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INTRODUCTION

This booklet addresses the emotional and behavioral problems faced by both patients and families in the early stages after a severe brain injury. We will introduce to you the members of the team of health professionals who work with these patients. We also want to acknowledge the critical role that family members play in the recovery process. We welcome your input and would like you to feel comfortable in asking for answers as well as advice.

Statistics show that brain injuries occur most frequently to young males. However, we have alternated the use of the pronouns “he” and “she” throughout sections of the book to accommodate all patients.
Each patient is under the care of a Neurosurgeon, assisted by residents. A “resident” is a fully qualified doctor who is taking extra training in a specialized area of medicine.
GUILT

Many people experience a sense of “If only...this hadn’t happened”. All of us want to protect the ones we love. Sometimes even the thoughts of an argument before the patient left home may leave us feeling somehow responsible. Once again, acknowledge your feelings (perhaps with a friend or a member of the treatment team with whom you feel comfortable). Then, try to put them aside until you can look at them more objectively. One cannot stop feeling guilty because someone tells you to stop, however, it is important to remember that there is nothing helpful or positive about feelings of guilt.

Don’t sell yourself short! Remember that any improvements your friend or relative makes are probably due in some measure to your help. You should take credit and satisfaction in them. Experiencing all the emotions we have talked about, and perhaps some others, will be tiring. You should ask for help when you need it. Develop and maintain support systems for yourself. Something that will get you away for a few hours, a day or a week, may give you some relief.

ACKNOWLEDGEMENTS

We would like to acknowledge The Professional Staff Association of the Rancho Los Amigos Medical Centre Inc., California, USA, for permission to use their Levels of Cognitive Functioning.

THE NURSING STAFF

Medical/Surgical/Neurosurgical Intensive Care:

Intensive Care nurses are specially trained to look after critically ill patients. A nurse is assigned to one patient for each shift. If you have concerns, questions about various machines/tubes connected to the patient, ask the nurse. The nurse can also give you information about any change in the patient’s condition and will contact the doctor if you wish to speak to him. The nurse will also ask for a family spokesperson in the case of large families. When the patient’s condition is stable he will be moved to the neurosurgery ward. (7.3).

The Nurse Manager

The Nurse Manager is responsible for the provision of nursing care to neurosurgical patients.

The Charge Nurse

The Charge Nurse works closely with nursing staff and other professionals. She is available to help coordinate all aspects of patient care including daily medical care, discharge planning, concerns and questions.

Nursing Staff

The nurses will observe any changes in condition, help to prevent complications and provide appropriate stimulation. Let them know of any changes you observe and continue to ask questions. If you wish to help with bedside care let the nurses know.

Physiotherapist

At first, the physiotherapist will mainly be concerned with keeping the patient’s chest clear and his limbs as mobile as possible. Later on the physio will concentrate on helping the patient become as independent as possible by working on strength, balance and movement. The physiotherapist welcomes the family’s participation in the treatment program.

Occupational Therapist

Occupational Therapists (O.T.) work with the patient to make him more independent in all areas of daily living - hygiene, dressing, eating, homemaking, leisure and work. To aid in the patient’s recovery the O.T. may need to assess and help retrain cognitive (thinking) skills. The O.T. may suggest necessary equipment or home adaptations to make the return home as safe and accessible as possible.
Speech-Language Pathologist
Some brain injured patients will have difficulty with communication which may involve understanding the spoken word as well as speaking. A speech-language pathologist may be asked to assess and provide advice on the best way to assist with communication.

Social Worker
The Social Worker makes an assessment of both the patient and family’s concerns, strengths and weaknesses and what kind of home supports are available. He/she may also help problem solve with the patient and family, provide reassurance, discuss financial concerns and help co-ordinate discharge plans. The Social Worker also co-ordinates family meetings (see section on Family Meetings page 8).

Dietitian/Nutritionist
After a brain injury, patients may have difficulty swallowing. The dietitian works with other team members to make sure the patient is getting the right type and amount of food. If a person is unable to eat enough to meet his needs, a tube feeding may be started. The feeding tube carries a special formula through the nose and into the stomach.

Neuropsychologist
A neuropsychological assessment may be helpful after a traumatic brain injury. This assesses how the injury affects skills like concentration, memory, language and problem-solving. A psychologist conducts the assessment. A trained assistant may help. They may ask the patient to answer questions, remember things, and write things down. Assessment results help the team decide if the person can be safely left alone. They may also help decide the best time to return to work, school or driving. In the feedback session, the psychologist explains the results of the test to the patient and family. Ways to get around some problems in daily life will be discussed.

Pastoral Care
The Pastoral Care Department provides spiritual and emotional support to all patients, families and staff who wish their services. Both chaplains and community clergy are part of the Pastoral Care Department.

Request for Pastoral Care may be made through the nursing staff or the Pastoral Care office (473-4055). The chapel is open to all.

ANGER AND FRUSTRATION
Many people feel angry that such a terrible accident could happen to their family. Anger is a strong emotion and must be acknowledged. If you are feeling angry over something which you cannot change, you are more likely to react strongly to the smallest details. You may then feel frustrated that more is not being done for your loved one. Acknowledge your anger. Try not to act on it until you have had time to think clearly and see things in perspective. Write down the things that seem to make you angry and frustrated. After you have thought about these things, discuss them with someone to whom you can relate. This may help you avoid misdirecting your anger toward the people around you and perhaps even toward the patient himself.

DENIAL/OVER-OPTIMISM
Almost everyone who hears of a friend or relative’s injury doesn’t want to believe what she is hearing. Denial helps to relieve our emotional suffering. There is nothing wrong with hope. However, there comes a time when denial can prevent one from facing some important facts and, subsequently, from helping the patient as much as can be possible.

Hope is important as long as it helps you cope. It becomes unhealthy when it causes you to set unrealistic goals for the patient and does not allow you to appreciate whatever gains she may be making. Talk to the doctors and therapists involved in her care and try to take one day at a time. Accept the patient as she is today. This does not mean you are giving up on the future!

CONSIDERATION OF OTHER FAMILY MEMBERS
Don’t forget about the other family members, especially children. They may need extra support and comfort. You can do this by continuing interest in their daily activities and trying to make time to attend special events.
Recreation Therapy
Promote physical, social, emotional and cognitive well-being through therapeutic interventions, leisure education, leisure counselling and recreation participation.

Family Meetings
Shortly after the patient has moved to the Neurosurgical Ward, the social worker will make arrangements for family to meet with the members of the team who are involved with the patient. The team will describe their roles in the patient’s care and will report their observations on the patient’s progress. Family members should feel free to make their own observations and to ask questions about any aspect of care. The team will appreciate learning more about the patient such as interests, occupation, hobbies and food preferences.

FATIGUE
Many things contribute to your increasing tiredness:

- Your desire to be with the patient as much as possible;
- An inability to sleep;
- Not stopping to eat properly;
- Feeling alone and trying to handle everything on your own.

You are just as important as the patient and indeed, within the family, you may now have a more responsible role. YOU MUST TAKE CARE OF YOURSELF. Once the crisis is over and the patient is stabilized, do not feel the need to be constantly at the bedside. If it is important to you to have someone with the patient daily, ask another family member or close friend to take a turn visiting and report to you.

Realize how important your rest is and make sure you get enough. Recovery from a brain injury is a very long, slow process and you will need to reserve energy for later months.

Eat properly. Failing to get the proper nutrition will add to your fatigue as well as increase your risk of illness.

Many people find that their free time and contacts with friends are markedly decreased. Time for yourself is not a luxury to be put on hold until the patient is better. It is essential to your mental and emotional well being to be involved with other people. A change of scene such as visiting with friends or attending a concert or a movie may help. Do not feel guilty about these activities because they are important for both you and the patient.
What is a Brain Injury?
A serious brain injury is an event that may result in loss of consciousness for varying lengths of time. The injury may occur as a result of a blow to the head, which may be suffered in a car accident or fall, with direct damage to the brain.

Brain damage may also occur due to a lack of oxygen and/or blood supply to the brain. This may happen in shock due to blood loss, chest injuries, stroke and even after a heart attack.

When injuries result in brief unconsciousness (minutes), recovery may be complete or nearly complete. As the length of time in coma extends to days and weeks, the person is increasingly more likely to be left with problems in physical, intellectual, communicating, behavioral and emotional skills.

Even minor brain injuries may produce changes in reasoning, perception and interpersonal relationships. These changes interfere with return to home, community, school and work.

Family members react to the injury in different ways. You may go through periods of disbelief, shock, confusion, anger and despair. These feelings can affect your ability to function and make decisions. This is normal in these circumstances.

When Will He Wake Up?
We don’t know for sure - you will just have to take each day at a time. This is one of the most frustrating answers you will receive but it is absolutely true. Brain injured persons rarely wake up all at once. The process of waking up can be gradual and can take anywhere from hours to many months. Recovery is usually most rapid in the first few months after injury and slows down as time passes. We will explain this process more fully in the section entitled, Stages of Recovery.

Can a Person Recover from a Brain Injury?
Yes, although some people recover with virtually no problems, subtle changes are often present. Some never regain full awareness of their surroundings or the ability to function independently. In the worst instances, recovery may not continue beyond eye opening. There is a wide range of outcomes.

REATIONS YOU MAY EXPECT FROM YOURSELF AND OTHERS
Brain injuries are unplanned traumatic events that leave family and friends in a state of shock and bewilderment. There has not been time to adjust to the shock of seeing someone close to you in an Intensive Care Unit, perhaps in a coma and surrounded by a frightening array of machines and tubes.

Understandably, everyone’s attention is focused on the person who has suffered a brain injury. Just as important are the reactions and feelings of the family. It is essential that you focus some attention and energy on your own health and well being so that you will be able to cope with the days ahead.

Stress is a major problem for families where a relative has suffered a brain injury. Stress in this situation is NORMAL, but not everyone has the same feelings at the same time. For instance, one person may think, “If only he lives, nothing else matters”, while another thinks, “If he must live with no chance of being the same person he was, perhaps it’s better if he dies”. These thoughts are neither unexpected nor wrong under such stressful circumstances. These and many others have been experienced by the families and friends of countless other brain injured patients.

In the next few pages we will describe some of the most common feelings and some ways in which you might deal with them. You may find that not all these feelings or behaviors will apply to you.

SHOCK AND WORRY
At first you are scared and worried, “Will he live?”; “What will he be like if he does?”; “Will I be able to take care of him?”. Some people will show their emotions outwardly and others will appear calm. Worry is natural when someone you care about is injured. You may find it hard to concentrate on what doctors, nurses and other team members tell you and perhaps you need to ask for the same information again later on.

One of the most helpful things you can do is to make a list of things about which you are worried. This should include concerns from home and work as well as questions about the patient. Then divide your list into three sections:

1. Things you might be able to change;
2. Things about which more information may help reduce your worry; and,
3. Things which you cannot control or change.

Try to put aside anything listed under #3.

Make a list of questions you have and discuss them with a staff member with whom you feel comfortable. Even when staff are busy, they will always try to take time to talk with you. Our Social Worker is always available to see you and help you sort through problems as well. You may also wish to see a hospital chaplain at this time. It is very important to ease or reduce your
LEVEL VIII - Purposeful/Appropriate

At this level most of the recovery in basic thinking skills will have been completed. Small improvements in memory and concentration will continue to occur but they will be less dramatic and occur more slowly. Although the brain injured person may now be physically independent at home, she may still have limitations.

Even though she can generally remember daily activities and learn new skills, new or complicated situations may produce frustration, intolerance and bring out problems in reasoning and judgement. She may be able to return to work, although perhaps at a lower level than before her head injury.

The types of feelings a patient may have at this stage will depend a great deal upon her personality. One patient may become more easily depressed, while another may impulsively forge ahead and take on tasks which are beyond her abilities. Another may be frightened and become more dependent than she needs to be.

Throughout all the levels of progress try to maintain a hopeful yet realistic attitude towards the patient’s future. Learning to cope with a brain injury and with the possible ongoing cognitive limitations is a continuous process. Ask for help from team members and from friends you meet in Brain Injury Support Groups. There is a Nova Scotia Brain Injury Association. Ask the team for additional information and contact phone number.

When Will I Know What the Outcome Will Be?

For several weeks no one can tell you, with certainty, what the outcome will be for your relative.

As time passes those caring for the patient will begin to get an idea of possible outcomes. These estimates are important for everyone, but try to remember that they are still educated guesses. Actual recovery may take longer and the pattern of recovery may be different than expected. It is important to realize that the outcome may not be known for many months.
THE STAGES OF RECOVERY

The stages of recovery from brain injury have been described carefully by a team of health professionals at Rancho Los Amigos Hospital in Los Angeles (The Rancho Los Amigos Scale of Cognitive Function). There are eight stages used in describing the recovery of brain injured patients. They are listed and described as a guide, to help you understand what is happening to your relative. We have included suggestions on how family, friends and staff may best help the brain injured patient.

LEVEL I – No Response
LEVEL II – Generalized Response
LEVEL III – Localized Response
LEVEL IV – Confused/Agitated
LEVEL V – Confused/Inappropriate/Not Agitated
LEVEL VI – Confused/Appropriate
LEVEL VII – Automatic/Appropriate
LEVEL VIII – Purposeful/Appropriate

LEVELS VI, VII, VIII

The Queen Elizabeth II Health Sciences Centre has the main adult Neurosurgical Unit in Nova Scotia where Stages I-V are cared for. Patients at stages VI - VIII are stabilized medically and are usually at home, the Nova Scotia Rehabilitation Centre or some other facility. For this reason, we have included only brief descriptions of these three stages.

LEVEL VI - Confused/Appropriate

The patient usually does not show frustration at tasks that can be done easily. She may be able to concentrate up to 30 minutes with some redirection when distracted. She has a general recall of the usual events of the day although she may have difficulty with details. She will still answer some questions incorrectly because of poor memory but her answers are more reasonable. She may recognize some of her limitations but is unrealistic about their effect on her future.

LEVEL VII - Automatic/Appropriate

The patient is now able to consistently remember events from day to day, although he may still have difficulty with details and in concentration. He will become confused if asked to do unfamiliar or complicated tasks.

Now he should be able to do personal care, if physically able. You may see a continued “flatness” in his feelings and actions. You will notice that he does not initiate activities and conversation as he did before the accident. He may appear cautious, unsure of himself and require prompting.

He may begin to worry about how his limitations may affect his future. His expectations may still appear unrealistic.

Vocational counselling may be appropriate at this stage.
LEVEL V - Confused: Inappropriate/Not Agitated

During this stage of recovery, the patient is easier to be with. Emotionally, he is not as unpredictable and explosive. However, he still frustrates easily and becomes angry or withdrawn when a task seems too difficult. He is often more cooperative with family than staff during this period. He can pay attention for only 2-3 minutes and will be distracted by almost any movement or activity near him. Memory is still a problem and he may need to be reminded of day, month, year or place. However, he will generally recall people and some events in the past. He may be unable to recall new information but may do common tasks that were learned before the accident. He may not always be aware of his injuries and physical deficits and his conversation may be sometimes confused and inaccurate. Facial expressions and voice patterns may seem flat, almost ‘robot-like’. At this stage the patient may be transferred to home hospital or the N.S. Rehabilitation Centre.

Approaches by the Treatment Team

It is important to try to reduce the patient’s confusion and to provide him with information about his life that he may not remember. The team will work on increasing attention to certain activities. Everyone will encourage him to take on more self care activities, such as washing, dressing and feeding. Depending upon each patient’s needs, specific programs for improving strength, coordination, and perception will be organized. A consultation to the N.S. Rehabilitation Centre may be arranged.

Suggestions for the Family

1. Keep in close contact with the treatment team and ask for instruction in ways you might help.
2. Provide clues to help the patient when answering questions about his past or present. Example: “After you left home didn’t you get an apartment?”, rather than, “Where do you live?”.
3. He is able to concentrate for longer periods (2-3 minutes), so try to give fewer clues.
4. Use short, simple directions but do not ‘talk down’ or in a childish manner.
5. Correct inaccurate statements gently.
6. Give him brief rest periods. If he becomes upset change the topic.
7. Do not ‘quiz’ him.
8. Structure his room, schedule and daily routine to remain as constant as possible. This will provide a sense of familiarity and predictability and lessen confusion.

LEVEL I - No Response

The patient is in a coma or appears to be in a deep sleep. He makes no response to attempts to awaken him.

Approaches Taken by the Treatment Team:

At this stage we are concerned with monitoring and stabilizing the patient and preventing complications. We will watch closely to make sure the patient does not develop problems with breathing, blood pressure, stiffening of muscles and joints, pressure on certain areas of the skin and other problems depending on the types of injuries.

A seriously brain injured patient may be admitted to the Intensive Care Unit. He will remain there until his condition stabilizes. It may be necessary to place him on a ventilator, a machine used to assist breathing. He may also be on a special bed, called a Roto-Rest bed. This moves him from side to side and helps to prevent chest and skin complications.

The brain injured person may have other injuries. The most common are chest and abdominal injuries and bone fractures. Doctors from other specialties may need to be consulted. The neurosurgical team includes other staff neurosurgeons and residents. The patient will be fed intravenously, have a catheter in his bladder and may be connected to a monitor to measure pressure inside the brain, heart rhythm and other functions. Vital signs, including size of pupils, blood pressure, pulse, temperature and level of awareness, will be checked frequently. Depending on the patient’s condition, he may need repeated scans of the brain and may even require surgery.

A tracheostomy may be necessary. This is a surgical opening into the windpipe to assist with breathing. The tube may remain in for some time but when removed the opening will heal over, leaving only a small scar.

You will be kept fully informed throughout these early stages. Express any concerns to the nursing staff, who can answer most of your questions or can call one of the doctors to speak with you.

Suggestions for the Family During this Period

In ICU you will see your relative amid a wide variety of unfamiliar, and perhaps bewildering, tubes and machines. Ask questions if you wish. The staff may not wish to overwhelm you with information and may wait until you ask. You may forget many things at the beginning, so do not hesitate to ask again on another day.

1. If you wish, talk to him in a normal conversational voice about familiar things. Be soothing and encouraging.
2. Touch him. His nurse can tell you whether there is anything that should not be moved such as an IV needle. Touch and hold his hands as much as you wish.
3. Visit for a few minutes, not longer than 10-15 minutes, then let him rest. Remember that a great deal is happening in the Intensive Care Unit and rest time is at a premium.

This will be a difficult time for you and other family members since what you do appears to have no effect. In very severe cases this stage can go on for many days/weeks with very little change.

Don’t feel you have to spend long hours in our waiting room. You can leave your phone number with the nurse and he/she will contact you if there is any noticeable change in condition. Also, take breaks - go for coffee or go for a walk. You may wish to talk with our Social Worker if you have difficulty finding accommodations and/or have any other problems. We also have a chaplain in the hospital on-call if you wish to speak with him/her.

8. Continue to provide pictures of family, familiar people and places to reorient the patient to her past. Label the pictures so that staff may help with reorientation. Please remember that space is limited in the patient’s room. A small photo album may be better than loose pictures lying about.

9. Visitors should be kept at a minimum to avoid overstimulation of the patient. This also helps to keep a calm, soothing atmosphere.
LEVEL II - Generalized Response

The patient is beginning to respond in very general ways to attempts to awaken her. For example, she may move an arm or leg in response to pain. The responses at this stage are likely to be slow and inconsistent. She may still be in ICU but when stable may be transferred to the Neurosurgery Ward.

Approaches by the Treatment Team

We continue to be concerned with preventing complications. The physiotherapist will visit daily to do chest physio and move her arms and legs through their normal range of movement. This will help to prevent chest complications and stiffening of muscles.

The Occupational Therapist may need to fit splints or casts to help prevent muscle and joint tightening.

Hearing is usually the first sense to return, so the patient may hear but be unable to respond. We will tell her what we are doing and why.

Suggestions for the Family

1. Continue to talk to her. Remember to be very careful about what is said in front of an apparently unconscious patient.
2. Continue to touch and ask for responses such as “turn your face toward my hand”, or “squeeze my hand”, and “wiggle your finger”.
3. After discussion with the nursing staff you may play a favourite music tape or a message from family or close friends, for a short time.
4. Remember to provide stimulation for short periods with rest in between. DO NOT OVER STIMULATE.
5. Bring in pictures of the patient and her closest family and friends so they may be shown to her. Remember to write names on the back so that everyone may refer to them.

LEVEL IV - Confused/Agitated

This stage is upsetting for families. A patient’s behavior is often excitable; she can be verbally and/or physically abusive. She is reacting to her own confusion, fear and disorientation and is not angry with you. Her attention span is very short and she will probably not remember new information. She may be aware of the hospital staff but unable to remember their names or what they do. Sometimes patients say unexpected and inaccurate things and may use or name common objects inaccurately. This indicates communication problems. She may not be accurate or reliable in telling what is going on around her or what is happening to her at this stage. If she is able to move about, she may get up and wander.

Patients may be transferred to their home hospital at this stage, if we feel the facilities are adequate for their continued care.

Approaches by the Treatment Team

The main concern during this stage is to help decrease the patient’s agitation, help her ability to pay attention, and to ensure her safety. If she is able to walk, but is very unsteady, it may be necessary to restrain her in her chair or bed to prevent her from getting up on her own. Sedation may be needed to help control agitation. The Physiotherapist and Occupational Therapist will continue to work with her. It may be appropriate to have a Neuropsychologist or Psychiatrist visit as well. Recreation Therapists are also involved to help reduce agitation and confusion.

Suggestions for the Family

1. Provide a calm, soothing, relaxed atmosphere when you visit. This can be difficult. If you find yourself getting upset or angry, leave the room for a short time until you regain your composure.
2. Use short, simple directions. Repeat them frequently.
3. Use simple words. Slow down the speed at which you speak. This does not mean to ‘talk down’ to the patient, but rather to avoid confusing her with too many words.
4. Don’t expect her to remember recent events or instructions. Tell her things that you want her to know, realizing that you may have to repeat them again and again.
5. Do not question her repeatedly as this is likely to make her more irritable.
6. Provide orientation information frequently (hospital name, date, city, reason for being in hospital). Correct her gently. Don’t argue or criticize her for being forgetful. It is o.k. to tell the patient about the event that brought her to the hospital. Remember to reassure her that she is getting better. If you are unsure about giving some information, discuss it with the team.
7. If restraints are being used, please leave them on unless nursing staff give permission to remove them. The restraints are there because the staff are concerned about the patient’s
LEVEL III - Localized Response

The patient’s level of awareness is increasing. Rather than reacting in a general way, he may now react in more specific ways. For example, he may turn his head toward a sound or focus his eyes on an object. He may follow simple commands such as “close your eyes”, but in an inconsistent and slow manner. The patient may respond one time but not the next. He may respond better to family or friends and may even begin to say a few words. He may also begin to show anxiety and fear because of decreased memory and confusion. Depending on his general condition he may still be in ICU, however, most patients are on the Neurosurgical Ward by this stage.

Approaches by the Treatment Team

We will continue to provide the best supportive care possible while encouraging the patient to move and respond as much as he is able. The patient’s nurse and the Charge Nurse are in daily touch with all the professionals who are seeing your relative. They will be able to give you the best progress reports. Call them if you wish to ask a question (473-2088).

Suggestions for the Family During this Period

1. Be alert to changes in the patient’s reaction to you. People respond best to familiar voices so you may be the first to notice changes. Please let other members of the team know about the changes you see.
2. Talk to him in a normal conversational tone.
3. Use only simple, one-step directions such as “wiggle your fingers” or “lift your arm”.
4. Give lots of time for response before repeating instructions.
5. Do not continually question him. You may increase his irritability as he probably cannot recall recent events.
6. Provide frequent orientation to the day of the week, the place, and the reason for being in hospital. He will not remember an earlier explanation. A large calendar, placed within the patient’s view, may help. Bring in a few familiar objects and place them so the patient can see or hold them. Bring only things that can be washed or cleaned as they may be soiled over the course of days or weeks. It is possible that they could be lost, so please do not leave valuable or irreplaceable belongings.
7. Allow for enough rest. While it is natural to want to spend most of your time talking and attempting to do things with him, it is better to allow frequent rest periods.
8. Let the nurse know if you wish to take part in daily care, such as bathing, shaving or perhaps helping to feed him. Your help is welcomed by both the patient and staff. Talk with any of the other team members such as the Physiotherapist, O.T., Speech-Language Pathologist, Social Worker and Dietitian, to see whether they have specific suggestions for ways in which you may help. You are an important part of the team, however, you have much on your mind at this time.
9. Give frequent reassurance to your relative that he is safe, secure and being well taken care of.
LEVEL III - Localized Response

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LEVEL II - Generalized Response

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2. Continue to touch and ask for responses such as “turn your face toward my hand”, or “squeeze my hand”, and “wiggle your finger”.
3. After discussion with the nursing staff you may play a favourite music tape or a message from family or close friends, for a short time.
4. Remember to provide stimulation for short periods with rest in between. DO NOT OVER STIMULATE.
5. Bring in pictures of the patient and her closest family and friends so they may be shown to her. Remember to write names on the back so that everyone may refer to them.

LEVEL IV - Confused/Agitated

This stage is upsetting for families. A patient’s behavior is often excitable; she can be verbally and/or physically abusive. She is reacting to her own confusion, fear and disorientation and is not angry with you. Her attention span is very short and she will probably not remember new information. She may be aware of the hospital staff but unable to remember their names or what they do. Sometimes patients say unexpected and inaccurate things and may use or name common objects inaccurately. This indicates communication problems. She may not be accurate or reliable in telling what is going on around her or what is happening to her at this stage. If she is able to move about, she may get up and wander.

Patients may be transferred to their home hospital at this stage, if we feel the facilities are adequate for their continued care.

Approaches by the Treatment Team

The main concern during this stage is to help decrease the patient’s agitation, help her ability to pay attention, and to ensure her safety. If she is able to walk, but is very unsteady, it may be necessary to restrain her in her chair or bed to prevent her from getting up on her own. Sedation may be needed to help control agitation. The Physiotherapist and Occupational Therapist will continue to work with her. It may be appropriate to have a Neuropsychologist or Psychiatrist visit as well. Recreation Therapists are also involved to help reduce agitation and confusion.

Suggestions for the Family

1. Provide a calm, soothing, relaxed atmosphere when you visit. This can be difficult. If you find yourself getting upset or angry, leave the room for a short time until you regain your composure.
2. Use short, simple directions. Repeat them frequently.
3. Use simple words. Slow down the speed at which you speak. This does not mean to ‘talk down’ to the patient, but rather to avoid confusing her with too many words.
4. Don’t expect her to remember recent events or instructions. Tell her things that you want her to know, realizing that you may have to repeat them again and again.
5. Do not question her repeatedly as this is likely to make her more irritable.
6. Provide orientation information frequently (hospital name, date, city, reason for being in hospital). Correct her gently. Don’t argue or criticize her for being forgetful. It is o.k. to tell the patient about the event that brought her to the hospital. Remember to reassure her that she is getting better. If you are unsure about giving some information, discuss it with the team.
7. If restraints are being used, please leave them on unless nursing staff give permission to remove them. The restraints are there because the staff are concerned about the patient’s
3. Visit for a few minutes, not longer than 10-15 minutes, then let him rest. Remember that a great deal is happening in the Intensive Care Unit and rest time is at a premium.

This will be a difficult time for you and other family members since what you do appears to have no effect. In very severe cases this stage can go on for many days/weeks with very little change.

Don’t feel you have to spend long hours in our waiting room. You can leave your phone number with the nurse and he/she will contact you if there is any noticeable change in condition. Also, take breaks - go for coffee or go for a walk. You may wish to talk with our Social Worker if you have difficulty finding accommodations and/or have any other problems. We also have a chaplain in the hospital on-call if you wish to speak with him/her.

8. Continue to provide pictures of family, familiar people and places to reorient the patient to her past. Label the pictures so that staff may help with reorientation. Please remember that space is limited in the patient’s room. A small photo album may be better than loose pictures lying about.

9. Visitors should be kept at a minimum to avoid overstimulation of the patient. This also helps to keep a calm, soothing atmosphere.
LEVEL V - Confused: Inappropriate/Not Agitated

During this stage of recovery, the patient is easier to be with. Emotionally, he is not as unpredictable and explosive. However, he still frustrates easily and becomes angry or withdrawn when a task seems too difficult. He is often more cooperative with family than staff during this period. He can pay attention for only 2-3 minutes and will be distracted by almost any movement or activity near him. Memory is still a problem and he may need to be reminded of day, month, year or place. However, he will generally recall people and some events in the past. He may be unable to recall new information but may do common tasks that were learned before the accident. He may not always be aware of his injuries and physical deficits and his conversation may be sometimes confused and inaccurate. Facial expressions and voice patterns may seem flat, almost ‘robot-like’. At this stage the patient may be transferred to home hospital or the N.S. Rehabilitation Centre.

Approaches by the Treatment Team

It is important to try to reduce the patient’s confusion and to provide him with information about his life that he may not remember. The team will work on increasing attention to certain activities. Everyone will encourage him to take on more self care activities, such as washing, dressing and feeding. Depending upon each patient’s needs, specific programs for improving strength, coordination, and perception will be organized. A consultation to the N.S. Rehabilitation Centre may be arranged.

Suggestions for the Family

1. Keep in close contact with the treatment team and ask for instruction in ways you might help.
2. Provide clues to help the patient when answering questions about his past or present. Example: “After you left home didn’t you get an apartment?”, rather than, “Where do you live?”. 
3. He is able to concentrate for longer periods (2-3 minutes), so try to give fewer clues.
4. Use short, simple directions but do not ‘talk down’ or in a childish manner.
5. Correct inaccurate statements gently.
6. Give him brief rest periods. If he becomes upset change the topic.
7. Do not ‘quiz’ him.
8. Structure his room, schedule and daily routine to remain as constant as possible. This will provide a sense of familiarity and predictability and lessen confusion.

LEVEL I - No Response

The patient is in a coma or appears to be in a deep sleep. He makes no response to attempts to waken him.

Approaches Taken by the Treatment Team:

At this stage we are concerned with monitoring and stabilizing the patient and preventing complications. We will watch closely to make sure the patient does not develop problems with breathing, blood pressure, stiffening of muscles and joints, pressure on certain areas of the skin and other problems depending on the types of injuries.

A seriously brain injured patient may be admitted to the Intensive Care Unit. He will remain there until his condition stabilizes. It may be necessary to place him on a ventilator, a machine used to assist breathing. He may also be on a special bed, called a Roto-Rest bed. This moves him from side to side and helps to prevent chest and skin complications.

The brain injured person may have other injuries. The most common are chest and abdominal injuries and bone fractures. Doctors from other specialties may need to be consulted. The neurosurgical team includes other staff neurosurgeons and residents. The patient will be fed intravenously, have a catheter in his bladder and may be connected to a monitor to measure pressure inside the brain, heart rhythm and other functions. Vital signs, including size of pupils, blood pressure, pulse, temperature and level of awareness, will be checked frequently. Depending on the patient’s condition, he may need repeated scans of the brain and may even require surgery.

A tracheostomy may be necessary. This is a surgical opening into the windpipe to assist with breathing. The tube may remain in for some time but when removed the opening will heal over, leaving only a small scar.

You will be kept fully informed throughout these early stages. Express any concerns to the nursing staff, who can answer most of your questions or can call one of the doctors to speak with you.

Suggestions for the Family During this Period

In ICU you will see your relative amid a wide variety of unfamiliar, and perhaps bewildering, tubes and machines. Ask questions if you wish. The staff may not wish to overwhelm you with information and may wait until you ask. You may forget many things at the beginning, so do not hesitate to ask again on another day.

1. If you wish, talk to him in a normal conversational voice about familiar things. Be soothing and encouraging.
2. Touch him. His nurse can tell you whether there is anything that should not be moved such as an IV needle. Touch and hold his hands as much as you wish.
THE STAGES OF RECOVERY

The stages of recovery from brain injury have been described carefully by a team of health professionals at Rancho Los Amigos Hospital in Los Angeles (The Rancho Los Amigos Scale of Cognitive Function). There are eight stages used in describing the recovery of brain injured patients. They are listed and described as a guide, to help you understand what is happening to your relative. We have included suggestions on how family, friends and staff may best help the brain injured patient.

LEVEL I – No Response
LEVEL II – Generalized Response
LEVEL III – Localized Response
LEVEL IV – Confused/Agitated
LEVEL V – Confused/Inappropriate/Not Agitated
LEVEL VI – Confused/Appropriate
LEVEL VII – Automatic/Appropriate
LEVEL VIII – Purposeful/Appropriate

LEVELS VI, VII, VIII

The Queen Elizabeth II Health Sciences Centre has the main adult Neurosurgical Unit in Nova Scotia where Stages I-V are cared for. Patients at stages VI - VIII are stabilized medically and are usually at home, the Nova Scotia Rehabilitation Centre or some other facility. For this reason, we have included only brief descriptions of these three stages.

LEVEL VI - Confused/Appropriate

The patient usually does not show frustration at tasks that can be done easily. She may be able to concentrate up to 30 minutes with some redirection when distracted. She has a general recall of the usual events of the day although she may have difficulty with details. She will still answer some questions incorrectly because of poor memory but her answers are more reasonable. She may recognize some of her limitations but is unrealistic about their effect on her future.

LEVEL VII - Automatic/Appropriate

The patient is now able to consistently remember events from day to day, although he may still have difficulty with details and in concentration. He will become confused if asked to do unfamiliar or complicated tasks.

Now he should be able to do personal care, if physically able. You may see a continued “flatness” in his feelings and actions. You will notice that he does not initiate activities and conversation as he did before the accident. He may appear cautious, unsure of himself and require prompting.

He may begin to worry about how his limitations may affect his future. His expectations may still appear unrealistic.

Vocational counselling may be appropriate at this stage.
LEVEL VIII - Purposeful/Appropriate

At this level most of the recovery in basic thinking skills will have been completed. Small improvements in memory and concentration will continue to occur but they will be less dramatic and occur more slowly. Although the brain injured person may now be physically independent at home, she may still have limitations.

Even though she can generally remember daily activities and learn new skills, new or complicated situations may produce frustration, intolerance and bring out problems in reasoning and judgement. She may be able to return to work, although perhaps at a lower level than before her head injury.

The types of feelings a patient may have at this stage will depend a great deal upon her personality. One patient may become more easily depressed, while another may impulsively forge ahead and take on tasks which are beyond her abilities. Another may be frightened and become more dependent than she needs to be.

Throughout all the levels of progress try to maintain a hopeful yet realistic attitude towards the patient’s future. Learning to cope with a brain injury and with the possible ongoing cognitive limitations is a continuous process. Ask for help from team members and from friends you meet in Brain Injury Support Groups. There is a Nova Scotia Brain Injury Association. Ask the team for additional information and contact phone number.

When Will I Know What the Outcome Will Be?

For several weeks no one can tell you, with certainty, what the outcome will be for your relative.

As time passes those caring for the patient will begin to get an idea of possible outcomes. These estimates are important for everyone, but try to remember that they are still educated guesses. Actual recovery may take longer and the pattern of recovery may be different than expected. It is important to realize that the outcome may not be known for many months.
What is a Brain Injury?

A serious brain injury is an event that may result in loss of consciousness for varying lengths of time. The injury may occur as a result of a blow to the head, which may be suffered in a car accident or fall, with direct damage to the brain.

Brain damage may also occur due to a lack of oxygen and/or blood supply to the brain. This may happen in shock due to blood loss, chest injuries, stroke and even after a heart attack.

When injuries result in brief unconsciousness (minutes), recovery may be complete or nearly complete. As the length of time in coma extends to days and weeks, the person is increasingly more likely to be left with problems in physical, intellectual, communicating, behavioral and emotional skills.

Even minor brain injuries may produce changes in reasoning, perception and interpersonal relationships. These changes interfere with return to home, community, school and work.

Family members react to the injury in different ways. You may go through periods of disbelief, shock, confusion, anger and despair. These feelings can affect your ability to function and make decisions. This is normal in these circumstances.

When Will He Wake Up?

We don’t know for sure - you will just have to take each day at a time. This is one of the most frustrating answers you will receive but it is absolutely true. Brain injured persons rarely wake up all at once. The process of waking up can be gradual and can take anywhere from hours to many months. Recovery is usually most rapid in the first few months after injury and slows down as time passes. We will explain this process more fully in the section entitled, Stages of Recovery.

Can a Person Recover from a Brain Injury?

Yes, although some people recover with virtually no problems, subtle changes are often present. Some never regain full awareness of their surroundings or the ability to function independently. In the worst instances, recovery may not continue beyond eye opening. There is a wide range of outcomes.

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COMMON QUESTIONS

REACTIONS YOU MAY EXPECT FROM YOURSELF AND OTHERS

Brain injuries are unplanned traumatic events that leave family and friends in a state of shock and bewilderment. There has not been time to adjust to the shock of seeing someone close to you in an Intensive Care Unit, perhaps in a coma and surrounded by a frightening array of machines and tubes.

Understandably, everyone’s attention is focused on the person who has suffered a brain injury. Just as important are the reactions and feelings of the family. It is essential that you focus some attention and energy on your own health and well being so that you will be able to cope with the days ahead.

Stress is a major problem for families where a relative has suffered a brain injury. Stress in this situation is NORMAL, but not everyone has the same feelings at the same time. For instance, one person may think, “If only he lives, nothing else matters”, while another thinks, “If he must live with no chance of being the same person he was, perhaps it’s better if he dies”. These thoughts are neither unexpected nor wrong under such stressful circumstances. These and many others have been experienced by the families and friends of countless other brain injured patients.

In the next few pages we will describe some of the most common feelings and some ways in which you might deal with them. You may find that not all these feelings or behaviors will apply to you.

SHOCK AND WORRY

At first you are scared and worried, “Will he live?”; “What will he be like if he does?”; “Will I be able to take care of him?”. Some people will show their emotions outwardly and others will appear calm. Worry is natural when someone you care about is injured. You may find it hard to concentrate on what doctors, nurses and other team members tell you and perhaps you need to ask for the same information again later on.

One of the most helpful things you can do is to make a list of things about which you are worried. This should include concerns from home and work as well as questions about the patient. Then divide your list into three sections:

1. Things you might be able to change;
2. Things about which more information may help reduce your worry; and,
3. Things which you cannot control or change.

Try to put aside anything listed under #3.

Make a list of questions you have and discuss them with a staff member with whom you feel comfortable. Even when staff are busy, they will always try to take time to talk with you. Our Social Worker is always available to see you and help you sort through problems as well. You may also wish to see a hospital chaplain at this time. It is very important to ease or reduce your
stress as much as possible.

Many people would like to help but don’t know how. You may wish to make a list of ways friends and neighbours can help reduce some of the stress arising from the worries you have listed. Suggest several things to each person who offers.

This exercise will, of course, not change your worries, but it should help you to deal with them.

FATIGUE
Many things contribute to your increasing tiredness:

• Your desire to be with the patient as much as possible;
• An inability to sleep;
• Not stopping to eat properly;
• Feeling alone and trying to handle everything on your own.

You are just as important as the patient and indeed, within the family, you may now have a more responsible role. YOU MUST TAKE CARE OF YOURSELF. Once the crisis is over and the patient is stabilized, do not feel the need to be constantly at the bedside. If it is important to you to have someone with the patient daily, ask another family member or close friend to take a turn visiting and report to you.

Realize how important your rest is and make sure you get enough. Recovery from a brain injury is a very long, slow process and you will need to reserve energy for later months.

Eat properly. Failing to get the proper nutrition will add to your fatigue as well as increase your risk of illness.

Many people find that their free time and contacts with friends are markedly decreased. Time for yourself is not a luxury to be put on hold until the patient is better. It is essential to your mental and emotional well being to be involved with other people. A change of scene such as visiting with friends or attending a concert or a movie may help. Do not feel guilty about these activities because they are important for both you and the patient.

Recreation Therapy
Promote physical, social, emotional and cognitive well-being through therapeutic interventions, leisure education, leisure counselling and recreation participation.

Family Meetings
Shortly after the patient has moved to the Neurosurgical Ward, the social worker will make arrangements for family to meet with the members of the team who are involved with the patient. The team will describe their roles in the patient’s care and will report their observations on the patient’s progress. Family members should feel free to make their own observations and to ask questions about any aspect of care. The team will appreciate learning more about the patient such as interests, occupation, hobbies and food preferences.
Speech-Language Pathologist

Some brain injured patients will have difficulty with communication which may involve understanding the spoken word as well as speaking. A speech-language pathologist may be asked to assess and provide advice on the best way to assist with communication.

Social Worker

The Social Worker makes an assessment of both the patient and family’s concerns, strengths and weaknesses and what kind of home supports are available. He/she may also help problem solve with the patient and family, provide reassurance, discuss financial concerns and help co-ordinate discharge plans. The Social Worker also co-ordinates family meetings (see section on Family Meetings page 8).

Dietitian/Nutritionist

After a brain injury, patients may have difficulty swallowing. The dietitian works with other team members to make sure the patient is getting the right type and amount of food. If a person is unable to eat enough to meet his needs, a tube feeding may be started. The feeding tube carries a special formula through the nose and into the stomach.

Neuropsychologist

A neuropsychological assessment may be helpful after a traumatic brain injury. This assesses how the injury affects skills like concentration, memory, language and problem-solving. A psychologist conducts the assessment. A trained assistant may help. They may ask the patient to answer questions, remember things, and write things down. Assessment results help the team decide if the person can be safely left alone. They may also help decide the best time to return to work, school or driving. In the feedback session, the psychologist explains the results of the test to the patient and family. Ways to get around some problems in daily life will be discussed.

Pastoral Care

The Pastoral Care Department provides spiritual and emotional support to all patients, families and staff who wish their services. Both chaplains and community clergy are part of the Pastoral Care Department.

Request for Pastoral Care may be made through the nursing staff or the Pastoral Care office (473-4055). The chapel is open to all.

ANGER AND FRUSTRATION

Many people feel angry that such a terrible accident could happen to their family. Anger is a strong emotion and must be acknowledged. If you are feeling angry over something which you cannot change, you are more likely to react strongly to the smallest details. You may then feel frustrated that more is not being done for your loved one. Acknowledge your anger. Try not to act on it until you have had time to think clearly and see things in perspective. Write down the things that seem to make you angry and frustrated. After you have thought about these things, discuss them with someone to whom you can relate. This may help you avoid misdirecting your anger toward the people around you and perhaps even toward the patient himself.

DENIAL/OVER-OPTIMISM

Almost everyone who hears of a friend or relative’s injury doesn’t want to believe what she is hearing. Denial helps to relieve our emotional suffering. There is nothing wrong with hope. However, there comes a time when denial can prevent one from facing some important facts and, subsequently, from helping the patient as much as can be possible.

Hope is important as long as it helps you cope. It becomes unhealthy when it causes you to set unrealistic goals for the patient and does not allow you to appreciate whatever gains she may be making. Talk to the doctors and therapists involved in her care and try to take one day at a time. Accept the patient as she is today. This does not mean you are giving up on the future!

CONSIDERATION OF OTHER FAMILY MEMBERS

Don’t forget about the other family members, especially children. They may need extra support and comfort. You can do this by continuing interest in their daily activities and trying to make time to attend special events.
THE NURSING STAFF

Medical/Surgical/Neurosurgical Intensive Care:
Intensive Care nurses are specially trained to look after critically ill patients. A nurse is assigned to one patient for each shift. If you have concerns, questions about various machines/tubes connected to the patient, ask the nurse. The nurse can also give you information about any change in the patient’s condition and will contact the doctor if you wish to speak to him. The nurse will also ask for a family spokesperson in the case of large families. When the patient’s condition is stable he will be moved to the neurosurgery ward. (7.3).

The Nurse Manager
The Nurse Manager is responsible for the provision of nursing care to neurosurgical patients.

The Charge Nurse
The Charge Nurse works closely with nursing staff and other professionals. She is available to help coordinate all aspects of patient care including daily medical care, discharge planning, concerns and questions.

Nursing Staff
The nurses will observe any changes in condition, help to prevent complications and provide appropriate stimulation. Let them know of any changes you observe and continue to ask questions. If you wish to help with bedside care let the nurses know.

Physiotherapist
At first, the physiotherapist will mainly be concerned with keeping the patient’s chest clear and his limbs as mobile as possible. Later on the physio will concentrate on helping the patient become as independent as possible by working on strength, balance and movement. The physiotherapist welcomes the family’s participation in the treatment program.

Occupational Therapist
Occupational Therapists (O.T.) work with the patient to make him more independent in all areas of daily living - hygiene, dressing, eating, homemaking, leisure and work. To aid in the patient’s recovery the O.T. may need to assess and help retrain cognitive (thinking) skills. The O.T. may suggest necessary equipment or home adaptations to make the return home as safe and accessible as possible.
Each patient is under the care of a Neurosurgeon, assisted by residents. A “resident” is a fully qualified doctor who is taking extra training in a specialized area of medicine.
INTRODUCTION

This booklet addresses the emotional and behavioral problems faced by both patients and families in the early stages after a severe brain injury. We will introduce to you the members of the team of health professionals who work with these patients. We also want to acknowledge the critical role that family members play in the recovery process. We welcome your input and would like you to feel comfortable in asking for answers as well as advice.

Statistics show that brain injuries occur most frequently to young males. However, we have alternated the use of the pronouns “he” and “she” throughout sections of the book to accommodate all patients.
VI REACTIONS YOU MAY EXPECT FROM YOURSELF AND OTHERS

- Shock and Worry
- Fatigue
- Anger and Frustration
- Denial/Over-Optimism
- Guilt

VII QUESTIONS YOU MAY HAVE

VIII ACKNOWLEDGEMENTS

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