in conjunction with the neuropsychologist, case manager and therapy team and provides counseling to both patient and family in attempt to promote adjustment to life changing events, like a brain injury. The social worker also provides assistance and acts as an advocate with identifying and securing community services (legal, transportation, housing, school, employment, attendant care, assistive technology and financial support.) He/she helps them navigate outside programs and assists with the process of initiating long term disability, In Home Support Services, Medicaid, etc.

Vocational Rehabilitation Counselor

When appropriate, a vocational rehabilitation counselor (VRC) is utilized to help an individual transition back to the work force. The VRC helps individuals gain skills for a new career, prepare for a job interview or write a resume. The VRC also helps develop/identify adjustments or accommodations necessary to successfully maintain employment. Often a vocational rehabilitation counselor is accessed through the County Office of the Department of Rehabilitation (DOR).

QUESTIONS TO ASK BEFORE LEAVING THE HOSPITAL

During the recovery process following a brain injury, you will have many questions. This may escalate as you prepare to leave the hospital. Most of your questions should be addressed by the facility discharging you and hopefully most will have been answered at this point.

This list provides some additional questions you may not even know you need to ask.

Medical Questions

- Who will be the main doctor for my brain-injured family member once he is released from the hospital? Is it the last doctor who cared for him in the hospital or is it his regular doctor he had before he was injured (primary care doctor)? What if I don't have a primary care doctor?
- What medical signs and symptoms should I pay attention to? When do I call the doctor?
- When should I contact the primary care physician after we leave the hospital? When do I follow up with the physical medicine and rehabilitation doctor?
- Who will re-new prescriptions for the patient after he is released from the hospital?
- What other follow-up care will my loved one need? Will he or she need physical therapy, occupational therapy, counseling or other care? And if so, where do I go and how do I arrange it?
- Where do I obtain copies of the patient's medical records? How do I gain access to them?

Legal Rights

- What are my rights as a family member after we are out of the hospital?
- What are my rights if the brain-injured family member is a student or minor? Do these rights change as the patient becomes an adult?
- Where do I go, or who do I contact, to find out about legal issues and rights, such as guardianship?

Am I Ready For Discharge Home?

- What sort of behavioral issues or emotional changes are we likely to see?
- How should I prepare my house? (see safety checklist, page 46)
- Can my brain-injured family member be left alone?
- How do I arrange for his or her care when I'm not there?

Where Can I Get More Information?

- Where do I go for support and to find answers to questions as they arise?
- Can you recommend resources or books, so that I can learn more about brain injuries?

Home Safety Checklist

General

- ☐ Do you have a Medi-Alert System in place?
- ☐ Is there a peep hole in the front door to identify visitors before opening the door?
- ☐ Are there signs posted to remind you to:
  - ☐ Take your keys when leaving the house
  - ☐ Lock the door when leaving the house
  - ☐ Turn off all appliances
- ☐ Do you have established places to store commonly used items, like your keys, purse, memory book, cell phone, etc.?
- ☐ Do you have a central or "universal" calendar where you record ALL events, appointments, etc.? Is it accessible to others who may need to use it or refer to it?
- ☐ Is your phone programmed with emergency numbers? (land line and cell phone) If your phone cannot be programmed, are these numbers posted near the phone?
- ☐ Are your keys color coded to help identify them?
- ☐ Does a neighbor have a copy of your house key to be used in the event of emergency or if you lose yours?
- ☐ Does the home have a functioning fire alarm? CO_2 alarm?

Bathroom

- ☐ Are there grab bars in the bathroom near the toilet and in the shower/tub area?
- ☐ Is there a slip resistant rug next to the shower or tub?
- ☐ Are there slip resistant strips on the shower or tub floor?
- ☐ If a shower seat or raised toilet seat is necessary, does it fit in the space where it will be needed? Is it stable on the floor of the area it will be used?
- ☐ Do you put your towel near the tub/shower so you won't have to walk anywhere to retrieve it when you are wet?

BEDROOM

❏ Is clutter removed from the floor?

❏ Are throw rugs and mats removed from the floor?

❏ Is there a lamp and a telephone near the bed?

❏ Is there a flashlight near the bed?

❏ Are there nightlights placed along the pathway from the bedroom to the bathroom?

COMMUNAL LIVING AREAS

❏ Have you walked through the home, room by room, to remove items that could be tripped over, bumped into or knocked down?

❏ Are all cords out of the way or taped securely to the ground with appropriate tape?

❏ Are the dining chairs stable? All four legs resting firmly on the floor or do they wobble? Identify a stable chair and use only that one.

❏ Is there a phone available where you typically sit?

❏ Is there a chair or a sofa that is easy to get in and out of? One with arm rests and a raised seat?

❏ Are all area rugs or throw rugs removed?

(continued on next page)

KITCHEN

- ☐ Are area or throw rugs removed?
- ☐ Are frequently used items in easy to reach, and consistent places?
- ☐ Are cabinets labeled to assist in finding (and returning) objects?
- ☐ Are there reminders near appliances cueing you to turn them off after use?
- ☐ Do you have a whistling tea kettle?
- ☐ Do you have a loud timer that won't go off until you turn it off?
- ☐ Do you clean up spills when they happen?
- ☐ Are chemicals and cleaning products kept away from food items?
- ☐ Are sharp utensils kept separate from other utensils and with blades pointing down?
- ☐ Are there checklists used for multi-step tasks to avoid skipping important steps?

STAIRS

- ☐ Are the stairs well lit?
- ☐ Is there a strong handrail, ideally on both sides?
- ☐ Using brightly colored tape at the edge of the stair makes it easier to see where the stair ends.

OTHERS

- ☐
- ☐
- ☐

Chapter VI.

The Post Hospital Phase:

Leaving the Hospital

What's in this section...

As the formal inpatient rehabilitation process draws to a close, you'll have questions about what happens next. This section describes the different settings and programs that follow inpatient rehab. For some this is home. For others, it may mean a transitional living situation. For others it may mean an assisted living center.

For all, it must be noted that recovery is rarely complete when the inpatient period ends. And for all, regardless of the destination ahead, there will be strategies and practices learned that must be maintained after you leave the inpatient setting to maximize safety and promote continued progress.

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WHERE FROM HERE?: LEAVING THE HOSPITAL

After leaving the hospital, you may transition from an *inpatient setting* (where you stay in the hospital and receive therapy and treatments) to an *outpatient situation* (where you come from home to a hospital or clinic for services or therapy sessions, and then return home.)

Leaving the hospital and initiating the next phase of the rehabilitation process may take several directions.

INDEPENDENT/HOME WITH SUPERVISION

Individuals who have recovered to the point of being able to live independently typically require 24 hour supervision initially to ensure that they are safe in a less structured environment. Individuals who go home will likely have some form of continued therapy: home care based therapies (where therapists come into the home and provide services) or outpatient therapy (where the individual goes to a hospital or clinic to receive therapy and then returns home).

You need to know...

The survivor of brain injury often feels that he will “be fine once I am home and in my own space.” The exact opposite may be the case. In a less familiar, more structured environment (like a hospital), individuals tend to be more attentive and aware of their surroundings. If the situation at home lacks structure and supervision or does not encourage carryover of the strategies taught during inpatient rehabilitation, there may be a slip back in function and possibly even safety issues.

Transitional Living Center

A transitional living center is a residential, non-medical program that continues after inpatient acute rehabilitation. The focus of transitional living programs is typically safety, cognition, behavioral issues and community reintegration. Transitional living is not a long term living situation.

Hospital-Based Outpatient Day Treatment Programs

A day treatment program should be a coordinated, integrated multi-disciplinary program that involves physical therapy, occupational therapy, speech language pathology, neuropsychology, vocational counseling with physiatry (physical medicine physician) oversight. Hospital-based day treatment programs often have a “return to work” focus.

Community Based Day Treatment Programs

Community based day treatment programs are often designed and managed by a non-profit organization that specializes in the area of acquired brain injury. The programs often offer group format courses throughout the day with the client returning home at night. The goal of day treatment programs is to offer a therapeutic setting for the brain injured survivor to attain continued rehabilitation in the areas of cognition, communication, socialization and psychological support. Often services are offered for caregivers/family members.

Assisted Living, Supported Living or Board and Care Programs

These settings are licensed personal care boarding homes (or group homes) that provide long term living situations for individuals who require more assistance or supervision than can be safely provided in a private home with family.

Traditional Outpatient Therapy

Outpatient therapy for physical therapy, occupational therapy and/or speech therapy may be recommended. These therapies may be scheduled several times a week. You may need one or a combination of all these therapies. Sometimes one of these therapies may continue for a longer period of time than the others. (For example, you may not need physical therapy any longer but speech therapy continues.)

What to Expect: Out of the Hospital

Going home after a long stay in the hospital can be exciting. **But it is important to note, recovery may not be complete when inpatient rehabilitation concludes.** You will have learned important strategies during inpatient rehabilitation that will help make the transition from institution to the community safe and successful. It is very important that these techniques be used consistently and reinforced regularly.

And although exciting, leaving the hospital can be challenging for a number of reasons. One of the less obvious reasons is the fact that often a survivor of brain injury feels that he will "be fine once I am home and in my own space. " The exact opposite may be the case. In a less familiar, more structured environment (like a hospital), individuals tend to be more attentive and aware of their surroundings. When a therapist or doctor is observing you, you tend to be focused on the approaches and techniques they taught you. The presence of a nurse, physician or therapist provides "cueing" even if nothing is said.

If the situation at home lacks structure and supervision or does not encourage carryover of the strategies taught during inpatient rehabilitation, there may be a slip back in function and possibly even safety issues.

Once an individual gets home after being hospitalized for a long period, the desire to continue therapy may diminish. Encouraging continued rehabilitative efforts may involve some cheerleading, but it is important that the process continue.

Below are general strategies and practices that are recommended for optimal performance and continued improvement after leaving the hospital.

Staying consistent with compensatory strategies

You or your loved one will have learned a number of compensatory strategies while in rehabilitation that need to be consistently maintained after leaving the hospital. This may include keeping a set schedule from which the survivor does not waiver. He may also need checklists to complete the morning routine or organizers to plan daily activities and schedule appointments. And it's crucial that he avoids situations (typically identified during rehabilitation) that trigger undesirable reactions or behaviors. These can include places that are noisy, bright, crowded, hot or cold—or avoiding complex, unfamiliar or new tasks at times when the brain injured person is tired, hungry, hot or cold.

Rest

Regular rest breaks or naps should be a scheduled part of her day. She won't need excessive sleep, but it's important to make sure she has scheduled downtime every day. Inadequate sleep or rest can lead to undesirable behavior and/or decreased cognitive function.

Nutrition

Eating a healthy, balanced diet, with adequate fluid intake, is crucial to helping the brain-injured person function at maximal level. Ask your doctor about sugar, caffeine and alcohol use.

Exercise

Regular exercise and activity is an important part of every day. Keeping active is not only good for the body, but the mind and brain. The extent and type of the exercise should be cleared by your physician.

Social contacts, especially with brain-injured peers

Being with people is important for everybody. And for the brain injured individual, it's particularly important to connect with others who have been through a similar experience. There are support groups, day treatment programs and adaptive courses—many available through local community colleges—that can provide a brain-injured person a structured way to be with other people. Please refer to the Resource Section of this handbook and *www.BINBA.org*.

Preventing a secondary injury

In order to prevent a secondary injury, it is important to monitor the brain-injured person's behavior. She may need to be supervised when engaging in new, unpracticed activities. And, as noted above, she will need to avoid situations that may cause undesired behavior or reactions. She will need to avoid recreational drug and alcohol use.

Accessing answers to questions as they come up

The facility that discharged you home would be the first place to contact when questions arise. If they are unable to answer your questions, ask where they can refer you. This may well be a community based brain injury organization or a state level association. A great deal of general information is available on line. See Resource Section of this handbook for more information.

Filling in Holes

CASE STUDY

When Karen Schurig's 14-year-old daughter, Lise, sustained a severe brain injury in a car accident in 1975, the situation was dire. And while Karen celebrated that her daughter was alive, caring for Lise placed an enormous burden on this single mother with two other children.

It was almost unheard of back then that someone would survive an injury like Lise's. Subsequently, community resources were scarce. And on a limited income, Karen lacked the financial ability to hire a community to help care for her daughter.

Karen saw no option but to leave her job and transition to welfare in order to stay home and tend full-time to Lise's round-the-clock medical and emotional needs. For eight years Karen was the sole caregiver for her daughter. Over time, Karen pieced together assistance from various government sources to help sustain Lise. This came from Golden Gate Regional Center (GGRC—a state agency providing service to individuals born with a disability or who become disabled as a minor), Medi-Cal, In Home Supportive Services (IHSS) to help fund attendant care, and a Section 8 voucher for housing. Karen's load finally lightened a bit with the receipt of these resources.

While Lise was receiving some support for much needed services, she still lacked a community. Karen and Lise had met individuals impacted by brain injury but these family members and survivors also felt isolated and as if they had "nowhere to turn" for information. In 1983, Karen began connecting these families and survivors and created a supportive network specifically focused on improving the quality of their lives.

In 1985, Karen turned tragedy into a gift when she formally started Marin Brain Injury Network (MBIN), an organization she envisioned as a place where brain injured individuals and their families could have community and support. She secured a small grant from the county, a room at a local rehab hospital and offered a weekly support group for TBI survivors. At first there were only a handful of people involved, but over time more came. MBIN eventually added a second group, and then a group for caregivers plus a structured, therapeutic day program that provided affordable classes to continue the rehabilitative process. As time went on, more services were added still and today, the organization (now known as Brain Injury Network of the Bay Area/BINBA) has 10 different programs, a freestanding building, and serves over 300 people a year, turning nobody away due to lack of financial resources to pay for service.

Lise, now in her 50s, improved to the point that she is able to live in an apartment with full-time aides, a situation Karen made possible with government aid and committed effort to advocate for support. Lise attends the day program at BINBA every week.

Karen worked tirelessly as an advocate for her daughter, and the TBI community as a whole. She passed away in 2009 but her legacy lives on in the program she developed and the many lives improved by it. BINBA is considered a model for other similar programs throughout the country.

Notes

Chapter VII. Common Sequelae

What's in this section...

Even after the most successful course of rehabilitation, the brain injured survivor may have some residual sequelae, or persistent issues, caused by the injury. The impact of these issues ranges from mild to severe and can be simply annoying or completely disabling.

These issues were likely identified during the inpatient phase of recovery. Being reminded of the possibility that they may linger makes addressing them easier. It also provides another opportunity to ask questions.

COMMON SEQUELAE FOLLOWING BRAIN INJURY: PERSISTENT ISSUES IMPACTING THE BRAIN INJURY SURVIVOR

There are a number of symptoms and side effects, or "sequelae," that are commonly experienced by people who have sustained a brain injury.

Cognitive Disorders

People who have sustained a brain injury often experience cognitive disorders, which may include the following:

Attention problems. Paying attention to simple tasks or following a conversation can be challenging for someone who has suffered a brain injury. In particular, he may have difficulty tuning out distractions like noise or light while attempting to complete a task. Or he may experience difficulty dividing his attention while doing two things at once, such as attending to conversation in a noisy restaurant; following instructions or retaining new information when fatigued; following a recipe with the TV on or children underfoot; recognizing cars coming from many different directions on a busy street corner.

Memory problems. It may be difficult for the brain-injured person to remember things, especially events that have happened since the injury (recent memory) and events that are to happen in the future (prospective memory). Memory issues may be related to **lack of attention** (if you don't hear something in the first place you won't remember it), difficulty **processing information** (if you don't understand something, you'll remember it inaccurately) and inefficient **retention of information** (if you lack a system to store information you cannot remember/recall/retrieve it).

Your keys haven't disappeared if you can't find them. You just don't know where they are because you lack a system for storing them. If you always put them in the same place, you have the system to recall where they are. The same is true with information. The information may not necessarily be "forgotten". You just lack the system to recall where it is. This is why compensatory strategies (organized planners and notebooks, journals, smart phones, routine, checklists, etc.) are essential to the brain injured individual who lacks "built-in" retention systems or is challenged by **remembering, retrieving or recalling information**.

Most *memory* issues relate to one or all of the first three issues: attention, processing/understanding and/or retention. If these issues are addressed or compensated for, recalling is less of a problem.

Executive Function. After a brain injury, an individual may have difficulty initiating, planning, organizing, sequencing or stopping an activity. He may also lack the *mental flexibility* necessary to adapt to the changing demands of that task. He may have difficulty evaluating the outcome or his performance. And he may not be able to use information from prior experiences to help with decision making in the future. These skills are called executive function.

Executive function impacts everything we do and every decision we make. An impairment in executive function may appear subtle but it can have significant impact on one's ability to be successful in his community.

The extent to which executive function is affected often depends on the location of the injury; executive abilities are regulated primarily by the frontal lobes of the brain.

Problem Solving: Being able to consider a situation and make a decision may be difficult for a brain injured individual for many reasons. He might not be able to recognize that a problem exists. He may lack awareness that will help formulate a "wise choice." He may have difficulty sequencing the steps necessary to making a decision or solving a problem. Disturbances in executive function (initiation, impulsivity, organization, flexibility, etc.) will also have an impact on problem solving.

Sensory Disorders

Sensory problems can refer to vision disturbances (double vision or "diplopia", field cuts, blurriness), loss of hearing acuity, poor hand eye coordination, unsteadiness/balance problems, difficulty knowing where your body is in space, ringing in the ears, dizziness/vertigo, perceived (but not actual) odors/bad smells, tingling, itching, pain.

Movement Disorders

A brain injury can result in difficulties ranging from muscle weakness to a lack of coordination to problems with balance. Movement disorders can be the result of any sensory disorder (as they provide a distraction) or can be more primary in nature, i.e., stemming from the injury itself. Weakness, tremor (uncontrollable shaking), ataxia (difficulty coordinating smooth muscle movements resulting in irregular, uncoordinated gait patterns) are common disorders in the brain injured population. Cognition can also have an enormous impact on movement. Lack of awareness, poor attention, impulsivity, poor insight ("I can make it across Geary Blvd before the light turns red…") can impact movement and safety.

Speech and Language Disorders

After a brain injury, the survivor may have trouble understanding language (listening or reading) or difficulty conveying her thoughts/ideas/needs through expressive language (speaking or writing). This is called *aphasia*. Or she may suffer from *dysarthria*, in which she can't use the muscles of her mouth effectively, and speech may be slurred and imprecise. Another common problem is *apraxia*, or difficulty sequencing sounds and words in a fluent way, resulting in speech that sounds "choppy." Also, some brain-injured people experience *hyper-verbosity* or *tangentiality*, in which they dominate a conversation or switch topics frequently without clear transitions. She may engage in *confabulation,* which is, essentially, making things up. This may seem to the healthy person like lying but is actually a coping strategy to fill in parts of the memory that are missing.

Behavioral Changes

A brain-injured person may behave in ways that seem peculiar or uncomfortable, such as crying inappropriately (or for no apparent reason), laughing inappropriately (or for no apparent reason), lack of proxemic boundaries (standing too close), staring or no eye contact, easily pushed to anger, *unfiltered* output ("You look fat in that dress"), inappropriate sexual advances, inflexible thinking/emotional rigidity. He may also behave impulsively, and act before thinking, because he doesn't recognize the consequences of his actions.

Psychological Disorders

One of the most difficult parts of a brain injury, for brain injured individuals and their loved ones, is dealing with the psychological disorders and mood problems that may accompany the injury. A brain-injured person may, for example, experience a lowered sense of self-awareness or ability to self-reflect. He may not consider the effects of his behavior on others and how that behavior might need to be changed. He might also over, or under, estimate his abilities after the injury. This may lead to unrealistic goals, possible safety problems, and awkward social encounters.

She may not be able to regulate her emotions and, when frustrated, might explode or have a catastrophic reaction. Finally, it's not uncommon for a brain-injured person to become egocentric, focusing on her own needs and wishes, without taking into account the needs of loved ones. Additionally, depression and anxiety can be common side effects of a brain injury.

Sexual Disorders

A brain injury can affect sexual desire. The person who has been injured may display an exaggerated interest in sexual activity or, conversely, a loss of interest in sex.

Substance Abuse

People who struggled with substance abuse before their injury are vulnerable to taking up this harmful behavior again. This is of particular concern if the brain-injured person's social circle includes people who still abuse alcohol or drugs, and might tempt them to do the same. The effects of elicit substances are magnified in an injured brain, they can harm or delay healing and may cause dangerous interactions with prescribed medications. Substance abuse greatly increases the risk of a secondary injury.

Sleep Disorders

The sleep-wake cycle is controlled by the brain and may be disrupted by injury. Setting a regular bedtime and waking schedule, as well as the use of physician-monitored medication, can help a brain-injured person return to normal sleep patterns. A healthy diet and exercise may also improve sleep. A brain-injured person may not only need more sleep at night, but also may need brief naps during the day.

Getting from Point A to Point B May Not be a Straight Line

Case Study

After surviving a subarachnoid hemorrhage at the age of 35, Maria figured she would be back to work in no time. Yes, she had almost died, suffered temporary blindness and underwent several brain surgeries. But Maria had always been an energetic multitasker. She had started her own business and was even a local actress prior to the aneurysm. She thought her injury would be a short-lived set back.

Maria made good progress in her rehabilitation. But when she was discharged home, she was frustrated to discover that she lacked motivation and initiation despite weeks of therapy. It was different at home. No one was around to make sure she was on track with her routine, like in the hospital. "I would tell my husband before he left for work in the morning that I would do the dishes in the sink or do a load of laundry," says Maria, "and then the whole day would go by and I wouldn't have gotten up from the couch. I couldn't complete one goal a day."

Maria asked her speech pathologist to return and the therapist explained that difficulty with initiation is a common characteristic of brain injury. The speech pathologist recommended that their sessions be conducted in the home office setting, which was the first step in getting Maria off the couch. The therapist reinforced compensatory strategies, such as using a schedule and checklists to help with follow through. She introduced computer based cognitive retraining exercises, which was a sneaky way of getting Maria to turn on her computer, something she had yet to do.

In conjunction with the one-on-one home therapy, Maria joined two out patient support groups for brain injury survivors- one was a cognitive strategies group and the other was a psychotherapy based group that addressed anxiety and depression, issues that often accompany brain injury. "I remember going and thinking, *I don't need to be here, these people are much worse off than me,*" she says. "I was really blind to the fact that I needed help."

Her thoughts changed quickly as she heard other's stories and realized they were similar to her own. "At least I felt like this is normal (following a brain injury)," she says. What was more, the groups gave her strategies for working around her injury. A valuable technique she learned to help with initiation and follow through was putting everything on her schedule, not just appointments. By scheduling projects and tasks, no matter how small, she found she was able to complete more of them. She knew what she had to do and when she would do it. And then she did it.

The psychotherapy group taught her necessary skills for coping with the negative emotions that may follow a brain injury. Irritability, a propensity to anger, and extreme anxiety were a few she dealt with. "Once I got control over my negative emotions and became educated as to what was happening to me, AND how to deal with it, it was easier to go back to work," she says.

In times of stress, she still turns to the binders that she received in each of the groups. And while she has made significant progress, the strategies she learned during her rehabilitation course are a permanent part of her life.

Five years later she has a thriving business and a very active life. She credits her participation in the groups and continued therapy for this, sharing her belief that if she hadn't stuck with the therapy, she might still be sitting on the couch.

NOTES

Chapter VIII.

Coping With Stress

What's in this section...

Stress following a brain injury is inevitable. The stress response is a normal physical reaction and can be helpful for short periods of time. However, long lasting stress can be unhealthy and damaging.

This section describes the unhealthy side effects of stress and provides suggestions for dealing with them.

Coping with Stress

Stress is a normal physical response to an event that makes you feel threatened or upsets your day to day balance. When subjected to an event that disrupts your life, your body moves into high gear in an automatic process known as the "fight-or-flight" reaction, or the stress response.

When you experience a traumatic event or perceive a threat to your normal day to day existence, your nervous system responds by releasing a flood of stress hormones, including adrenaline and cortisol. These hormones prepare the body for action. Your heart beats faster, muscles tighten, blood pressure rises, your breathing quickens, and your senses (hearing, vision, smell) become sharper. These physical changes increase your strength and stamina, speed your reaction time, and enhance your focus—thereby preparing you to either fight or flee from the danger at

hand. In small doses, this reaction is helpful. But our systems were never intended to endure this response for sustained periods of time. If unmanaged and prolonged, stress becomes a problem and a hindrance to our well being (physical, emotional and psychological) and negatively impacts our ability to solve problems effectively.

Stress caused by a brain injury is inevitable. An injury that results in hospitalization can be overwhelming. There is the obvious impact of a brain injury that causes stress. But so do the less expected, or unexpected, aftereffects of the injury.

Prolonged unmanaged stress can lead to physical, emotional or behavioral symptoms including headaches*, upset stomach*, elevated blood pressure*, chest pain*, racing heart*, constant aches and pains*, diarrhea or constipation*, frequent colds*, problems sleeping (too much or too little)*, memory problems, difficulty concentrating, poor judgment, anxious or racing thoughts, constant worrying, eating more or less, isolating yourself from others, procrastinating or neglecting responsibilities, using alcohol, cigarettes, or drugs to relax, nervous habits (e.g. nail biting, pacing).

**Physical symptoms should be evaluated by a physician.*

There are many proven tools that can be helpful with coping and reducing the severity of side-effects associated with stress. Often we seek to relieve or "get a break" from stress by using alcohol, drugs and tobacco. Unfortunately, instead of relieving the stress, these substances provide only a temporary escape from stress and frequently have a negative impact on one's ability to solve problems effectively and rationally.

You may also find the Centers for Disease Control website helpful.

www.cdc.gov/features/CopingWithStress/

Below are tips for coping during times of increased stress.

- **Don't try to control the uncontrollable.** Many things in life are beyond our control. Rather than focusing on those things outside your control, focus on the things you CAN impact and change.
- **Share your feelings.** Talk to a trusted friend or family member. Talking about what you're going through releases stress, even when the actual situation cannot be changed. People who enhance your life will lend perspective and offer strategies that have worked for them. Not all stressful situations are the same, but EVERYONE has experienced them.
- **Connect with others.** Seek support and guidance from others whose lives have been impacted by a brain injury. There are often organized support groups in the area for survivors of a brain injury or for caregivers/family members. These groups are often free of charge and offer information, guidance, and support. Visit *www.biacal.org* to locate a support group for survivors and/or caregivers in California. If there are no support groups in your area, consider starting one. A helpful website for locating support groups plus information on starting one is *www.caregiver.org*.

- Another helpful website for information is *www.brainline.org.*
- **Do something you enjoy every day.** Find some space in each day for yourself, even if taking a short walk outside the hospital is all you have time to do. Try to keep up your involvement in activities and hobbies that you enjoy, whether it is hiking, playing the piano, or working on your bike. Even if a short period of time is all you can squeeze in, it will help release stress, allow you a brief opportunity to focus on something else and provide a bit of "normalcy" to your day.
- **Exercise regularly.** Physical activity plays a key role in reducing and preventing the effects of stress. All forms of exercise are beneficial for physical and emotional health, including mild-moderate exercise (e.g. walking, Yoga, Tai-Chi, etc.).
- **Eat a healthy diet.** Well-nourished bodies are better prepared to cope with stress, so be mindful of what you eat. Limiting sugar, caffeine and alcohol is important. Maintaining regular healthy meals of protein, vegetables, grains and fruit will help provide energy to cope. Additionally, stay hydrated by drinking plenty of water.
- **Avoid alcohol, cigarettes, and drugs.**
- **Get enough sleep.** Adequate sleep fuels your mind, as well as your body. Feeling tired will increase your stress and may cause you to think irrationally. Maintain a regular sleep schedule, as much as possible. Take naps if sleeping through the night is not possible.
- **Learn how to say "no".** Refuse to accept added responsibilities when you're at your limit. Taking on more than you can handle will guarantee an increase in your stress level.
- **Take control of your environment.** If the evening news makes you anxious, turn the TV off. If certain people add to your stress, avoid them. Ask a good friend to interact with that person for you. If a situation is overwhelming, attempt to change it or walk away from it. Return when you are better able to handle the situation.
- **Pare down your to-do list.** Analyze your schedule, responsibilities, and daily tasks. If you've got too much on your plate, distinguish between the "shoulds" and the "musts." Delegate tasks that you don't need to do yourself (see page 20).
- **Ask for help from professionals or friends to help fill out the forms and paperwork** often needed when in the rehabilitation process and after discharge. Forms can include those related to insurance and medical care.
- **As a caregiver, allow yourself some respite time.** Ask others to sit in for you at the hospital so you can take breaks (even if short) and continue to schedule respite time when your loved one is at home. If the survivor can attend groups or classes without you, take advantage of that time for yourself. If not, ask a friend, someone from your church or community to cover for you for a period so you can have some down time. Hiring a

Practice relaxation techniques like:

1. *Deep breathing*
2. *Meditation*
3. *Visualization*
4. *Thought control*

caregiver is a luxury but often a necessary one. A couple of websites with helpful tips: *www.caregiver.com* and *www.lotsahelpinghands.com*.

- **Consult with a therapist or psychologist** to obtain support, guidance, and information about coping with the life changes brain injury can bring, for both the patient and family member.
- **Pay attention to your emotions** and be aware if you are overwhelmed with feelings of anxiety or depression. Know the signs and symptoms and seek support through therapy or your physician to find successful treatment before these emotions impact your life in unhealthy ways. A helpful website for understanding anxiety and depression symptoms: *www.adaa.org*.
- **Read Jon Kabat-Zinn, PhD.** He is the author of numerous scientific papers on the clinical applications of mindfulness in medicine and health care, and of a number of books for the non-professional: Start with *Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain and Illness (Delta, 1991) or Wherever You Go, There You Are: Mindfulness Meditation in Everyday Life* (Hyperion, 1994)
- **Practice relaxation techniques** that help reduce the body's physical and emotional reaction to stress. Examples include:
  - Deep breathing—focusing on equal inhalation and exhalation. Here is a website with instructions: *http://www.webmd.com/balance/stress-management/stress-management-breathing-exercises-for-relaxation#*
  - Meditation—even five minutes a day makes a difference. A helpful website with meditation instructions: *(http://marc.ucla.edu/body.cfm?id=22)*
  - Visualization—using imagery to relax. Here is a link to a script: *http://www.pent.ca.gov/trn/guidedimageryscript.pdf*
  - Control Your Thoughts—notice and redirect negative, harmful thoughts to supportive, helpful thoughts during times of stress.
- **Write in a journal.** Releasing thoughts and feelings in writing can result in healthier coping and an increased ability to face challenges successfully.
- **Listen to relaxing music** that calms the mind and emotions.
- **Keep your sense of humor.** This includes the ability to laugh at yourself. The act of laughing helps your body fight stress in a number of ways.

Note: visit www.binba.org for resources (websites, publications) that may be of assistance.

Remember: YOUR QUALITY OF LIFE MATTERS AND DOING WHAT YOU CAN TO SUPPORT YOURSELF THROUGH THE STRESS OF COPING WITH BRAIN INJURY IS IMPORTANT FOR YOU AND THOSE YOU LOVE.

Chapter IX. Legal Issues

What's in this section...

This section briefly addresses legal information that you may find helpful depending upon your situation. This information is not legal advice; rather, is some basic definitions and descriptions to help you determine when you may need the more specialized assistance of an attorney.

LEGAL INFORMATION

The services of a skilled, specialized attorney can be invaluable to the brain injury survivor and his family or caregiver. There are numerous occasions for consulting a legal specialist. Some are obvious, some less so. Often there are specific time deadlines that attorneys must meet in order to comply with the law. This means that you cannot wait indefinitely to contact a lawyer. These deadlines, called *Statutes of Limitations*, can be as little as 180 days in some circumstances.

Many find that they are hesitant to seek the advice of an attorney, but legal counsel, often at no cost at the onset, may provide essential information that will prove indispensable when making critical decisions or planning for a loved one's future.

The need for attorney consultation may be necessary if an individual, or his caregiver, has need to:

- Establish power of attorney
- Establish conservatorship or legal guardianship
- Develop a will
- Develop a trust
- Plan an estate
- Investigate patient rights
- Apply for social service benefits (Social Security Disability, State Disability, Workers Compensation, Unemployment benefits, etc.)
- Investigate possibility of financial recovery from an insurance policy or elsewhere
- Investigate a personal injury and possibility of monetary compensation

Power of Attorney: Power of attorney allows an individual to assign, or appoint, someone to handle important legal, financial or medical matters in the event that the individual is unable to make decisions for himself. This can only be done if the individual is of sound mind.

Guardianship: A legal guardian is a person who has the legal authority to care for the personal and property interests of an individual who is incapable of caring for his or her own interests due to disability. Parents are legal guardians until a child reaches the age of 18. If a minor's parents are deceased or unavailable, the Courts may appoint a guardian. The person a guardian protects is called a ward. Wards may be either minor children or incapacitated adults. In some other jurisdictions, "custodial" or "conservator" is used instead of "guardian".

Conservatorship: Conservatorship is similar to guardianship in that it is a legal relationship between a protected person and one or more individuals appointed by the court to make decisions on behalf of the protected person. However, while a guardianship may encompass all personal affairs (support, care, health, rehabilitation, therapeutic treatment, and if not inconsistent with an order of commitment or custody, the residence) of a protected person, a conservatorship is limited to the management of the property and financial affairs of a protected person. As with guardianship, a conservatorship may be full, limited, temporary, or joint.

Will: A will is a legal declaration where by a person (the testator) names one or more persons to manage his estate and provides for the distribution of his property at death. The testator must be of sound mind (have appropriate mental capacity) to draft a will.

Application for most first-party benefits needs to be filed in a timely manner. Report accidents as soon as they occur to assure that you receive the proper medical care without delay in insurance approvals.

Trust: A Trust is a relationship where property (real or personal) is held and protected by one party for the benefit of another. A trust may be created for the financial benefit of a surviving spouse, child or other dependent.

Estate Planning: This is the process of anticipating and arranging for the dispersal of an estate during your life. Estate planning often involves wills, trusts and powers of attorney. Estate planning is often seen as a necessary process for the caregiver of a brain injured individual when it is anticipated that the survivor will outlive the caregiver.

Personal Injury: Personal injury is a legal term for an injury to the body, mind or emotions. Personal Injury attorneys work with the injured party to determine whether an injured party is eligible for monetary compensation depending upon determination of intent or negligence of the responsible party.

Insurance Policies and First Party and Third Party Insurance: There are two parties in an insurance contract; the insured and the insurer, or the insurance company. The insured is the "first party." The insurance company is the "second party." And the "third party" is someone other than the insurance company or the insured.

When someone is injured, he may be entitled to payment of medical bills from first-party insurance benefits. An attorney will assist in identifying and monitoring first-party coverages and determine if third party coverage is available to the injured person. An injured person may have more than one of the following examples of first-party insurance (or third party) coverage to pay for accident-related medical expenses:

- Private Medical Insurance
- State Medical Insurance—Quest, Medi-Cal, Medicaid Benefits
- Federal Medical Insurance—Medicare
- Personal Injury Protection (PIP)/No-Fault/Excess Medical Pay through automobile insurance
- Worker's Compensation Benefits
- Travel Insurance Medical Pay
- Medical Care Claims Recovery Act and Veteran's Affairs Benefits
- Labor Union Trust Benefits.

Social Service Benefits and Employment Related Benefits: Depending on employment status and individual insurance coverage at the time the accident, the injured party may be entitled to:

- Temporary disability insurance (TDI)
- Long-term disability insurance
- Worker's Compensation indemnity benefits

- Labor union disability benefits
- Wage loss through optional automobile insurance
- State disability and assistance
- Federal disability programs through the Social Security Administration (i.e. SSI or SSDI).

Contact the human resource representative for the injured worker's employer as soon as the accident occurs in order to identify the filing requirements for Temporary Disability Insurance and/or any long-term disability policies through the injured worker's employment and/or labor union.

If you decide to seek the advice of an attorney, it may be beneficial to contact more than one law firm to get a feel for the different styles and personalities of each firm. When seeking legal counsel, it is helpful to be proactive in researching the attorney that will represent your case. Not all personal injury lawyers or law firms are experienced in the intricacies of brain injury cases, even though they may advertise that they accept that type of case. In the event you decide that you need an attorney to represent you or your family, be sure to retain a lawyer and law firm that has extensive experience in this highly specialized field.

To find firms to contact, ask people you know personally or medical providers for recommendations. Ask who they would recommend if it was their family member who was injured. Additionally, searching the web, yellow pages, and other legal directories can be helpful. Also consider consulting your state affiliate that helps people with similar injuries (e.g. Brain Injury Association of California). The questions below are helpful to ask in determining the true experience of an attorney:

- What percentage of your practice is traumatic or acquired brain injury?
- Do you have a curriculum vitae that discusses your brain injury experience? May I have a copy?
- When was the last brain injury case you settled? The amount?
- Do you have any brain injury case set for trial? May I come and watch some portion of that trial?
- Have you ever been invited by any group or organization to speak on the subject of brain injury cases?
- Do you have any upcoming speaking engagements that I could attend?
- Have you ever given lectures to any group on a topic related to brain injury?
- Have you ever written any articles on brain injury? Were they published and if so, by whom?
- How do you go about proving a brain injury if all the scans are "normal"?

You need to know...

If you wish to contact the legal firms that contributed to this section of the guide contact information is here:

- Law offices of Ian Mattoch
  (808) 523-2451
  ianmattoch.com
- Michael Shea of Shea & Shea
  (408) 292-2434
  www.shea-shea.com
- Sterling Ross of Robb and Ross
  (415) 332-3831
  www.robbandross.com

A detailed document pertaining to seeking legal counsel for personal injury advice and representation is located at *www.binba.org* on the Brain Injury Information Handbook page.

Chapter X. Financial Issues

What's in this section...

The information noted here may be helpful in understanding and coping with financial issues that can arise. To learn more, please visit the Insurance, Social Service Program, Suggested Reading, and Resources section of this guide.

HEALTH INSURANCE

Health insurance (Medicare, Medicaid, commercial insurance) generally cover much of the cost associated with care when you are in the hospital. However once you leave the hospital setting, coverage varies widely and may not cover interventions that are often critical for continued rehabilitation (e.g. day treatment, outpatient therapies, etc.).

- Review your policy carefully or have an insurance expert/hired case manager/attorney review your policy to help you understand what will and will not be covered. It is ultimately YOUR responsibility to understand the policy.
- Search the internet, review resource listings, and visit your local brain injury chapter to research continued therapy options/organizations.
- Ask about extra-contractual or going-out-of-contract exceptions that may be of benefit to you and to the insurer. Obtain these agreements in writing.
- Apply as early as possible for federal and state health insurance programs, such as Medicaid/MediCal/Medicare. Approval can take a long time and obtaining application assistance from an attorney, case manager, or other professional with expertise may be helpful. Visit *www.medicaid.gov* or *www.dhcs.ca.gov* or *www.medicare.gov* for more information and to locate local offices.

LOSS OF INCOME

Return to work following a brain injury is a process that varies widely from individual to individual. Some are able to return directly to their former place of employment, some need a graduated return to work, some may need a modified work environment or an entirely different situation, some may not be able to work at all.

- **Worker's Compensation:** If the injury is work related, you may qualify for Worker's Compensation benefits and coverage. Worker's Compensation benefits vary widely and are best defined by the carrier. The human resource department of the patient's employer can provide specific information about the benefits and coverage available to the employee. Visit *www.dir.ca.gov/dwc* for more information.

- **Family and Medical Leave Act (FMLA):** If employed at the time of the injury, the employer may have a plan that provides medical leave with or without pay. You may find you will only receive pay for the amount of vacation and sick time you have accrued. This Federal legislation entitles eligible employees to take unpaid, job-protected leave for specified family and medical reasons with continuation of group health insurance coverage under the same terms and conditions as if the employee had not taken leave.
  Visit *www.dol.gov/whd/fmla* for more information.

- **Victim Compensation Program:** may help pay bills and expenses that result from certain violent crimes. Victims of a crime who have been injured or have been threatened with injury may be eligible for help. Your attorney, the local legal-aid society, or the office of your state's attorney can tell you whether your state has a victim's compensation fund. Visit *www.vcgcb.ca.gov/victims* for more information and to find a local office.

- **Vocational Rehabilitation:** Each state has a Department of Rehabilitation (DOR) that assists qualifying individuals in obtaining employment. It can be a helpful resource for a person living with a brain injury who is ready to return to work. Many DOR offices will offer training, work programs, and other services to help with the transition back to work. Visit *www.rehab.cahwnet.gov* for more information.

- **Short-Term /Long-Term Disability Benefits:** If the injured person was employed at the time of injury, they may be eligible for short term and/or long term disability coverage through the employer. Check with the employer's human resources department and/or with the insurance carrier to discuss eligibility. For more information, visit the following websites:
  - Employment Development Department: *http://www.edd.ca.gov/disability/*
  - Disability Benefits 101: *http://ca.db101.org/ca/programs/income_support/std/program.htm*

More Ideas

- Visit *www.govbenefits.gov* for information about governmental benefit sources.
- If denied coverage by a disability insurance or other social services organization, do not give up and continue to advocate for coverage through contact with the organization, by re-filing a claim, and if necessary, consulting with an attorney. Coverage can be denied initially and eventually provided through perseverance and continued advocacy.
- If medical insurance has denied coverage of completed procedures OR requested procedures, continue to advocate for coverage through contact with the provider (hospital, physician, therapist and/or their billing office). Documentation generated by the provider is what often determines coverage. Make sure the documentation supports the purpose of the procedure. If not, ask if the provider can produce a more comprehensive explanation for the necessity of the procedure that is being requested or denied.
- Some hospitals have patient assistance programs for people with low incomes. Speak with the hospital billing department to see if they will establish a payment plan you can afford.
- A patient's auto insurance and/or homeowner's insurance policy may contain resources that cover the cost of medical care, if the injury was the result of a car accident or occurred at the patient's home. Review the individual's policies and/or consult with the insurance company representative for better understanding of eligibility. Additionally, if the injury was caused by another person, their auto insurance or homeowner's insurance may contribute to the cost of care.
- If it is possible that the injury was caused by someone other than the patient, consider consulting with an attorney.
- Check with the local and state government about free legal services should you determine you need to obtain legal counsel or advice.
- Some employer's offer a 'leave sharing' program, through which coworkers can contribute vacation leave to the injured employee.
- Consider sharing your situation with creditors, doctors, mortgage banker, etc. You may be able to negotiate payment plans that are easier to meet.
- Contact religious organizations in your community about funds and services available to people in need.
- Discuss programs for obtaining prescription medications at reduced prices with your doctor or case manager.
- Consult with your bank representative to inquire about services that may help while you or your loved one recovers (e.g. managing money, obtaining credit, etc).
- Consider hosting a raffle, yard sale, concert, or other type of event to raise funds for a patient's medical expenses. This has been successful for many survivors.
- In some cases, medical expenses may be tax deductible. Consult with your accountant for more information.

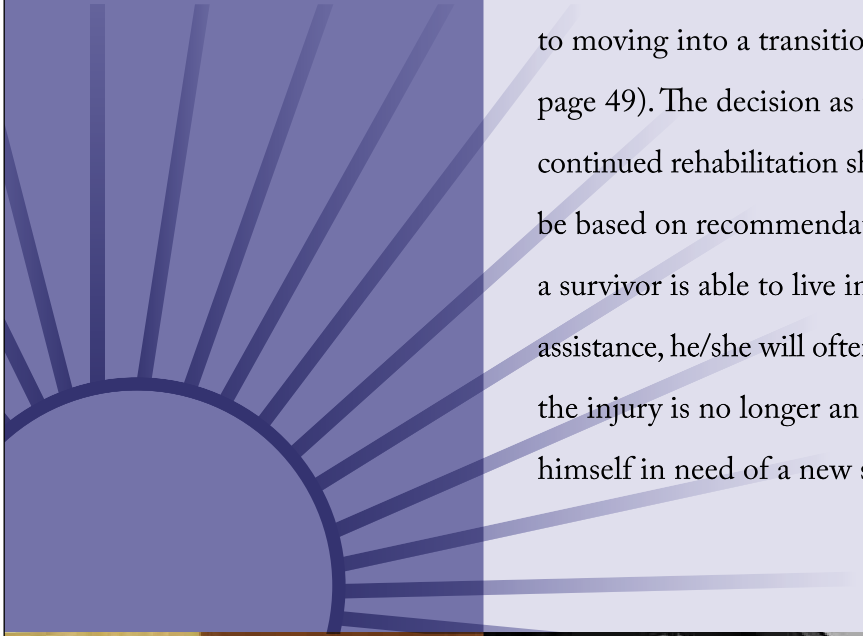
Notes

Chapter XI. Housing

What's in this section...

Housing specific to the Brain Injured population is scarce.

This section provides suggestions for locating an appropriate living situation for the survivor, and suggests looking in places that might not be obvious.



INDEPENDENT HOUSING ISSUES

Finding appropriate and affordable housing options for survivors of a brain injury has been, and remains, one of the most difficult tasks survivors and families face. Locating a situation that meets an individual's special needs while remaining affordable on a fixed income is often a challenge.

There is a range of housing options for an individual once released from the inpatient hospital setting. These settings range from returning home, to moving into a transitional, assisted, or residential living center (see page 49). The decision as to which living environment is best for continued rehabilitation should be discussed prior to discharge and should be based on recommendations from the medical treatment team. When a survivor is able to live independently, alone or with supervision and/or assistance, he/she will often be discharged to home. Often the "home" before the injury is no longer an appropriate disposition and the survivor finds himself in need of a new situation.

Finding housing options that are the 'right fit' for an individual as they navigate continued rehabilitation and life with a brain injury presents unique challenges. Being creative and 'thinking outside the box' are often necessary approaches to locating a successful living situation.

There are agencies and organizations that provide housing information and assistance (see section XII—resource listings). However, survivors and family members may need to find the 'right fit' for accessible and affordable housing on their own, utilizing creative ideas and resources (see Case Study: Thinking Outside the Box, page 75). Websites such as *Craigslist.org* offer shared housing/roommate situations, as do classified ads in local newspapers. There are often postings for roommate situations in public places (like libraries or rec. centers) that may prove fruitful. And contacting organizations that provide services for other types of disability (developmental, mental health, etc.) can result in a viable shared apartment living situation as well. Good old-fashioned networking and word of mouth from friends, family and co-workers is often the most effective means of locating a situation.

Here are a few approaches that have been viable for survivors and their families in locating housing options:

- Reviewing classifieds in the local newspaper
- Posting housing need on websites such as *www.craigslist.org* or bulletin boards in local areas
- Contacting organizations and agencies who assist individuals with brain injury to ask for referrals and suggestions
- Attending caregiver or survivor support groups in the area to learn successful tips from others whose lives have been impacted by a brain injury
- Contacting local community and county organizations that help with housing assistance (e.g. housing authorities, section 8 housing office, etc.).
- Accessing online websites that provide specific information regarding brain injury *(e.g. www.biausa.org)* or blogs/other sites created by survivors *(e.g. www.brainline.org)*
- Contacting organizations and agencies that specialize in providing service to individuals with similar characteristics and special needs
- Helpful websites for various housing options:
  - County Housing Authority (examples: *www.marinhousing.org, www.sfha.org*)
  - Group Homes—found through Community Care Licensing: *www.ccld.ca.gov*
  - Traumatic Brain Injury Group Homes List in California: *http://www.redwoodcrc.org/factSheets/HeadInjury/TBIGroupHomesInCalifornia.doc*
  - Senior Board and Cares: *www.stegnerregistry.com*
  - Local Shelters—often provide 6 month shelter bed with case management
  - Independent Living Centers by County: *http://www.rehab.cahwnet.gov/ILS/ILC-List.html*

Thinking Outside the Box

CASE STUDY

Very few residential homes exist that are specifically designed for the brain injured individual. And when they do, they can be prohibitively expensive. Laurel H. provides a perfect example of the creative, outside-the-box thinking that is necessary when you are the guardian of a brain injury survivor in need of appropriate housing.

Several years ago, Laurel "inherited" care of her younger brother, Ringo, after their mother passed away and their father's health declined. She received a crash course in finding housing, arranging help, and overseeing finances and medical care.

Ringo sustained a brain injury in his 20s during an operation to remove a cyst from his brain. This injury resulted in cognitive, psychiatric and physical problems. Though Ringo is capable of living on his own (he can do basic tasks like microwaving meals and basic self care activities), he needs a living situation that accommodates his special needs. This, coupled with the fact that he lives on a fixed income that stipulates that only $500.00 of the $879.00 he receives monthly can be spent on housing, makes finding a suitable living situation in Marin County challenging. Due to his SSI status, he is prohibited from living with a relative.

In Southern California he had always rented a room in a private home, which is what Laurel wanted to find for him when he moved to Marin County. Before he arrived, she called several county and state agencies, trying to find housing. "These places were very helpful," says Laurel. "But one assistant said 'I hate to tell you this but I think you're on your own. You should look on Craig's List or in the *Marin Independent Journal* (local newspaper)." This is where creative thinking comes in to play.

> *They have taken Ringo under their wing and provided him with a community.*

After six months of searching, Laurel finally found a private home on Craig's List near her home in Marin County that was owned by an older woman. The situation was perfect: she needed companionship and additional income and Ringo had a clean room and another male roommate in the house who helped keep an eye on him. When circumstances in that situation changed, she found another great situation through the *Marin Independent Journal* in a private home owned by an older man. Six men live there. They were all middle-aged. They all have special needs of their own. They have taken Ringo under their wing and provide him with a community.

While dealing with Ringo's housing, Laurel was also handling other areas of her brother's life. She oversees all of Ringo's finances and medical care, and has arranged aides to support him through In Home Support Services (IHSS). IHSS (see page 29) provides an aide three hours a week to do his laundry, vacuum his room, and take him grocery shopping.

At the moment, life is pretty settled, although it could change suddenly at any time. Laurel has organized Ringo's life and he's living in a comfortable, safe place, with people who care for him. This gives Laurel a sense of relief and Ringo a sense of independence. "Everybody kind of looks out for everybody else in his house," says Laurel, "and they *all* look out for Ringo."

Notes

Chapter XII. Resource Listing

What's in this section...

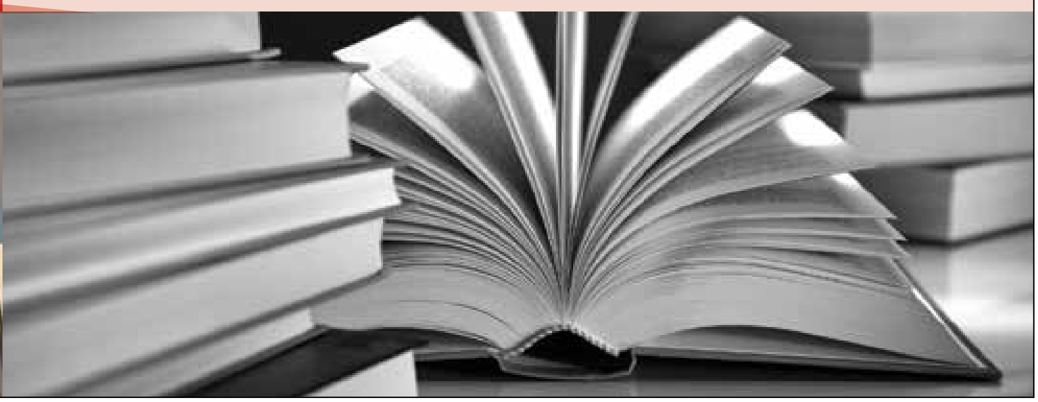
Following is a short list of organizations and websites that contain information and resources that can be helpful.

Please visit *www.binba.org* for a comprehensive list of resources that can be viewed and printed for your convenience.

Community and Internet Based Resources

Finding resources to help with life changes that occur following a brain injury can be challenging, for both the survivor and the family. Below is a short list of brain-injury-specific and county resources that are available online. These sites offer information about brain injury and other areas of disability care, plus they often have resource referral webpages.

The information and resources listed here are not intended to be an endorsement, nor are the listings all-inclusive. While we have tried to check all resources as thoroughly as possible, we cannot guarantee the accuracy of all information. Additionally, there may be omissions that are unintended. While it is not an exhaustive list, there are many helpful resources listed that may point you in the right direction to find the service you need.



COMMUNITY & INTERNET BASED RESOURCE WEBSITES *(visit www.binba.org for more resources)*

American Brain Tumor Association
www.abta.org

American Stroke Association
www.strokeassociation.org

Brain Aneurysm Foundation
www.bafound.org

Brain Injury Association of America
www.biausa.org

Brain Injury Association of California
www.biacal.org

Brain Injury Network of the Bay Area
Larkspur
415-461-6771
www.binba.org

Brain Injury Recovery Network
www.tbirecovery.org

BrainLine
www.brainline.org

California Caregiver Resource Centers
www.californiacrc.org

California Health Advocates
www.cahealthadvocates.org

Caring Bridge
www.caringbridge.org

Commission Accredidation of Rehabilitation Facilities (CARF)
866-888-1122
www.carf.org

Concussion Information Website
www.concussionmarin.org

Disability Rights California
800-776-5746
www.disabilityrightsca.org

Family Caregiver Alliance
San Francisco
415-434-3388
www.caregiver.org

Golden Gate Regional Center
www.ggrc.org

Make The Connection (for Vets)
www.maketheconnection.com/tbi

Marin Stroke Directory
www.strokeinfomarin.org

National Aphasia Association
www.aphasia.org

Rehabilitation Research Center – for Traumatic Brain Injury and Spinal Cord Injury
www.tbi-sci.org
**extensive .pdf printable resource guide (TBIRD): http://tbi-sci.org/tbirdvi_all.pdf*

Services for Brain Injury (SBI)
San Jose
408-434-2277
www.sbicares.org

The Brain Injury Information NETwork
www.tbinet.org

The National Institute of Neurological Disorders and Stroke
www.ninds.nih.gov

Transportation Information
http://transit.511.org/accessible/disabled/
www.whistlestop.org

State & County Services –
Many bay area county offices offer the following services via phone and website:

California Department of Rehabilitation
List of Independent Living Centers by County and other resource information
www.rehab.cahwnet.gov/ILS/ILC-List.html

Center for Independent Living
www.cfilc.org

Department of Health and Human Services
www.chhs.ca.gov

Disability Benefits 101
www.db101.org/

Housing Authority Offices
http://portal.hud.gov/hudportal/HUD?src=/states/california/renting/hawebsites

In-Home Supportive Services – Public Authority (IHSS)
www.cdss.ca.gov/agedblinddisabled/pg1785.htm

Legal – Bar Associations
www.barassociationdirectory.com/ca/

Medi-Cal
www.medical.ca.gov

Social Security Disability Resource Center
www.ssdrc.com

State of California Employment Development Department
www.edd.ca.gov/disability/

Superior Courts – Self Help webpage
www.courts.ca.gov/selfhelp.htm

Glossary

ADL:	Activities of Daily Living (eating, bathing, grooming, dressing, household chores, etc.)
Agitation:	Non purposeful activity resulting from confusion. Agitated responses are generally short lived and may not be related to a specific incident. Agitation is often attributed to identifiable precipitants (noise, pain, touching, too much activity, etc.) and can result in screaming, abusive language, pacing, pulling at lines and tubes.
Anoxia:	An absence of oxygen.
Aphasia:	Impaired ability to effectively use spoken words, written words or gestural symbols to express ideas (expressive aphasia) and/or impaired ability to understand spoken, written or gestural symbols (receptive aphasia.)
Apraxia:	Inability to perform purposeful movements although no muscular paralysis is present. Difficulty with execution of a task due to problems with the inherent motor program required to carry out a skill.
Aspiration:	The entry of food or liquid into the lungs because of swallowing difficulty. Can cause pneumonia.
Assistive Device:	Equipment used to help with a task. (walker, cane, reacher, etc.)
Ataxia:	Inability to coordinate and control muscle movements in a smooth manner.
Attention Span:	The length of time a person is able to focus on one subject or task; The ability to ignore distractions and mentally focus on the task at hand.
Bowel and Bladder Program:	Retaining bowel evacuation and bladder emptying at scheduled times.
Brainstem:	The life support entity of the nervous system, the structure that connects the body of the brain to the spinal cord. Responsible for respiration, heart rate and blood pressure, swallowing, motor production of speech, hearing and consciousness.
Catheter:	A tube inserted in the bladder for the purpose of draining urine. There are several kinds (Foley catheter, condom catheter and straight catheter.)
Cerebral Spinal Fluid:	A clear fluid produced in and for the support of the brain and spinal cord. It provides a medium in which the brain floats, and assists in constant purification of the brain by removing waste.
Closed Head Injury:	Trauma to the head causing brain damage without fracture of the skull.
Cognition:	The set of intellectual skills, which include knowing, perceiving, understanding, reasoning, problem solving and remembering.

Coma:	A state of deep unconsciousness wherein the patient does not interact with the environment. Resulting from trauma or induced by medication to promote healing in a severely injured individual.
Community Reintegration:	Application of skills learned in therapy to more functional skills in the community. These may include using public transportation, shopping and transacting cash, dining in a restaurant, prevocational training, education programs, use of community based resources or recreational opportunities.
Concussion:	A sudden sock or blow to the brain, can result in a loss of consciousness.
Confabulation:	Subconscious fabrication of facts or events, emerging from confusion, to fill in gaps in memory. Different from lying, the patient truly believes a confabulated event took place.
Confusion:	An inability to make sense of the environment, disorientation to time, place and circumstance. Confusion may be reflected in confused language, agitation and inaccurate memories.
Contracture:	Lack of full range of motion in a joint due to spasticity, insufficient movement or an orthopedic problem.
Cortex:	The upper ¼ inch of brain matter, often referred to as gray matter. It is responsible for sensation, movement, communication and intellectual function. Because of it's location on the top surface of the brain, it is quite vulnerable in the event of a traumatic brain injury.
Coup-Contra coup:	Two locations of injury resulting from the same insult. The coup refers to the initial impact site where contra coup is the opposite side of the head. Caused by the acceleration/deceleration movement of the brain within the skull.
CT Scan:	Computerized Tomography. A series of x-rays.
Craniotomy:	Removal of part of the skull to perform an operation on the brain. The cranial plate or bone flap (the part of the skull removed) may not be immediately replaced to allow for swelling associated with injury or surgery. In this case, the individual would wear a helmet to protect his brain until the skull plate is replaced.
Cranioplasty:	Replacement of the bone flap/skull plate removed during craniotomy.
Diffuse Axonal Injury (DAI):	The twisting, shearing, stretching, tearing forces imposed on the brain in rotational acceleration/deceleration injuries causing diffuse damage to the nerve cells. DAI is often responsible for the widespread cognitive and behavioral consequences of brain injury. DAI may cause coma if the brainstem is involved.
Disinhibition:	A loss or abandonment of the rules of expected social behavior and language. Often associated with frontal lobe damage. The disinhibited person acts on impulse and may speak without restraint or regard for social consequences.
Disoriented:	Confused as to person, place, time and /or circumstance.

Distractibility:	Inability to screen internal/external stimuli resulting in difficulty focusing or concentrating on a task.
Dysarthria:	Difficulty with speech as a result of muscle weakness or coordination coming from the brain. May result in slurred or imprecise articulation.
Dysphagia:	Difficulty with swallowing. Often as a result of neurological damage, but may also be due to mechanical problems (like the placement of a tracheostomy tube). Can also be due to impaired motor function or decreased sensation of the mouth and throat. Patients with dysphagia are at risk of aspiration.
Edema:	Swelling.
EEG:	Electroencephalogram. A procedure used to assess electrical activity in the brain. Often used to detect the presence of seizures.
Elevations:	Unlevel surfaces when walking. Negotiating elevations is necessary in functional walking. Includes stairs. Ramps, curbs and inclines.
Embolism:	A clot or foreign body that blocks an artery. Originates in the circulatory system and travels through the blood stream until it reaches the site of blockage.
EMG:	Electromyogram. A test that converts electrical activity in the skeletal muscles into legible images to facilitate the diagnosis of neuromuscular disorders.
Emotional Lability:	Uncontrollable crying, laughing, cursing, etc., often at inappropriate times, and often in excess of a patient's genuine emotional state.
Executive Function:	Most associated with frontal brain function. Executive function refers to the ability to plan, initiate, execute and revise a task.
Facilitation:	Promoting normal movement.
Flaccid:	Paralyzed muscle appearing heavy, limp, floppy. Due to low muscle tone.
Functional:	Skills or tasks which are applicable in daily living. Practical activities like preparing a meal, balancing a checkbook, taking a shower. Functional may also refer to a level of skill which, while not perfect, is adequate for the completion of a task.
Gait:	Walking pattern.
Gastrostomy:	A surgically implanted feeding tube that provides non-oral feeding directly to the stomach.
Glasgow Coma Scale:	A scale used by emergency medical personnel to determine the level of consciousness based on eye opening, verbal responses, and motor responses.
Hematoma:	A localized collection of blood caused by bleeding of a ruptured blood vessel.

Hemiparesis:	Weakness on one side of the body.
Hemianopsia:	A problem of visual perception where half the visual field is either disorganized or missing altogether.
Hemiplegia:	Paralysis of one side of the body.
Hemorrhage:	Bleeding.
Incontinence:	Inability to control the bladder and/or bowel.
ICP:	Intracranial Pressure Monitor. A device inserted through the skull used to monitor the amount of pressure exerted on the brain by swelling after a brain injury.
I and O:	Intake and Output. Measurement of the amount of fluid taken in and eliminated during a 24 hour period.
Impulsive:	Acting before thinking. A problem of judgment often associated with executive dysfunction and frontal brain damage.
Inhibition:	Stopping abnormal movement or behavior.
Intensivist:	A physician specializing in critical care.
Level of Assistance:	Degree of physical or cognitive facilitation required to do a task. Graded by the following levels: Independent: The patient is able to begin and complete a task safely without physical assist or direction. Supervised: The patient is able to begin and complete a task requiring only verbal cues or supervision for safety and thoroughness. Modified Independence: The patient may need to use an assistive device to complete the task. Contact Guard: Requires hands on help for guiding. Minimal Assistance: 0-25% physical assistance is required to complete the task. Moderate Assistance: 25-50% physical assistance is required. Maximal Assistance: 50-75% physical assistance is required. Dependent: 75-100% physical assistance is required.
Lower Extremity:	The legs and feet.
Memory:	The ability to retain and recall information. Immediate Memory: memory of information a few seconds after presentation. Short Term Memory: memory of information up to 24 hours after presentation. Long Term Memory: memory of personal information from the past, including that which was learned prior to the injury or illness.
Motor Control:	Control of movement, which is impacted by many factors including strength, coordination, sensation and the ability to plan purposeful movement.

MRI:	Magnetic Resonance Imaging-imaging of the body using magnetic field and radio waves instead of x-rays. Proficient in describing damage to soft tissue (brain, muscle) with great clarity and resolution.
Neurogenic Bowel/Bladder:	Difficulty with bowel and/or bladder function and control as a result of nerve damage.
NG Tube:	Nasogastric feeding tube. A feeding tube inserted through the nose, down the back of the throat, through the esophagus that provides a means of present nutrition, hydration and medication.
NPO:	Nothing by Mouth. This person is not allowed to take anything by mouth, including medication and water.
Orthotics:	Braces or splints.
Orthotist:	Professional who makes custom braces and splints.
OT:	Occupational Therapist; Occupational Therapy.
PTA:	Post Traumatic Amnesia. The time period between the occurrence of a brain injury and the resumption of functional daily memory and orientation. May last for minutes to months. The patient cannot remember events during this period, requiring the use of a memory book or journal to compensate and maintain orientation.
Perception:	Awareness, recognition, and meaningful interpretation of that which is seen, felt or heard.
Perseveration:	Unnecessary and unintentional repetition of verbal and/or motor acts.
Physiatry:	A physician (MD) expert in enhancing and restoring functional ability in and quality of life to those with physical or cognitive impairments.
PO:	To be taken by mouth, as with medication.
Pressure Area:	Reddened or whitened area (or colored differently from usual skin color), blister or abrasion which could "break down" or become a pressure sore.
Pressure Sore:	Any break in the skin caused by prolonged pressure over a bony prominence. Severity can range from Stage I through Stage IV, with Stage III and Stage IV presenting potential serious complications.
PRN:	Pro Re Nata- as needed. Often refers to medication that is taken as needed.
Proprioception:	The sensation of knowing the position of limbs and joints.
Prone:	Lying on the stomach.
Prosthesis:	Artificial limb.

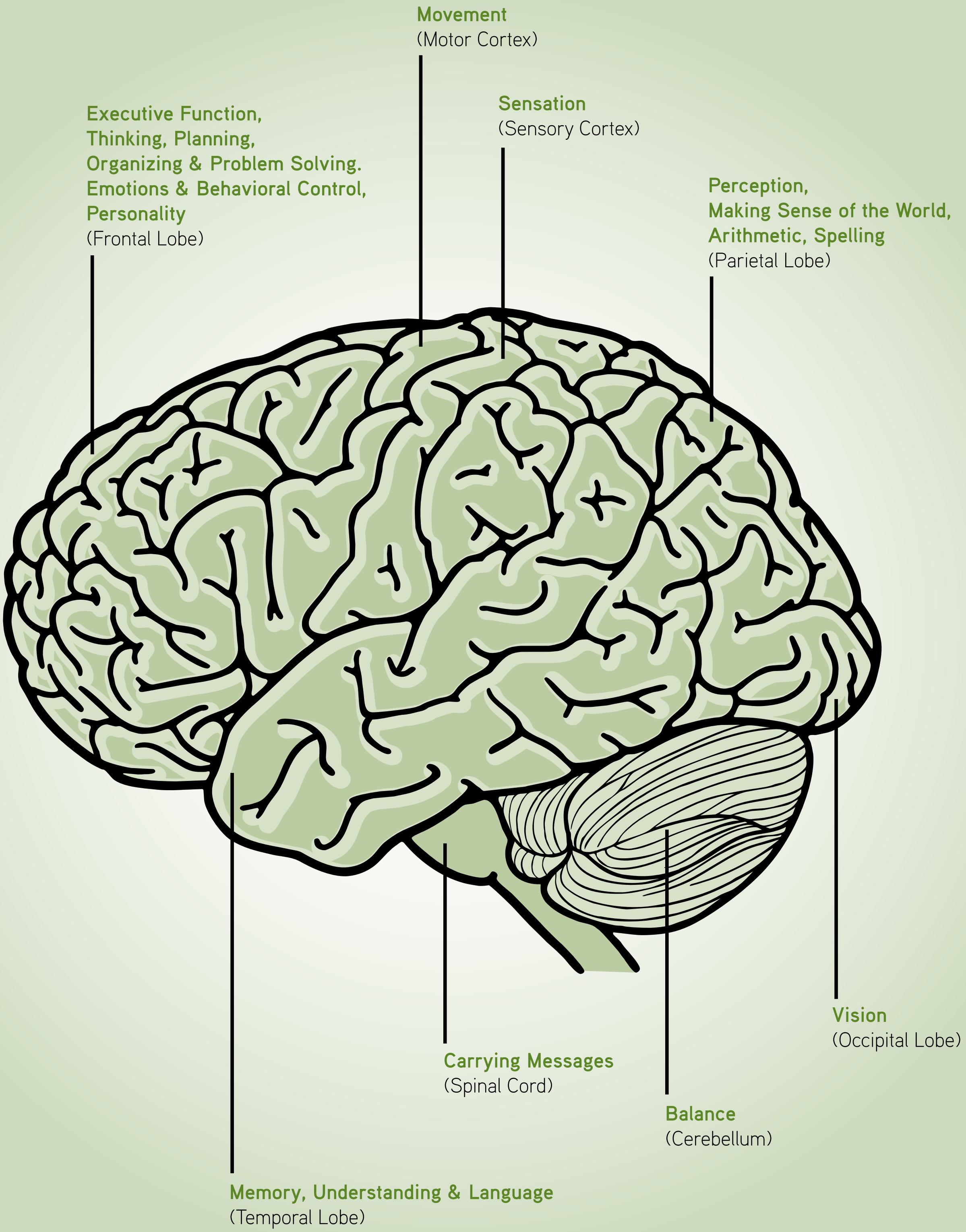
PT:	Physical Therapy, Physical Therapist.
Quad Cane:	4 legged cane.
Rancho Los Amigos Levels of Cognitive Function:	A scale of cognitive functioning used to describe specific cognitive and behavioral characteristics associated with brain injury. (See page 10)
SCI:	Spinal Cord Injury.
Seizure:	A sudden episode of uncontrolled electrical activity in the brain. Seizures can range in severity from small and focal resulting in twitching of a single muscle or muscle group to large and pervasive resulting in loss of consciousness and whole body involvement.
Sequelae:	An after effect of a disease or injury.
Sequencing:	Performing a task or expressing a thought in an orderly and meaningful manner.
Shearing:	A tearing of nerve fibers in the brain, especially along the outer surface or cortex, resulting from the brain rubbing along the coarse inner surface of the skull in rotational or acceleration/deceleration injuries.
Spasm:	A sudden contraction of a muscle (muscle jerk); usually uncontrollable.
Spasticity:	An abnormal increase in muscle tone causing the muscles to resist being stretched; limbs may appear very still or in a fixed, rigid position.
Suctioning:	Inserting a tube to remove excess secretions from the mouth or lungs.
Supine:	Lying on the back.
Tangentiality:	A disturbance in the thought process where an individual tends to move from one topic to another often losing the main point.
Tone:	See muscle tone.
Tracheostomy:	An opening in the trachea (wind pipe) placed to provide an alternative airway, access to the lungs and/or protection from oral secretions.
Transfer:	Moving from one surface to another (bed to wheelchair, wheelchair to toilet) either by standing, sliding or being lifted.
Upper Extremity:	The arm and hand.
UTI:	Urinary Tract Infection.
Ventilator:	A machine that performs the breathing function for someone who is unable to breathe on his own.

Recommended Reading

1. Brain Injury Association of America, *The Essential Brain Injury Guide. www.biausa.org*
2. Cassidy, John W., M.D., *Mindstorms: The Complete Guide For Families Living with Traumatic Brain Injury*
3. Jameson, Larry and Beth, *Brain Injury Survivor's Guide*
4. Kabat-Zinn, Jon, *Wherever You Go, There You Are*
5. Kabat-Zinn, Jon, *Full Catastrophe Living*
6. Meyer, Maria M. and Derr, Paula, *The Comfort of Home – A Complete Guide For Caregivers (3rd ed)*
7. Osborn, Claudia L, *Over My Head, A Doctor's Own Story of Head Injury from the Inside Looking Out*
8. Parker, James N., M.D., and Parker, Philip M., Ph.D., editors, *The Official Patient's Sourcebook on Traumatic Brain Injury*
9. Prowe, Garry, *Successfully Surviving a Brain Injury: A Family Guidebook*
10. Ross, Maria. *Rebooting My Brain. www.rebootingmybrain.com*
11. Ryan, Joan, *The Water Giver – The Story of a Mother, a Son, and Their Second Chance*
12. Senelick, Richard C., M.D., and Dougherty, Karla, *Living with Brain Injury – A Guide For Families (2nd edition)*
13. Shapiro, Alison Bonds, *Healing Into Possibility*
14. Skloot, Floyd, *In The Shadow of Memory*
15. Sullivan, Cheryle, M.D., *Brain Injury Survival Kit*
16. Taylor, Jill Bolte, Ph.D., *My Stroke of Insight*
17. Timothy, Megan, *12,000 Miles For Hope's Sake*
18. Wooton, Carol Howard, *www.keepinghopealive.org*
19. Woodruff, Lee, *Perfectly Imperfect – A Life In Progress*

Notes

THE BRAIN AND ITS FUNCTIONS



California Pacific Regional Rehabilitation Center

CPMC Foundation

Brain Injury Network of the Bay Area

To request a copy of this handbook

or to download a printable version, visit www.binba.org.

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