

BRAIN INJURY

A Booklet for Families



BRAIN INJURY ASSOCIATION OF TEXAS

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In collaboration with the
Brain Injury Association of Texas

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**In collaboration with members of the
Brain Injury Association of Texas**

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Many suggestions and helpful criticisms were provided by members of the Brain Injury Association of Texas and members of the brain injury teams at the University of Texas Medical School at Galveston and Houston.

First Printing	- 1983 - 5,000
Second Printing	- 1984 - 5,000
Third Printing	- 1985 - 10,000
Fourth Printing	- 1986 - 10,000
Fifth Printing	- 1987 - 5,000
Sixth Printing	- 1988 - 5,000
Seventh Printing	- 1989 - 5,000
Eighth Printing	- 1991 - 5,000
Ninth Printing	- 1992 - 5,000
Tenth Printing	- 1993 - 5,000
Eleventh Printing	- 1995 - 1,000
Twelfth Printing	- 1995 - 1,000
Second Edition	- 1996 - 2,500
Second Printing Second Edition	- 1997 - 4,650
Third Printing Second Edition	- 1999 - 5,000

Serious and even life-threatening injury to the brain of a loved one is frightening and confusing to the family and friends of the injured person. Many questions come to mind all at once, and family and friends often feel overwhelmed and very much alone. This booklet is designed to answer some of your questions. More than this, we hope that this booklet will be a starting point for many helpful discussions between the family, friends, and the team caring for the person with a brain injury.

This booklet has been prepared and distributed by the Brain Injury Association of Texas, an organization of survivors of brain injury, their families and friends, and interested professionals. One of the goals of the Brain Injury Association of Texas is to work with you, and with the brain injury team, to provide information and emotional support during the time of crisis.

QUESTIONS YOU MAY HAVE ABOUT BRAIN INJURY?

WHAT IS A BRAIN INJURY?

The term **BRAIN INJURY** refers to an injury to the **BRAIN** which is usually the result of an accident, or sometimes an assault. Often the injury results from a blow to the brain such as may be suffered in an automobile accident, a fall, or a gunshot wound. The injury may also occur as a result of lack of oxygen (such as in drowning), or as a result of lack of blood supply to the brain (such as following a cardiac arrest or stroke). People with multiple injuries (as in serious automobile accidents) often suffer brain injury by more than one of these mechanisms. *The term **BRAIN INJURY** is preferable to the term **BRAIN DAMAGE** because the brain has tremendous powers of recovery.* Furthermore, shortly after a brain injury, it is usually impossible to tell how much permanent damage will remain. The terminology is less important than what actually happens. The underlying process in all injuries is similar in that the injury to the brain occurs over a relatively short time.

WHAT HAPPENED?

You may never know the exact cause of the accident or injury, and chances are the person with the brain injury will never remember what happened.

WHEN WILL HE OR SHE WAKE UP?

No one can tell you when he or she will wake up. You can only **WAIT** and **SEE**. Furthermore, survivors of brain injury rarely wake up all at once. Rather, the process of full recovery of consciousness is gradual and takes hours in the mildest cases and may take months in the worst cases. Some people improve only to a point and never fully regain awareness of their surroundings.

IS RECOVERY FROM BRAIN INJURY POSSIBLE?

Yes, in contrast to the short time it takes to injure the brain, recovery is measured in weeks, months and even years. Recovery is most rapid shortly after injury and slows down with the passage of time. Many people with severe brain injuries end up with almost no noticeable problems, but others require constant care for the rest of their lives.

WHAT WILL BE THE ULTIMATE OUTCOME?

This is the most important question of all, and the most difficult to answer. The **ONLY** way to be sure of the outcome is to **WAIT** and **SEE** what happens. As time passes, members of the intensive care and rehabilitation teams can begin to get an idea of what the possible outcomes might be. Estimating outcome like this is important but almost always takes longer, and is far more inaccurate, than we would like. Most people who survive a serious brain injury eventually wake up from coma; that is, they begin to open their eyes. In the best cases recovery proceeds from this point to **NEARLY COMPLETE RECOVERY**. In the worst cases, there is no recovery beyond opening their eyes. People who wake and sleep but have no meaningful interaction with the world around them are said to be in **PERSISTENT VEGETATIVE STATE** or minimally responsive. This is probably the worst possible outcome. In between these extremes is a very wide range of outcomes, some fortunate, and some tragic. It is very important to know that the outcome may remain **UNKNOWN** for many months.

WHEN WILL WE KNOW HOW BAD THE BRAIN INJURY IS?

It is very difficult to predict the outcome of a brain injury in the first hours or days after it has happened. There are some statistical observations which tell us **ON THE AVERAGE** what the outcome will be; but we cannot absolutely predict the outcome of any one person's injury. It may seem cruel and uncaring when the doctor says we just have to **WAIT** and **SEE** but this is the accurate answer. In general terms, the longer a person remains in coma, the less likely he or she is to recover completely. The process of recovery almost always takes much longer than the family and friends expect. A few people may eventually become essentially normal after several months in coma, whereas others may suffer permanent injury after only a brief period of coma. As would be expected, people with brain injuries generally do better if just their brain is injured and they do not also have serious injuries to other parts of their bodies.

WILL MY LOVED ONE DIE?

No one can accurately predict whether a person with a brain injury will die. Brain injuries are often serious enough themselves to cause death. In addition, many survivors of brain injury who have also suffered multiple injuries often do worse than people with brain injuries alone. There are two critical periods in the immediate recovery of a

person with a brain injury. The first is in the first day or two after the injury when the injuries may be so overwhelming as to cause death in spite of the most intensive medical treatment. Those who survive this period face another critical period beginning a few days later and continuing for two weeks or more. This critical period results from swelling of the injured brain.

WHAT IS BRAIN SWELLING?

BRAIN SWELLING (also called cerebral edema) is unavoidable, and is the end result of many different kinds of injury to the brain. If it cannot be controlled, brain swelling may cause death by producing excessive INTRACRANIAL PRESSURE (pressure in the head, also called ICP).

HOW CAN BRAIN SWELLING BE CONTROLLED?

Control of intracranial pressure depends on intensive monitoring and control of every bodily function; this requires around-the-clock attention and usually takes place in an intensive care unit. It is usually necessary to control breathing by a machine called a ventilator or respirator. The neurosurgeon may choose to insert a monitoring device into the brain or tissues that surround it to assess ICP. Very strong medications are often given to temporarily paralyze the patient, and even deepen the level of unconsciousness, in order to control breathing, blood pressure and other vital functions. In some cases removal of small amounts of fluid from around the brain may help. In other cases surgical procedures may be of benefit. Some of the life supporting devices used in the intensive care unit are illustrated in the drawing at the end of this booklet.

WHAT HAPPENS IF BRAIN SWELLING CANNOT BE CONTROLLED?

Too many times the most heroic efforts to control intracranial pressure fail, and the person dies. As stated above, the presence of multiple injuries complicates the management of brain swelling and adds the risk of dying from other causes.

WHAT IS BRAIN DEATH?

Brain death is defined by law in Texas as the total absence of any brain function, whether or not the person's heart is still beating. The time of death is defined as the time at which the physician determines that there is no longer any brain function. There are a number of medical criteria that physicians use to determine that there is no longer any remaining brain function. Once this has been determined, then the injured person is legally dead. No decision is required to turn off the machines that are maintaining breathing and heart beat.

In rare instances, a decision must be made whether to continue intensive care of a person who is not brain dead but, in the opinion of the attending physician, prognosis is hopeless. These are very

difficult decisions and most physicians try to involve the family as much as possible in making them. Such decisions are never properly made on the spur of the moment.

WHAT REACTIONS MAY I EXPECT IN MYSELF AND OTHER FAMILY MEMBERS AND FRIENDS?

Most people are shocked at the news that a loved one has suffered a brain injury. Most people experience some normal thoughts and feelings which may be disturbing to them. Some examples of these feelings are:

1. **GUILT** is a common reaction to a loved one's brain injury. You may feel irrationally that if only you had done something differently the injury wouldn't have happened. Often the best thing is to acknowledge your feelings and then put them aside until they can be viewed more in perspective.

2. **DENIAL** occurs in almost everyone who hears of a loved one's injury. This is manifested as a refusal to believe what one is hearing. Sometimes people secretly refuse to believe what the doctors are telling them; others openly refuse to hear what they are being told. Still others manifest their denial by becoming angry at the bearer of bad news. Hope is important, and even irrational hope can be helpful so long as it doesn't lead to inappropriate actions.

3. **ANGER** is often directed at the doctors, the persons perceived as causing the accident, ourselves, and even God. Anger is a strong emotion and sometimes is justified. Often, however, the anger one feels after a loved one is injured is inappropriate and not helpful. The best thing to do if this happens to you is to be aware of your anger, acknowledge it, but not act on it until you have had time to see things more in perspective.

4. **SHOCK** affects people differently. Some show their emotions outwardly; others appear calm. Most people are anxious and have a feeling of unreality, like they are in a bad dream. Forgetfulness is common and people may have to ask the same questions over and over. It is important to know that the way someone reacts to shock does NOT indicate whether he or she is 'good' or 'bad'. There is usually plenty of time for people to grieve in their own way. Shock is a normal and healthy reaction, and most people manage to find the inner strength necessary to make good decisions when they need to be made.

WHAT SHOULD I DO IF I FEEL I NEED HELP?

Sometimes family members become unduly stressed. It is important that they look out for themselves since there is no point in having someone else ill. If you feel you are becoming unduly stressed, you should ask for help. Often just having an outsider to listen is all that is needed to get back on an even keel. Most of the members of the team caring for the injured person can refer family members to an appropriate person for support. In addition to persons affiliated with

the hospital, your own clergy person, doctor, social worker or friend may be of invaluable help. Some early warning signs of undue stress are:

1. Inability to sleep
2. Poor self care
3. An overwhelming sense of guilt or worthlessness
4. Feeling completely alone with nowhere to turn
5. Excessive use of alcohol or drugs
6. A sense of hopelessness, that nothing at all can be done
7. Not understanding anything you are told about your loved one's condition.

If you are having any of these warning signs be sure to ask for help. Members of the Brain Injury Association may work with the brain injury team to help provide the emotional support you need.

WHY DOESN'T THE DOCTOR EVER TALK TO ME?

It is best to designate one or two family members to facilitate communication between medical professionals and family, so information is consistent and physicians know that information is being relayed appropriately so the physician's time can be spent delivering patient care.

There are many times when you will feel frustrated and angry that no one seems interested in answering your questions. Write your questions down, then keep asking them until they are answered. But remember that you are under stress and are apt to be forgetful - so be prepared. You may not want to believe it but that is normal; it even has a name. It is called DENIAL or denying that anything is wrong - pretending that nothing bad is going to happen.

It is also difficult to assimilate all the new vocabulary and information you may be hearing.

WHAT IF THERE AREN'T ANY ANSWERS TO MY QUESTIONS?

One reason that you may feel your questions are not answered is that there are no answers. Most members of the brain injury team say "I don't know" many times, but afterward few family members ever remember them saying that. "I don't know" is the proper answer to many questions in the early stages of brain injury. Be sure to talk to several members of the brain injury team. The nurses can answer many questions because they are with the injured person more than anyone else. Most brain injury team members communicate well with each other and pass on your concerns. It is important to note that members of the brain injury team are also human and may be preoccupied or impatient at times. In the best situations, family members and the brain injury team are open with each other and work together toward their common goal, which is the best possible recovery for the person with the brain injury.

WHAT IS COMA?

COMA is defined in a number of ways. One of the most useful ways to define coma is that it is a sleep-like state in which the injured person does not open his or her eyes, does not speak, and cannot obey commands like "Stick out your tongue!" or "Hold up one finger!" There are several levels of coma. A number scale called the Glasgow Coma Scale is often used to describe the responses of people in coma. There is nothing magic about this scale, it just attaches numbers to the responsiveness of the person with brain injury in terms of eye-opening, speaking, and moving his or her extremities. People are usually no longer considered to be in coma if they open their eyes, speak, or can obey simple commands.

Many patients will develop sleep-wake cycles and no longer be in coma but may still not be able to follow commands. This is called the vegetative or minimally responsive state.

CAN'T THEY GIVE HIM OR HER SOMETHING TO WAKE UP?

There are currently no medicines known that will shorten the duration of coma. In fact, some medicines are used which actually deepen the state of unconsciousness. Other medicines temporarily paralyze the body. These effects of the medicines may have to be tolerated for the overall well being of the patient.

HOW CAN SOMEONE BE IN COMA IF HE OR SHE IS MOVING?

People who are in coma cannot obey commands. They may move, however, in response to touch or pain, or even on their own. **EXTENSOR POSTURING** is commonly seen in patients in coma. This is characterized by marked "tone" or stiffness of the legs, arms and neck in a characteristic posture with the legs straight out and feet pointed downward, and the arms straight out at the sides with the wrists bent down and the fists clenched. This posture is often worsened by touch or pain. The person may become so rigid that he or she quivers from muscles straining. **FLEXOR POSTURING** is similar except that the arms are bent at the elbow. **WITHDRAWAL** is a more complex movement in which the person in coma may pull away from a painful stimulus, or may even attempt to push away a source of pain.

DO PEOPLE IN COMA FEEL PAIN?

Being in coma may be compared to being under anesthesia. People in coma may well react to pain by moving, or even groaning, but most often have no memory of the pain. Many painful procedures are necessary for the care of persons with brain injury. Nurses and doctors are aware of this and avoid unnecessarily painful procedures, or give additional sedation or anesthesia when indicated. Those unfamiliar with people in coma may have difficulty watching these procedures. If you feel uncomfortable with these procedures you should leave until they are finished. Then, at a convenient time, you

should ask members of the team to explain what they are doing, and why. Ask them about the person's reactions to pain.

DO PEOPLE IN COMA HEAR?

People in coma sometimes show signs that they are able to hear and understand. Often these signs are just simple reflexes - like turning head to sound, squeezing a hand, or sucking, in response to a touch. Occasionally people in coma seem to become calm when they hear a familiar voice. Since they never remember these events; it is impossible to decide if they actually recognized a voice or understood what was said. However, as a rule, it is good to talk to, and about, people in coma AS THOUGH they could hear and understand what was being said.

WHAT IS BRAIN STEM INJURY?

The brain stem is the part of the brain that connects the larger portion of the brain with the rest of the body. Many functions are tightly packed in the brain stem and, consequently, it is quite susceptible to injury. Among other things, the brain stem controls consciousness, breathing, heart beat, eye movements, pupil reactions, swallowing and facial movements. Furthermore, all the sensations going to the brain, as well as the signals from the brain to the muscles, must pass through the brain stem. The brain stem is often damaged in severe brain injuries, but it is almost never the ONLY part of the brain that is injured.

WHAT CAUSES COMA IN PEOPLE WITH BRAIN INJURIES?

Coma in people with brain injuries almost always results from injury to all parts of the brain, not just the brain stem. In very rare circumstances the major portion of the brain is spared and only the brain stem is injured. This may result in prolonged coma with rapid and nearly complete recovery when the person wakes up. In the vast majority of cases, however, prolonged coma implies diffuse injury to all parts of the brain, including the brain stem, and recovery is slow. Residual effects of brain stem injury may include prolonged difficulty with movements, vision, swallowing and other functions controlled by the brain stem. Residual effects of injury to other parts of the brain may include problems with movement, memory, attention, speed of thinking, complex thinking, speech, language, behavior and personality.

WHAT ARE SEIZURES? - HOW CAN THEY BE CONTROLLED? - DO THEY DO ANY HARM?

Seizures are the result of abnormal brain activity and are common in persons with severe brain injuries. Seizures are not good for the brain and it is desirable to control them. Medicines such as phenytoin (Dilantin) and phenobarbital are commonly used. Some people's seizures cannot be controlled by medicines and the best that can be

done is to support the other bodily functions to minimize any further brain injury from continued seizures. Sometimes the medicines used to control seizures are used to deepen the state of unconsciousness or coma, and other medicines paralyze the body to prevent the muscle contractions produced by seizures. These effects of the medicines may have to be tolerated for the overall well being of the patient.

HOW LONG IS SEIZURE MEDICATION NEEDED?

It is no longer believed that survivors of brain injury will need long term antiseizure medication, unless they develop post-traumatic epilepsy. Once a patient is medically stabilized and risk of damage as a result of seizures has passed, many physicians will slowly withdraw anticonvulsant therapy. Seizures will sometimes develop long after the injury and are then called Post-Traumatic Epilepsy. These are more frequent in people who have had a penetrating injury to the brain, had blood clots (hematomas) in the brain, or who have had seizures in the first week after the injury, though they can happen to any brain injury survivor. Suddenly stopping seizure medicines may CAUSE seizures in people who would not otherwise have them. Therefore, it is very important to take the medicine as directed and, as directed by the physician, the dose may be slowly reduced.

WHAT IS SPASTICITY?

Spasticity is abnormally increased muscle tone of some muscles as a result of partial or complete disconnection of the muscles from the brain. Spastic muscles usually have very brisk reflexes and sometimes they will quiver on their own. It is important to exercise spastic muscles to maintain the normal movement of the joints. The physical therapist plans appropriate exercises for each person with brain injury individually. Spasticity may improve with time as the connections with the brain are restored, or it may increase. Interventions such as splinting, casting and injections may be chosen to help maintain range of motion and decrease spasticity.

WHO WILL BE INVOLVED IN CARING FOR MY LOVED ONE?

Most hospitals take a team approach to the care of people with brain injury since the job involves many people with different skills. Family members sometimes become angry because the neurosurgeon isn't at the bedside all the time. In most cases the best care is given by the people who are at the bedside because they are the ones who are best at their particular job. Some people involved in the care of persons with brain injury are the nurse, respiratory therapist, physical therapist, occupational therapist, speech therapist, social worker, neurosurgeon, physiatrist, neurologist, neuropsychologist, and consulting physicians. Some of these people are involved from the very first and are often present in the intensive care unit. Other

team members become more involved in the rehabilitation phase.

WHAT ARE INTERNS AND RESIDENTS?

Most teaching hospitals have interns and residents who provide the major part of the medical care for persons with brain injury. Interns and residents are physicians who have finished their medical training and are taking additional training in a specialty such as neurosurgery. Because they are in training, there is always an attending physician with whom they consult in caring for people. This system usually results in there being more physicians who are more readily available to care for critically ill patients. *The highest quality of care is given in some units that have interns and residents, and also in other units that do not have interns and residents.*

WHAT CAN BE DONE INITIALLY?

The initial phase of the care of people with brain injury is the INTENSIVE CARE phase. Recovery from brain injury depends on careful maintenance of body functions to prevent further brain injury, and to allow time for the brain to heal. INTENSIVE CARE is just that, maintaining the body functions as well as possible to prevent further damage, and to allow the brain to heal. Numerous complications to body systems are common after a brain injury and must be carefully monitored and addressed. Some of the life supporting devices used in the intensive care unit are illustrated in the drawing at the end of this booklet.

WILL HE OR SHE HAVE TO HAVE SURGERY?

People with brain injury, especially those with multiple injuries, may need to have several surgical procedures in the course of their hospitalization. In most cases, people in coma have suffered injury to all parts of their brain. There are no surgical procedures that can correct this injury, or prevent the injured brain from swelling. However, about one third of severely injured people require surgery to remove collections of blood or portions of the brain that are hopelessly damaged or infected. This provides the best chance for the remainder of the brain to heal itself. Recovery from brain injury depends on careful maintenance of body functions to prevent further brain injury and to allow time for the brain to heal.

WHAT THINGS CAN FAMILY MEMBERS DO TO HELP?

Most hospitals and nursing staffs encourage a few close family members to become involved in the daily care of the injured person. Gradually they learn to do more and more. This allows the family member to spend more time in a productive way with the person with brain injury. It also helps to provide more of the tender-loving-care which is so important in recovery. It is important to let the nursing staff and doctors decide when, and how much, of this sort of care is helpful. Family members should let their own feelings be known so that their

feelings can be considered in deciding how much care they may be involved in.

HOW IMPORTANT IS NUTRITION IN RECOVERY FROM BRAIN INJURY?

Adequate nutrition is very important for maximum recovery from brain injury. Persons with brain injury need a lot of calories and it is not unusual for them to lose as much as 25% of their body weight. Providing adequate nutrition is often very difficult and dangerous in the critical stage of treatment because other injuries and the need to control brain swelling take precedence. Vitamins, minerals and some calories are provided intravenously from the time of admission to the hospital, and optimal nutrition remains a high priority throughout the hospital stay.

WHAT ABOUT MEGAVITAMINS AND OTHER NON-STANDARD THERAPIES?

More than adequate amounts of vitamins and minerals are provided from the time of admission. Megavitamin therapy, however, has no proven value in the treatment of brain injury. The shock and tragedy of a serious brain injury often prompts people to try a host of non-standard treatments. One of the appeals of non-standard therapies is that they carry essentially no risk. Often the risk is low because the therapy has no direct effect at all on the body, either good or bad. Although the treatments may not be harmful in and of themselves, the harm comes from two areas. First, most non-standard therapies are supported by testimonials and exaggerated claims of effectiveness that are not borne out under proper testing. This leads to false hope and eventual disappointment. More importantly, the false hope held out by non-standard therapies often undermines the relationship between the brain injury team and the family and friends of the person with brain injury. This leads to suspicion and mistrust, and sometimes to failure to use necessary and effective therapies. In the final analysis it is the person with brain injury who is harmed.

WHAT THERAPIES ARE BEST?

Not all the therapies used in the hospital have been proven to be effective. The best brain injury teams are constantly reassessing their treatments to be sure that the treatments offered are of the greatest benefit to the injured person. The therapies that are "best" are determined only by the needs of each person with brain injury. A therapy that is essential for one person may not be necessary for another. Most persons will require many therapies.

WHAT ABOUT EXPERIMENTAL THERAPIES?

You may be asked to give your permission for your loved one to participate in experimental procedures. Almost all hospitals in the

United States have committees which review experimental procedures to be as sure as they can that the potential benefits of the treatment outweigh the risks. Studies of this kind are the only way advances in treatment can be made. At the same time, most experimental procedures employ the very latest, and hopefully the best, treatments available.

WHO SHOULD I ASK ABOUT TREATMENTS?

You should discuss various treatments with the brain injury team to be sure you understand what is being done. If you have questions about other modes of therapy, you should ask them. It is also important to know that well meaning family members and friends may suggest a number of different treatments that are not in the best interest of the person with brain injury. If you are not sure, you should discuss these treatments with the health care team.

CAN THE DOCTORS TELL HOW MUCH BRAIN DAMAGE THERE IS?

Most people with brain injuries have extensive DIFFUSE INJURY which involves many parts of the brain. Certain tests such as the CT scan, EEG and brainstem auditory evoked potentials and somatosensory evoked potentials provide some information about the extent of the injury. However, in the final analysis, it is the FUNCTION of the brain in thinking, speaking and moving that provides the most useful information about the extent of the damage. Since the function of the brain often continues to improve for months or even years after a brain injury, measurements of brain function must be repeated several times as the recovery progresses.

DOES THE BRAIN HEAL ITSELF?

Injured brain tissue can recover to variable degrees. However, once brain tissue is dead or destroyed, there is no evidence that new brain cells can grow. The process of recovery usually continues even though new cells do not grow. We presume this happens as other parts of the brain take over the function of the destroyed brain tissue. Obviously, the more extensive the damage, the less likely it is that the remaining brain can take over the function of the destroyed areas. Recovery also occurs as reversible injury resolves such as resolution of swelling or resorption of blood.

WHAT ARE THE STAGES OF RECOVERY FROM A BRAIN INJURY?

The early stages of recovery from a brain injury are indicated in the Table. The more severe brain injuries are followed by a period of COMA lasting from seconds to a few months or more. People are coming out of coma when they can open their eyes, speak, or begin to obey commands.

WHAT IS POST-TRAUMATIC AMNESIA?

The next stage in the recovery from brain injury is called POST-TRAUMATIC AMNESIA. Coming out of coma is not just waking up as people often imagine. Rather, it is most often a gradual process of regaining contact with the world. One of the most striking things about recovery of consciousness is that it takes so long to begin to restore memory. The kind of memory that is most often affected is the ability to remember the events of the day continuously. When people with brain injury are awake but unable to recall what happened just a few hours or even minutes ago, this state is called POST-TRAUMATIC AMNESIA. People in this state are disoriented (confused) about the day and time, about where they are, and sometimes about who they are. Patients will not remember that family visited earlier in the day. Sometimes people in this state are very restless and cannot be comforted. This reflects the state of their brain injury and does not necessarily mean they are in pain. People who are fully recovered from a brain injury usually have no memory at all of this stage of their recovery.

WHAT CAUSES COMBATIVENESS AND RESTLESSNESS?

Combativeness and restlessness are states of extreme irritability present in some people with brain injury who are neither in coma nor fully oriented. They are often seen immediately after a relatively mild brain injury or when a person with brain injury is recovering from coma. Verbal abusiveness and swearing are common at this stage and are often distressing to family and friends. These states are beyond the injured person's control. Furthermore, they do not imply that there has been a permanent personality change or that the person with brain injury is in severe pain. Excessive sweating is also common at this stage of recovery. Restlessness and combativeness may last for weeks or months and are very taxing on family members. Behavioral interventions and/or medications may be suggested by the treating team. It is important not to overstimulate the patient. Examples of this would be limiting the number of visitors and amount of noise, avoiding arguments with the patient, and making sure the patient gets adequate sleep at night.

WILL HE OR SHE REMEMBER THINGS FROM BEFORE THE ACCIDENT?

In contrast to memory for the events happening a few minutes or hours ago, people with brain injury often have much better memory of things that happened before the accident. The problem seems to be in the recording of new memories rather than in the recall of old ones. However, people with brain injury almost never recall the accident causing the injury or the events immediately preceding the accident. This is called RETROGRADE AMNESIA.

WHEN DOES REHABILITATION BEGIN?

Rehabilitation is the process of helping a person achieve his or her maximum functional potential after injury. This process begins immediately. Once memory of the events of the day begins to be restored, the rate of recovery often appears to be much more rapid. However, many problems may persist for a long time. These may be problems related to movement, poor memory, lack of attention, slowness of thinking, difficulty with complex thinking, difficulties with speech and language, or behavior problems and personality changes. These problems are dealt with in the rehabilitation of the person with brain injury. It should be pointed out, however, that rehabilitation begins very early in recovery. Some aspects of rehabilitation begin even while the person with brain injury is in coma.

WHAT HAPPENS AFTER THE INITIAL RECOVERY PHASE?

Continued recovery after discharge from the acute care hospital depends on proper rehabilitation. In some cases rehabilitation can continue at home or on an outpatient basis. In other cases rehabilitation is best accomplished at a rehabilitation center where several hours per day are devoted to specific therapy. Finally, in a few cases, the nursing care requirements are so great, and the rehabilitation potential so limited, that the best placement is in a skilled nursing facility. Where to go next is a complex problem that depends on the needs of the person with brain injury, the family's needs, and the facilities available. These problems should be worked out toward the end of the patient's hospital stay.

WHEN DOES RECOVERY STOP?

Gradual recovery from brain injury may continue for several years. Improvements have been achieved by intensive retraining of people who have regained their intellectual functioning but are severely handicapped by specific problems in thinking or behavior, and in social or vocational skills. It is important to note, however, that recovery may stop at any stage. In the worst cases, people may survive for years, totally dependent, and with no awareness of their surroundings.

WHAT ABOUT RECOVERY FROM OTHER INJURIES?

People with brain injuries often have suffered serious injuries to other parts of their bodies which complicate their recovery and rehabilitation. The recovery from these other injuries will not be discussed in this booklet.

DOES IT MEAN THAT ALL IS WELL WHEN THE PERSON WITH THE BRAIN INJURY CAN LEAVE THE HOSPITAL AND GO HOME?

Many persons with brain injury have continued problems when they return to their home and family, particularly after severe brain injuries producing prolonged coma. Problems with complex thinking,

and with emotional instability and personality changes, are especially common. Both the person with the brain injury and his or her family may be frustrated and disturbed by these continued difficulties. There may be setbacks in self-care and independence, or in progressing to a meaningful life style or livelihood. The rehabilitation team may suggest continued therapy as an outpatient, or as provided by a visiting therapist. Other resources exist which may assist the survivor of brain injury and his or her family to overcome the long-term problems which usually become apparent only when he or she returns home. One such resource is the Brain Injury Association, which can provide emotional support to people with brain injuries and their families and can help them find an appropriate rehabilitation setting.

PEOPLE WHO MAY BE PART OF THE BRAIN INJURY TEAM

ANESTHESIOLOGIST - A physician who administers anesthesia. More importantly, he or she is an expert in the workings of the heart, lungs and kidneys, as pertains to anesthesia.

ATTENDING PHYSICIAN - The doctor ultimately responsible for the care of the injured person.

CONSULTING PHYSICIANS - Doctors in other specialties who have been asked to give their advice on certain aspects of the injured person's care.

INTERN - A physician who has completed medical training and is in the first year of specialty training. Interns work under the supervision of Residents and the Attending Physician. In some places "intern" and "first year resident" are used interchangeably.

INTERNIST - A physician with expertise in internal medicine. Internists are often consulting physicians for persons with brain injuries because they are knowledgeable in infectious diseases and diseases of the heart, gastrointestinal tract and other internal organs. Some internists are subspecialized in the heart (cardiologist), or gastrointestinal diseases (gastroenterologist). They may also serve as consultants.

NEUROLOGIST - A physician who specializes in diseases of the brain, nerves and muscles.

NEUROPSYCHOLOGIST - A psychologist with special skills in dealing with people with brain injury. Neuropsychologists often administer special tests of brain function and assist with the coordination of the rehabilitation of persons with brain injury.

NEUROSURGEON - A surgeon who is an expert in diseases of the nervous system and also operates on the brain. A neurosurgeon is often the attending physician supervising the care of persons with brain injury in acute care.

NURSE - A person with expert training in the direct care of persons with brain injury. Nurses in the ICU and on the rehabilitation team often have extra training and experience in treating injured people.

NUTRITIONIST - An expert in the feeding and nutritional needs of people.

ORTHOPEDIC SURGEON - A physician who specializes in diseases of the bones. Orthopedic surgeons are often involved in the treatment of injuries to the limbs and backs of persons who also have brain injuries.

OCCUPATIONAL THERAPIST (OT) - Occupational therapists establish a routine of self-care activities of daily living, and work on improving thinking through interaction and activities with people with brain injuries.

PHYSIATRIST - A physician who is an expert in physical medicine and rehabilitation, physical retraining and other aspects of the rehabilitation of people with injuries. The rehabilitation team is usually headed by a physiatrist.

PHYSICAL THERAPIST (PT) - An expert in maintaining and improving the movement of joints and limbs. Physical therapists perform specialized techniques to maintain normal muscle tone, and begin a program of active physical reconditioning when recovery has progressed far enough. When tone is too great, they use techniques to try to decrease it.

PSYCHIATRIST - A physician who specializes in the management of behavioral problems.

PSYCHOLOGIST - A non-physician who is an expert in the management of behavioral problems. Psychologists also assess the thinking functions of the brain and participate in the rehabilitation team. They may also be available to help family/friends with their adjustment.

PULMONOLOGIST - A physician who specializes in problems of the lungs.

REHABILITATION COUNSELOR /

VOCATIONAL REHABILITATION COUNSELOR - A person with a degree specializing in the skills to assist persons with brain injury in adjustment to disability. The therapists and counselors assess a person's employment potential and help the person return to work if possible.

RESIDENT - A physician who has finished his or her medical training and is taking additional training in a specialty such as neurosurgery. Residents are always supervised by the Attending Physician who is responsible for the care of the injured person.

RESPIRATORY THERAPIST/PULMONARY THERAPIST (RT) - A person with special skills in operating machines to aid breathing and in keeping the injured person's airway open.

SOCIAL WORKER - An expert in the social aspects of brain injury treatment and rehabilitation. Social workers do a wide range of work from finding sources of funds to providing emotional support for families and assisting with discharge plans.

SPEECH PATHOLOGIST - An expert in caring for problems with expressing and understanding language. Language problems are among the most common and long-lasting problems in persons with

brain injury. Speech pathologists also assess and help the patient with swallowing.

UNIT CLERK - A person who coordinates messages and keeps records in the nursing station for each patient.

THE CENTRAL NERVOUS SYSTEM

The central nervous system (CNS) consists of two parts, the BRAIN and the SPINAL CORD. The largest part of the brain is made up of the two hemispheres and their interconnections. This part of the brain controls thinking, movement, vision, and speaking and understanding language.

The BRAIN STEM is the part that connects the larger portion of the brain with the spinal cord and the rest of the body. A large number of functions are tightly packed in the brain stem. Among other things, the brain stem controls consciousness, breathing, heart beat, eye movements and pupil reactions, and swallowing and facial movements. Furthermore, all the sensations going to the brain, as well as the signals from the brain to the muscles, must pass through the brain stem.

The SPINAL CORD is the final connection of the brain to the body. Spinal injury may result in paralysis and loss of sensation in the limbs as well as loss of bowel and bladder control.

The CEREBROSPINAL FLUID (CSF) is the fluid which surrounds the brain and spinal cord and fills the ventricles (cavities) in the brain.

EQUIPMENT USED DURING ACUTE BRAIN INJURY TREATMENT

ARMBOARD - A piece of wood or plastic taped to the injured person's arm to prevent the catheters in the arm from being bumped.

ARTERIAL LINE - A catheter in one of the injured person's arteries - usually in his or her arm. An arterial line is used to measure blood pressure and the amount of oxygen and carbon dioxide in the blood.

BRAIN STEM EVOKED RESPONSES (BSER, BAER, AER) - An electrical test used as an indicator of evoked potentials of how well the brain stem is functioning.

CATHETER - Also called a LINE. Catheters are thin tubes which may be placed in several parts of the body to put materials in, drain body fluids out, or to take samples and measurements.

CENTRAL VENOUS PRESSURE (CVP) LINE - A catheter inserted in a small vein and moved to the large vein near the heart in order to measure the blood pressure there.

CHEST TUBES - Tubes inserted between the ribs and lungs to remove air and/or fluid collapsing the lungs.

COMPUTERIZED TOMOGRAPHY SCAN (CT SCAN) - An X-ray test that makes pictures of the brain on a computer.

ELECTROCARDIOGRAM (EKG or ECG) - An electrical test of the function of the heart. Most injured persons in the ICU have their hearts continuously monitored.

ELECTROENCEPHALOGRAPH (EEG) - An electrical test of the functioning of the brain. The EEG is helpful for detecting seizures. Unfortunately, the EEG is very inaccurate when used to estimate the extent of brain damage and what the outcome will be.

ENDOTRACHEAL TUBE (ET TUBE) - A tube inserted into the injured person's trachea (windpipe) to control his or her breathing and prevent foreign material from entering the lungs.

EXTERNAL FIXATION DEVICE - A special splint to hold broken bones in place. Such devices are connected to pins through the bones.

EYE TAPE - Injured persons in the ICU often have their eyes taped shut to prevent them from drying out or being scratched. Sometimes salve or artificial tears are used for this purpose.

FOLEY CATHETER - A tube inserted into the injured person's bladder for the drainage of urine. The urine drains into a plastic bag hanging by the side of the bed.

HALO - A metal ring placed around the head for patients with spinal injuries to prevent their heads from moving.

INTRACRANIAL PRESSURE MONITOR (ICP MONITOR) - A tube inserted through the skull into the space outside the brain or into one of the cavities (ventricles) in the brain. The pressure in the brain is measured by an instrument (transducer) connected to the other end of the line. Some ICP monitors are small catheters, others are hollow metal bolts screwed into the skull.

INTENSIVE CARE UNIT (ICU) - The place in the hospital where critically ill people are cared for. Sometimes injured people are cared for in a special Neurological ICU (NICU).

INTRAVENOUS LINE (IV) - A catheter inserted into a vein through which fluids and medicines are given. Sometimes a needle can be seen at the end of the catheter.

MONITOR - A television screen near the injured person's bed which shows his or her heart beat, blood pressure and other important information. Most monitors have alarms to alert the staff that something may be wrong. Interpreting the information shown on a monitor requires considerable training and experience. Many family members become unduly concerned with watching the monitor. If it seems to you that no one is paying attention to the monitor then you should ask one of the team to explain the monitor to you at a convenient time.

NASOGASTRIC TUBE (NG TUBE) - A tube going from an injured person's nose into his or her stomach. Initially this tube is used only to remove air and secretions from the stomach. Later it may be used for feeding as well.

RESPIRATOR/VENTILATOR - A machine that moves air in and out of the lungs of a person with brain injury. Sometimes the person can trigger the ventilator by starting to take a breath.

RICHMOND BOLT/SUBARACHNOID SCREW - One kind of ICP monitor.

SPACE BOOTS, WRIST SPLINTS AND SHEEPSKINS - Some of the devices used to maintain the normal posture of joints and to prevent sores caused by rubbing on the bed. Normal posture is also maintained by moving the joints in exercises planned by the physical and occupational therapists.

SWAN-GANZ CATHETER - A special catheter inserted into a small vein and moved along the vein into the heart. This catheter may be used to measure pressures in different parts of the heart and to measure how hard the heart is working.

TRACHEOSTOMY -A hole made in a brain injury survivor's neck which allows him or her to breathe with a ventilator or on his or her own. Tracheostomy is safer and provides better control of breathing than an endotracheal tube in persons who require long term breathing assistance. The tracheostomy closes up by itself when the tube is no longer needed.

TRACTION - An arrangement of weights and pulleys to keep fractured bones aligned while they are healing.

TRANSDUCER - An instrument used to measure blood pressure, ICP and other important information. Transducers are usually connected to a monitor.

ULTRASOUND/ECHO -A means of making pictures of internal body parts using sound waves instead of X-rays.

VENTRICULOSTOMY - A catheter placed through the skull into one of the cavities (ventricles) in the brain. The catheter may be used to measure pressure, withdraw fluid or, in some cases, to administer medicines.

MEDICINES WHICH MAY BE USED FOR PEOPLE WITH BRAIN INJURIES

ANTIBIOTICS - Seriously injured people are susceptible to many kinds of infections because of their injuries and the many lines and tubes inserted into their bodies. Several kinds of antibiotics may be given. Most antibiotics are given through an intravenous catheter (IV) whereas others may be placed on the skin or into the nasogastric tube. Occasionally antibiotics must be given through a ventriculostomy catheter directly into the ventricles of the brain.

DECADRON (DEXAMETASONE) - One of the STEROIDS given to lessen brain swelling.

DILANTIN (PHENYTOIN) - An anti-seizure drug which is usually given to prevent seizures after serious brain injury. If patients actually do develop a seizure disorder, they will most likely be treated with

less sedating anti-convulsants (example: Carbamazepine).

DOPAMINE - A potent drug used to increase blood pressure in critically ill persons.

LASIX (FUROSEMIDE) - This drug assists the body in eliminating water. It may be used to treat intracranial pressure, too much water in the lungs, or kidney problems.

MAALOX - A medicine given usually by the nasogastric (NG) tube to help prevent the stomach ulcers which brain injured people are prone to develop.

MANNITOL - A medicine used to remove water from the brain and thereby lower intracranial pressure (ICP). The mannitol and water are then eliminated by the kidneys.

MORPHINE (MS) - A strong sedative which is also an excellent pain reliever. Brain injury survivors who receive this narcotic in the ICU almost never become addicted to it because of this treatment. Morphine is often used to sedate people with brain injuries so that they do not 'fight' the ventilator.

PAVULON (PANCURONIUM BROMIDE) and **CURARE** - Muscle paralyzing drugs which temporarily paralyze all the muscles of the person with brain injury. These medicines are used to prevent the person from 'fighting' the ventilator and to control intracranial pressure (ICP).

PENTOBARBITAL (NEMBUTAL) - A strong sedative which has been used to control intracranial pressure. When used in this way, pentobarbital acts as an anesthetic which places the survivor of brain injury in a deeper coma. Since the physical examination can no longer tell how the patient is doing, monitors must be used for this purpose.

PHENOBARBITAL - An anti-seizure drug used to prevent seizure in persons with brain injury, especially children. Phenobarbital may occasionally be used like pentobarbital to control intracranial pressure (ICP).

STEROIDS of which **DECADRON** is an example - Potent drugs which are used to lessen brain swelling.

VALIUM (DIAZEPAM) - A sedative tranquilizer which is very effective at quickly stopping repetitive seizures when given intravenously.

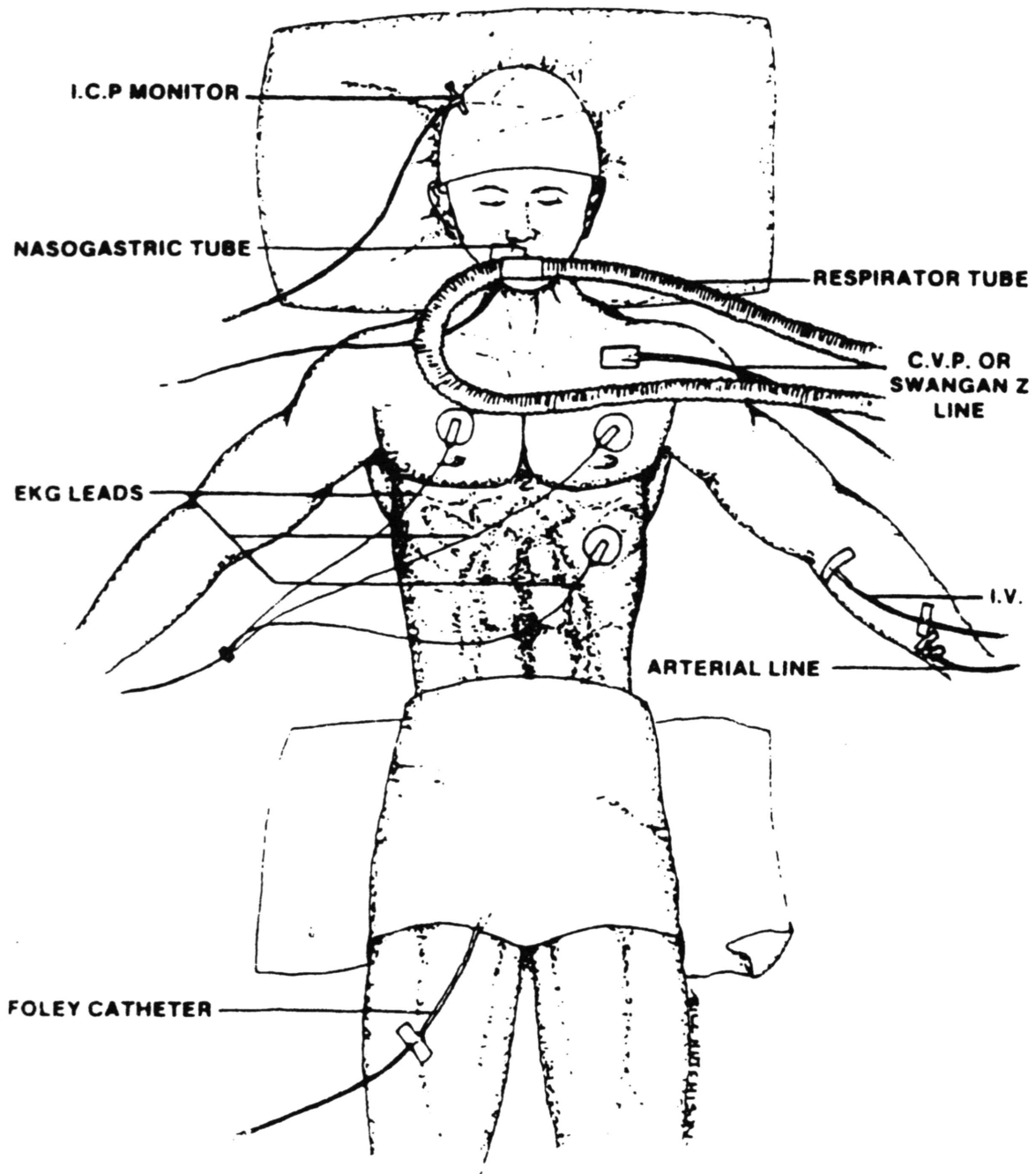
ZANTAC, PEPCID - A drug used to help prevent the stomach ulcers to which survivors of brain injury are so prone.

TABLE

	:I:		
	:N:	: Post	:Restoration
Continuous: Retrograde	:J: COMA	: Traumatic	: of
Memory : Amnesia	:U:	: Amnesia	: Memory
	:R:		
	:Y:		

Adapted from "Neurobehavioral Consequences of Closed Brain Injury," HS Levin, AL Benton & RG Grossman, Oxford University Press, 1982, p 74.

ACKNOWLEDGMENT: This booklet was inspired by a booklet of similar style and purpose entitled "Brain Injury" published by the Comprehensive Central Nervous System Injury Foundation, PO Box 9494, San Diego, CA 92109.



Acknowledgments for the Second Edition:

**Corwin Boake, PhD
Cindy Ivanhoe, M.D.
Mary Ellen Young, PhD
Ted M. Thayer, M Ed, CRC**

Single copies and quantity orders of this booklet may be obtained from the Brain Injury Association of Texas. Please call or write for prices on this and other available literature.

The Brain Injury Association of Texas is a non-profit organization dedicated to improving the quality of life for survivors of brain injury and their families. Tax exempt donations and grants will permit the publication of additional booklets on rehabilitation and post rehabilitation life for persons with brain injury.

To obtain more information about any aspect of problems relating to brain injury or facilities for the treatment of survivors of brain injury, contact your nearest Chapter or:

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