

AN INTRODUCTION TO HEAD INJURY

(Formerly Head Injury and the Family)

2007

Karin M. Buchanan, R.S.W.

Social Worker & Clinical Instructor
Division of Neurosurgery, Royal University Hospital
Saskatoon, Saskatchewan

with

Robert E. Capp, M.D., F.R.C.P. (C)

Consultant in Physical Medicine and Rehabilitation (retired)
Wascana Rehabilitation Centre
Regina, Saskatchewan

Seventh Printing, August 2007

Printed and Distributed by:

The Saskatchewan Brain Injury Association

230 Ave. R South,
(St. Paul's Hospital Residence, C-Wing, Rooms 421-423)
Saskatoon, SK S7M 0Z9

Phone: (306) 373-1555
Toll Free in Saskatchewan: 1-888-373-1555
<http://www.sbia.ca>

Acknowledgements

1. We acknowledge Rancho Los Amigos Medical Centre in Downey, California for its pioneering work in defining the levels of recovery and for permission to refer to this work. We recommend and refer families to Rancho's excellent and varied publications (Rancho Los Amigos Medical Centre, PO Box 3500, Los Amigos Station, Downey, California, USA 90242).

2. We especially acknowledge Thom's Rehabilitation Hospital in Asherville, North Carolina, for the generous permission to quote directly many of the descriptions and suggestions from its very helpful publication, "Getting Our Heads Together." (Thom's Rehabilitation Hospital, One Rotary Drive, Asherville, NC, USA 28803).

Permission for any reproduction of this booklet must be obtained from all three original sources: Thom's Rehabilitation Hospital, Rancho Loas Amigos Medical Centre, and the Saskatchewan Brain Injury Association (formerly the Saskatchewan Head Injury Association).

3. We appreciate the ongoing interest and support, as well as the financial assistance for this booklet, from both the SECRETARY OF STATE and the ROYAL UNIVERSITY HOSPITAL, Saskatoon.

Preface

Society is suffering a “head injury epidemic.” In Saskatchewan, with our population of about a million people, there are approximately 3,000 head injuries in a year, of which, about 50% are the result of traffic accidents. Most other head injuries result from falls, work accidents, and assaults.

Some head injuries are catastrophic, causing death either instantly, or within a few hours or days. Head injuries account of approximately 20% of all traumatic deaths and about 50% of deaths due to traffic accidents. A significant number of head injuries leave victims with various long-term disabilities. The magnitude of this problem is accentuated by the fact that the majority of patients are young males between the ages of 15 and 25, who may live for many years afterward with serious disabilities.

The majority of head injuries are very mild, requiring little medical attention and a short period of time to recover. However, the recovery process for a major head injury is long and difficult and filled with uncertainty. This uncertainty is frustrating for patients and relatives to cope with and to understand. It also poses difficult problems for those providing care.

This booklet is a supplement to information provided by the medical team. Not everything applies to every patient and it is essential for families to maintain a close liaison with health care staff. Hopefully, the booklet will help you to have a better understanding of what you see and hear after someone in your family has had a head injury.

R.E. Capp

Contents

Introduction..... 1

Levels of Recovery.....2

Levels I-III..... 4

*(No-Response, Generalized Response,
& Localized Response)*

Description of Levels I-III

Suggestions for Levels I-III

Level IV..... 8

(Confused-Agitated)

Descriptions of Level IV

Suggestions for Level IV

Levels V & VI..... 11

*(Confused - Inappropriate - Non-Agitated
& Confused - Appropriate)*

Descriptions of Levels V & VI

Suggestions for Levels V & VI

Level VII 15
(Automatic-Appropriate)
Description of Level VII
Suggestions for Level VII

Level VIII17
(Purposeful-Appropriate)
Description of Level VIII
Suggestions for Level VIII

General Medical Comments20

General Suggestions and Summary . . .27

Introduction

Head injury hurts. As a mom or dad, husband or wife, brother or sister of someone who has just suffered a severe head injury, YOU hurt. You're likely to hurt because you feel scared and worried. You ask, and are afraid to ask: "Will s/he survive? Will s/he be normal? How long will it take?" You're likely to hurt because you feel so helpless. You wonder: "What can I do? How can I help?"

It's normal to be confused when trying to sort out what doctors and nurses and relative and friends have told you. As well, it's a very stressful but very normal process to question whether there was anything you could have done to prevent the actual accident. On top of all this, some people feel tired but can't sleep. For some people food tastes like sawdust and some may have head or stomach aches.

In the critical first few days after the accident, most family members put the outside world "on hold." However, after the head injured person has stabilized, some semblance of normal family routine needs to be re-established... back to work, back to school, back to sleeping in a bed at night. Understandably, everything will not be the same, but some stability is essential.

Sound familiar? This booklet was written to help answer your questions, to explain what to expect, and to make suggestions about what you can DO. We also hope you'll realize the necessity of TAKING CARE OF YOURSELF. This is likely to be what the head injured person would want you to do. As well, you are an extremely important member of the team that is dedicated to the rehabilitation of your loved one.

This booklet focuses on the stages of cognitive recovery¹ from head injury² and YOUR role in helping that process. It is an introduction only. It is meant to supplement the more detailed information and suggestions you get from doctors, nurses, therapists and others about the unique needs of your "patient." Many of the suggestions we're making were originally developed by the Thom's Rehabilitation Hospital in North Carolina and the Rancho Los Amigos Medical Centre in California.

¹ "Cognitive recovery" is the relearning of the processes involved in thinking, understanding, and reasoning.

² We may see the same pattern in patients who have suffered a brain haemorrhage, or lack of oxygen to the brain, or sometimes following a stroke . . . any condition which can sometimes result in coma.

Levels of Recovery

Unfortunately, real life head injured patients don't resemble television head-injured patients or Sleeping Beauty. In real life, patients in the Intensive Care Unit don't instantly sit up in bed after being unconscious and ask, "Where am I? What happened in the last eight days?" (or two or twenty). The long, slow process of rehabilitation experienced by most patients and their families just doesn't make good television. Think of being completely healthy as the colour white; then death would be the colour black. Head injury, depending upon the severity, is some shade of grey. Very severely head-injured patients, who are deeply unconscious are like the colour charcoal . . . and they can't go from charcoal to white instantly. The doctor may describe the head-injured person as getting "lighter." The doctor doesn't mean losing weight, but getting closer to mental alertness. You may be frustrated by trying to determine when someone is conscious or unconscious, when the best way to describe him is "semi-conscious"... another shade of grey, but getting "lighter."

The levels of recovery that we're going to discuss describe what a head-injured person goes through as he "wakes up." The type and severity of the initial head injury, the length of time until medical help was available, the presence of other injuries and complications, the age and the general health of the person, and your involvement as a concerned family all play a role in determining how long this process takes. It *always* requires patience. In general, the more serious the head injury, the longer the person is unconscious (in coma), and the more likely it is that there will be some long-term disability. Therefore, the longer the person is unconscious, the longer the rehabilitation process. The coma is a result of, and caused by, the head injury, not a separate problem.

Rancho Amigos Medical Centre has defined eight levels of recovery:

Level I: No Response

Level II: Generalized Response

Level III: Localized Response

Level IV: Confused - Agitated

Level V: Confused - Inappropriate - Non-Agitated

Level VI: Confused - Appropriate

Level VII: Automatic - Appropriate

Level VIII: Purposeful - Appropriate

It is important to realize that these levels are descriptive of the overall *pattern* of recovery following most head injuries. We usually describe a patient's condition or behaviour, we do not label or number a level. Head-injured people usually don't move from one level to another (remember the shades of grey); they frequently show characteristics of more than one level at the same time. Remember, as you read further, that these are *general* guidelines and many of the suggestions made by Thom's Hospital are useful at several levels.

These are descriptions of what you *see* at each level and some of the things you can *do*. It is important to remember that many patients, even at their worst, are never Levels I, II, or III.

Levels I, II, & III ***(No Response, Generalized Response, & Localized Response)***

(Note that the latter responses may only be possible at Level III)

Descriptions

Level I: No Response

The person looks as if he is in a very deep sleep and does not respond to stimulation. He is usually on a ventilator (respirator) in the Intensive Care Unit. *He is not suffering physically or emotionally at this stage. YOU are the one experiencing the most pain.*

Level II: Generalized Response

At this level, the person appears to be asleep most of the time, but does respond, inconsistently and non-purposefully, to some stimulation. His responses are limited in nature, are often the same regardless of the stimulus, and are likely to be delayed. He may groan or make a face when he is sponged, when blood is taken, or even when he hears your voice. . All very different stimuli. Responses may be physiological changes (a change in blood pressure), gross body movements (squirming), or vocalization (moaning). Pain will likely cause the first response. He may pull away from stimuli, like injections or being suctioned (the staff may purposefully stimulate him to see if he moves his right and left sides equally. It is *not* that he's paralysed or "locked in" and just unable to communicate. He does *not* have well-developed thoughts and feelings yet.

Level III: Localized Response

The person appears more alert for several minutes at a time and responds more consistently to stimuli. He may follow simple commands, such as closing his eyes or sticking out his tongue, although not every time, and usually very slowly. Eye *opening* may not be to command, for it is a normal response for a person to open his eyes to any noise. As well, hand squeezing is a basic reflex seen even in the newborn. These are good signs of responsiveness, but aren't the best way to assess the ability to understand a command. At this level, a person usually begins to respond more to nursing care by turning away when being suctioned or pulling at his catheter or nasogastric tube (feeding tube).

Suggestions for the Family for Levels I, II & III

1. Speak to him in a calm, slow, normal voice. Say things that are important to you.
2. “Introduce” him to the nurses and other staff: his job, his hobbies, the things that make him unique.
3. Make sure you meet the main doctors and feel free to ask questions. Sometimes the answer will be “We don’t know,” or “It’s too soon to say.” Nobody is hiding bad news from you or trying to mislead you - the answers to all questions just aren’t known early in treatment. (When someone is in the Intensive Care Unit, the responsibility for his care is usually shared by a neurosurgeon and an Intensive Care specialist. They are helped by “residents” - doctors who have completed an internship and are now doing specialty training.)
4. Most families find that communication is least confusing when the one or two closest family members take the responsibility for obtaining information. This helps establish clearer, more consistent lines of communication and usually increases understanding all around.
5. Speak in reassuring tones. We know the ability to *hear* comes back long before the ability to *understand* the content of what is being said. Think of how a baby smiles and giggles when held and spoken to lovingly by a parent, even though he may not understand the words being used, for the parent may be counting or reciting a poem. Therefore, in these early stages, although a relaxed tone may not come too easily, it is far more meaningful to the person than the actual message.
6. Even though the person, at this stage, cannot understand everything that is being said, do not discuss his condition as if he were not there. This is a bad habit to develop and can lead to talking about him later on, when he *is* aware of being treated like a non-entity.
7. Stimulate him when he begins to have periods of being awake. If you are helping with the bath, for instance, you can say, “I’m washing your right hand now.” Stimulation time should be brief (5 - 10 minutes), and should be as meaningful as possible. Do *not* overtire him.
8. Continue to calmly show affection in any way you can.
9. Check with the occupational therapist or the nurse about an organised way to try to stimulate the senses. For instance, for the taste and the smell, a “Q-tip” can be favoured with lemon or mint or salt and touched to his tongue. Or, hold some garlic powder, shaving lotion, a clove or raspberry jam under his nose. Tell him what it is and ask him to stick out his tongue if he can smell it.
10. Intermittently play music (tapes or radio) which he would enjoy. Don’t leave it on all of the time or it will become “white noise” (meaningless background sounds). Turn off or dim the lights for periods of time, in order to increase the possibility of response when the lights are bright.

11. Ask him to follow one-step commands such as, "Raise your arm," "Close your eyes," "Stick out your tongue," "Show me your teeth," "Wiggle your toes." Allow plenty of time for the response.
12. Each time you see him, say who you are. Tell him the day and the date and that he is in the Hospital. Tell him how he was hurt and that he is getting better.
13. Limit the overall number of visitors and explain to the visitors about speaking calmly and about the appropriate forms of stimulation.
14. Talk to him about familiar people and things - names of family members and close friends, school and jobs, vacations, hobbies, etc.
15. It is especially helpful to illustrate conversations about familiar people and things with pictures. Bring in the family album and show him pictures of who and what you are talking about. In addition, have a family member or close friend take some "ordinary" pictures... whether they are photos of a favourite chair, the kitchen, the curling rink, his baseball glove, the crop, the school gym, his stamp collection, his office, or the vegetable garden. These photos form a picture of ordinary, everyday life, not just special occasions.
16. As he gradually becomes more alert, help him to start doing routine self care activities, such as washing his face with a washcloth.
17. Sometimes a person may be alert enough during Level III that you can ask him questions about his past that have "yes" or "no" answers. Reaction time will be slow. Don't yell at him as if he were deaf. His hearing is probably as good as it ever was. The problem is in his brain, not his ears. Speaking too loud will not help get the message through.
18. Many families find it useful to establish a journal, in which a daily record of the person's progress can be documented. (Later, this journal can be the head-injured person's personal record). This can also serve as a means of communication between family members and members of the health care team.
19. In general, Level I is characterized by *no* response to the environment and Level II and III by greatly decreased responses to the environment. This is a time of low activity, or *underactivity*. The goal is to first illicit responses to sensory input, then slowly increase the frequency, rate, duration, variety, and quality of responses.

GO SLOWLY, MAKING EXCESSIVE DEMANDS AND PROVIDING TOO MUCH STIMULATION WILL *NOT* MAKE THE BRAIN HEAL ANY FASTER.

20. Particularly in the very early stage, you may be afraid to even leave the hospital because you're worried and want to help. Indeed, you worry

about whether or not he will even survive. In the later stages, there's more you can do to help, so it is important to learn early to pace yourself. Get enough sleep. Schedule some relaxation and physical exercise. Eat at least one nutritious meal a day. Work out rotating schedules with other family members. Learn to ask for and accept help from friends and relatives - whether it's to mow your lawn, help with the children, or take your car to the garage. Such favours reduce your other worries and allow friends and family to feel helpful.

21. Not everybody has the same feelings at the same time. Mom may be saying "He's got to live. He's just got to live... no matter how disabled." Grandma and Grandpa may criticize with, "Don't ever talk like that, he'll be back to playing football before you know it." Meanwhile, Dad may be thinking, "If he can't have a good recovery I almost hope he dies." Obviously everybody is worried and overwhelmed by their fears. However, despite the common concern for the head-injured patient, some family members are distressed to learn about the feelings of others. Don't be embarrassed to discuss these conflicts with the social worker or another member of staff.

Level IV ***(Confused-Agitated)***

Description

This new stage is very different from Levels I-III. The pendulum has swung: the person has gone from *underactivity* to *overactivity*. His needs have changed from stimulation to structure because he *overreacts*. The person will usually be very active and may behave strangely. He may cry, yell or scream, flail his arms, or thrash about in his bed as an overreaction to stimuli, even after they are removed. He may show aggressive behaviour, like hitting out at others or he may attempt to remove his tubes or to crawl out of bed. He shows “all or nothing” behaviour... he’s either asleep or he’s awake and *too* active. This can be frightening for some family members.

He can only pay attention for very short periods of time. When he does pay attention, even for a minute or two, he may look and act so much like himself that it’s a common mistake to *overestimate* his abilities. Although he’s improving, he is still severely cognitively disabled. As he has become more alert, he has become more aware of the stimulation from his environment, but his brain is still not functioning well enough to make order or sense out of all that stimulation... extreme confusion is the result.

The only memory he has is for events that happened *before* the head injury. If he is able to speak, he may use the wrong words, mix up the order of words, or tell disconnected or inappropriate stories. He cannot be held accountable for his behaviour; he is not yet capable of producing thought-out action. He is usually unable to co-operate directly with treatment efforts. The brain is like a computer. It processes, stores and retrieves information. Everything that happened before the accident was well processed and stored... now it only needs to be retrieved. On the other hand, recent events or *new* information is being processed, stored and retrieved by this “computer” that is still “short-circuited.”

Suggestions for the Family for Level IV

1. Always remember, this is a *stage*, a sign of improvement, *not* a personality change. It is one of the “shades of grey” that are part of the process of recovery.
2. When he is not agitated, use this time to improve his ability to respond correctly. Work in a quiet environment.
3. Encourage him to try simple self-care tasks, such as brushing his teeth and washing his face. Place the objects he needs within reach. Don’t

expect co-operation at this stage, be pleased if you get it.

4. Do not startle him, especially when you wake him up from sleep.
5. If you visit him during a meal, give him only one choice of food at a time and let him do as much for himself as possible.
6. Limit the number of visitors to one or two at a time. Don't talk to the head-injured person, play the radio, feed him, stroke his arm and visit with other visitors all at the same time. He needs *structure and order*... too many things happening at once just add to his confusion.
7. Communication is important for a person's recovery. If the person is not speaking, use another *consistent* way of communicating, such as head movement or finger tapping to indicate "yes" or "no." The speech therapist and/or occupational therapist may be able to help you with this.
8. Continue to calmly reorient him to both his past and present. As he becomes more alert, make sure there aren't mixed-up family patterns which may increase his confusion. For instance, if a 35 year old man is being treated like a baby by both his mother and his 12 year old daughter, he will have even more difficulty sorting out that he is an adult, as well as a son, and a husband and a father.
9. Correct inappropriate or inaccurate responses matter-of-factly. If he thinks he is at the farm, don't ever agree and make a comment about the cows. Gently, but clearly tell him how he was injured and that he's in the Hospital. Repeat this once if necessary. If he continues to insist that he's at the farm, don't argue. Change the topic. Comment on the weather or tell him what he's having for lunch.
10. Never scold or threaten or ridicule him by saying things like, "Grow up and act your age," or "You know better...," or "Behave or I won't come back to visit." It also doesn't help to laugh *at* him, instead of *with* him.
11. When he becomes agitated, do NOT walk out on him or ignore him until he calms down (unless, for some reason, YOU seem to be triggering his agitation that particular day). Human contact and reassurance by family usually have a soothing effect. Touch him, wash his face or body with warm water, or play soft music.

Check with his nurse. If he is capable of swallowing, you can try giving him water, juice, a warm drink or finger foods to help him calm down.

12. It's very normal for family members to sometimes get impatient and frustrated. After all, this childish behaviour you see doesn't "fit" with an adult who probably by now looks very much like he did before the accident. If he swears at you or you witness a tantrum, don't take it personally. Remember, it is the "head injury" swearing at you, not your son or husband. Be patient, for he doesn't usually know what he's doing or saying.
13. The great fluctuations from deep sleep to thrashing in bed, which characterize this stage can cause additional problems with families. The patient's wife may report to her in-laws that her husband is very restless and aggressive. The in-laws visit an hour later and he is calm. Then they might ask themselves, "Is our son *mad* at his wife?" Please remember that behaviour fluctuates greatly according to fatigue, amount of stimulation, time of day, etc. It is important not to "blame" these circumstances on each other.
14. By this stage, many family members feel as if they are on an emotional "roller-coaster." They've gone from the initial "low" of worrying about survival to the "high" of seeing the person stabilize and become more alert. However, when "alertness" reflects confusion and agitation, illustrating the severity of the head injury, many people feel another "low." It is common to feel overwhelmed as you begin to realize that some disability has resulted from his head injury and that rehabilitation is a long, slow process. These feelings are normal and you may feel better if you discuss them with a member of the team.
15. Don't forget about the other people in the family. Try not to assume that children and adolescents "understand" that a brother/sister/mother/father has been hurt, so it "doesn't matter" that no one asks about the math test or goes to watch the peewee hockey game. Because of the need for security, comfort, and support, it probably matters more.
16. Medications to settle the head injured person are used as little as possible because sedatives slow the thinking process and can make the confusion worse.
17. Remember tears and yelling do not represent great physical pain or emotions like anger, hatred, or grief, but a generalized response to stimuli. Please do not label him as stubborn or unco-operative. HE IS UNABLE TO CO-OPERATE!!

Levels V & VI (Confused-Inappropriate & Confused Appropriate)

Descriptions

Level V: Confused-Inappropriate

The person appears alert and is able to respond to simple commands fairly consistently, but has difficulty following more complex commands. He is able to concentrate longer, but will need frequent redirection because he is so easily distracted. Memory for events in the past is now evident, but memory for everything that has happened since the accident is poor. He may not remember what you told him to do five minutes ago. He may be able to do automatic, over-learned tasks, such as eating and dressing, but he is still unable to learn new information. He may seem to have lost all good manners. He may be sexually inappropriate, or may gobble his food and then belch proudly.

Level VI: Confused-Appropriate

The person follows simple directions consistently and is able to remember how to do routine activities, like feeding, dressing, and bathing. Memory for recent events is still poor, which makes learning new information very difficult. The person's mind wanders less often, and he is more aware of time and place. His attention can sometimes be held for as long as 30 minutes, and, during that time, he will talk and behave more appropriately, although he may act somewhat "robot-like" or "mechanical."

Suggestions for the Family for Levels V & VI

1. Go over information about family and friends. Use photo albums you've put together as a way to stimulate memories.
2. The capacity to experience normal grief returns much later than the ability to understand and remember factual details. This does not represent psychological "denial." Instead, this illustrates poor short-term memory. Any bad news is another piece of "new learning." By this stage, it is appropriate to tell the head-injured person the painful but important information that someone else was killed or badly injured in the accident. There is far, far more pain in the *telling* of this news than there is in the *hearing* of it. It will *not* "make him go back into the coma."

Even though you don't *feel* calm, try to tell him calmly, "Unfortunately, Joe was killed in the accident... he didn't suffer or have any pain... Joe died almost instantly..." The person may get momentarily upset, but this is likely to pass very quickly. If someone stays upset, it is usually because he sees the distress of the person telling him, and he responds to or possibly even mimics this.

3. You may notice that he may be more confused in spontaneous conversation than he is on direct questioning. For instance, if you sit with him quietly and wait for him to initiate conversation, he may say something bizarre, e.g. he has seven brothers, all named Joseph, who ride motorcycles. However, when you *ask* him one minute later, he may be able to name the starting line-up for the National League in last year's all-star game. This illustrates how much he needs your help *focussing* on topics as part of reducing his confusion.
4. Work with him to help bring out the information which is stored in his brain, but is not easy for him to recall without help. Ask him a question, and if he can't give the correct answer, give him some clues. For example, if you ask him immediately after breakfast what he ate and he cannot remember, be more specific. Ask him what he drank. If this doesn't help, tell him it was white and see if he can remember that it was milk.
5. It sometimes happens that a person completely misinterprets kissing, embracing, or stroking as sexual messages instead of affection and encouragement. If he is exhibiting sexually inappropriate behaviour (to the "wrong" person or at the "wrong" time or in the "wrong" way at the "wrong" place), try to *desexualize* contact. Encourage him with lots of verbal praise and limit physical contact to a peck on the cheek, a warm handshake, or a pat on the shoulder. If the person does respond inappropriately, tell him so, in a calm, matter-of-fact way... such as, "I don't want you to touch me like that."
6. Ball games, memory games, simple card games, etc. are all good relearning experiences. Always remember, though, that concentration and attention are still impaired. He may play well for a while, become distracted and then no longer remember how. Try again later, possibly in a quieter environment. Remember that his performance will often be inconsistent during recovery. Don't criticize or nag him. Try to be patient... though some

days this may be very difficult.

7. If he has trouble with his bowel and/or bladder control, do not reprimand him. Instead, try to be helpful by offering *reminders/suggestions* such as, "I'll be ready to go for a walk as soon as you've gone to the bathroom." This gentle prodding is more likely to work than asking, "Do you need to go to the bathroom?" He may not be able to interpret the "warning" signals from an almost full bladder. As well, when you take him home on pass, you may find it useful to limit his fluid intake in the evening. This reduces the chance of bed wetting and increases the chance of him sleeping through the night... then everybody will be more rested.
8. Encourage his success by praising everything that he is able to do. Success is far more effective than too much "challenge." If a task is overwhelming, frustration is the result. This frustration sometimes leads to aggression and almost always increases confusion. For instance, if he is only able to play cribbage for ten minutes, don't push him to play bridge instead. He may become so overwhelmed that he can't even identify the cards and ends up throwing them in the air out of frustration.
9. He may laugh or cry easily and not always appropriately. Usually, the best thing to do is to ignore this response and/or suggest another activity and/or change the topic until he calms down.
10. Assist him with "homework" or assignments that he is given by the speech therapist, occupational therapist, or physiotherapist. Help him to start making entries in his journal on his own.
11. Slowly increase independence by gradually decreasing the amount of help you give him for specific activities.
12. Continue to keep his activity moderate. He is likely to need rest during the day, but may not have the insight to realize this. Therefore, don't ask "Are you tired?" or "Do you feel like a snooze?" Instead, suggest or model, "Why don't you have a rest," or "While you're lying down, I'm going to rest in the waiting room."
13. Ask him how to get from the gym, back to the ward. Have him describe the best route from home to school.
14. Ask him to tell you about the hockey game on television, conversations, or other events immediately after he has seen or heard them.
15. Despite the fact that he is quite well-oriented, he may occasionally still say something strange because he can't sort out fact from fantasy, dreams, or fears. Have you ever wakened from a deep sleep and not known whether the phone rang in the night or if you *dreamt* that the phone rang? Particularly when tired or when first awakened, he may not be able to differentiate between *hoping* his girlfriend would visit and an actual visit. He may not be able to tell the difference between *worrying* about a possible dispute and whether or not one actually happened. Always try to calmly re-establish "fact vs fiction."

16. When you take him on a pass, vary the daily routine as little as possible. Simplicity, consistency, and routine all improve function. If, for instance, he has trouble “remembering” to shower, help him develop the *habit* of showering at approximately the same time every day.
17. Within his tolerance, use every situation as a learning experience. Everyday tasks may still be difficult. Help him count money, make change, and ask about the steps involved in making orange juice or washing clothes or making a bed, and then have him actually do the task he has described.
18. How are the children? If they’re not getting enough attention, they’ll find a way to make sure you notice them.

Level VII

(Automatic-Appropriate)

Description

By this time, the person appears normal on the surface, at the hospital, and then at home. He performs daily routines automatically, with little or no confusion, but has limited recollection of what he has been doing. He has poor judgment, reduced problem-solving ability, and cannot plan realistically for the future. He has very limited insight into these problems.

He is able to learn new information, but at a slower speed and with more difficulty. For the sake of his safety and learning, supervision is required both at home and in the community. He is able to take part in and enjoy more recreation and social activities.

Suggestions for the Family for Level VII

1. Discuss with the person situations within the home that could be dangerous and have him tell you what he would do to avoid them. Go over safety and emergency measures. Have him take point form notes. Even if the person is able to tell you what he would do in a fire, in the real situation, he is likely to panic, unless his response has been “well-rehearsed.” The stress of a situation can slow a head-injured person’s response time and ability to function, both mentally and physically.
2. Encourage him to write in his journal daily.
3. Have him practice using the telephone directory and reading a map. Take him to the grocery store and have him locate items and estimate costs. Have him make up a “chores list” for the day so that he can make his bed, help with house-cleaning, fix light meals, carry out trash, do some weeding in the garden, etc.
4. Work on a computer may be helpful as a part of redeveloping step-by-step logic. This is particularly true if he was familiar with computers *before* his accident (then he won’t have to learn to use the computer as well). Discuss the appropriate programs to be working on with the speech therapist and/or occupational therapist.
5. It is very important to make sure that your words, actions, and gestures are all clear and congruent. For instance, don’t nod and say “yes, yes”

out of impatience when you're listening to him. Rushing him is not only stressful, but he can easily interpret *this* way of doing is in complete agreement with everything he's said. For the same reasons, teasing, cajoling, and sarcasm are frequently misunderstood by the head-injured person.

6. Do *not* let him drive a car, ride a motorcycle, take a boat out alone, or operate saws or farm equipment.

7. Many people occasionally find themselves "at odds" with both immediate and extended family, as well as friends, on the amount of supervision required. Teenagers may complain that their parents are "babysitting" an injured sibling. Friends may complain that a wife should allow her husband to drive or return to work so that it will "cheer him up" and "make him better." Especially if the head-injured person has a good physical recovery, it can be easy for others to ignore the *cognitive* disability. This usually leaves the family members feeling unappreciated by the patient, and unsupported, even criticized, by others. Contacting other families from the Saskatchewan Brain Injury Association may help to reduce the loneliness and isolation that can result from such interactions.

8. He may still be slow in responding to questions, or hesitant in initiating conversation and/or activities. Be patient and be creative. He may appear "unmotivated," "lazy," or "lethargic" because he can't think of anything to do but watch television. *Never* label him in any of these ways.

If he is not overwhelmed by choices, make two suggestions and encourage him to choose between them. Would he like to... go for a walk or visit a friend, play a video game or go shopping, watch his kid brother play baseball or paint the fence? For necessary things, like homework, offer him a choice of when, not whether he'll do it... "do you want to do your speech therapy exercises before or after dinner?"

9. Rather than being slow to respond, he may be too fast, blurting out what's on his mind, without regard to social appropriateness. For instance, when the two of you are waiting in line at the grocery store, you may both notice the woman ahead of you. You may *think*, but he may *say*, "Gee, she's fat!!" You need to calmly and matter-of-factly offer feedback about such behaviour as soon as it's appropriate.

Level VIII

(Purposeful-Appropriate)

Description

Memory for past information is good, while memory for recent events and “new learning” may still seem foggy and fuzzy. He is able to learn new information, although not as much as before the accident and not as quickly. If he was a university student before the accident, he is likely to have difficulty returning to full-time studies.

Following severe head injury, a person frequently continues to show a decreased ability to reason, tolerate stress, or use good judgment in emergencies or unusual situations. Frequently, social, emotional, and intellectual capacities continue to be less than before the injury, but are good enough for the person to function in most social situations. If he is unable to return to his former employment, vocational assessment and then retraining may be necessary.

Suggestions For The Family for Level VIII

1. Encourage maximum involvement in the home, school, or job within the person’s physical and intellectual limits. Help him pace himself.
2. Involve him in complex tasks, such as total meal planning and preparation, organization of several home tasks into a daily routine, planning leisure time, initiating activities independently, and developing individual aids to plan his time such as schedules, reminder lists, etc. Have him assume responsibility for specific chores.
3. If he requires regular medication, it should be his responsibility to take the correct dosage at the proper time.
4. Have him practice balancing his chequing account, handling an allowance appropriately, and budgeting.
5. He needs to practice using public transportation by himself. Initially, you will have to accompany him, to direct him, and then to supervise him as he tries on his own.

Before driving a motor vehicle again, first he is required to complete a Supplementary Insurance form, explaining that he has suffered a brain

injury (these forms are available from any Motor Licensing Office of Saskatchewan Government Insurance). Next, he is likely to require some retraining before retesting.

6. Establish and maintain a relatively stable daily routine. This helps the person feel more secure in his environment. Frequent changes, even little ones, may be upsetting. For instance, he may not be able to adjust to the unpredictability of the hot meal of the day being served at noon one day, 5:00 p.m. another day, and 8:00 p.m. the next.

7. The need for structure, order, and direction, combined with a need for acceptance can leave him very susceptible to the influence of cults and certain religious groups, which have rules, regulations, and prescribed patterns of behaviour.

As well, some people are very gullible and susceptible to peer pressure. They will readily do even foolish things because it is “required.” Therefore, families sometimes need to watch out for others who may take advantage of the brain-injured person.

8. Familiar sayings that we use to express a more complicated idea, such as, “There’s no use crying over spilled milk,” can be very confusing. He may take your words very literally. For instance, you may ask “What’s on T.V.?” and he may answer, “A vase with some flowers.” He’s not being sarcastic or difficult, he’s answering the question... literally.

The inability, or reduced ability, to think abstractly (at more than one level) means that he may mostly enjoy concrete or slapstick humour. If a situation is *not* funny, simply disregard the laughter by not laughing yourself.

9. Don’t assume that a brain-injured person will be able to learn from his mistakes as well as he did before the accident. For instance, he might go to the bar, drink beer all evening and have his wallet stolen. The next morning, hungover, and without a wallet, he might be very remorseful. He realizes that his doctor was right when he told him he should *not* drink beer at all. However, several days later, he might consider going out to drink *rum*, not beer, because he sees no connection to his previous escapade. This is called a problem of generalization and when combined with poor judgment (for drinking in the first place), it reduces the chance of learning from one’s mistakes. Calm feedback and interpretation from others can help “tie” situations together.

10. Try to measure improvement from the time of the accident and avoid comparing him to “how he used to be before.” As well, learn to appreciate the new person, who is likely to be different in many ways after the injury. There may be personality and behavioural changes, as well as differences in his patterns of likes and dislikes, and ongoing problems with memory and judgement. However, he is still a person who needs your support, affection, and companionship.

11. You need to demonstrate patience, tact, and intelligence, while “walking the fine line” between encouraging and rewarding independence, yet still providing the necessary background support and interpretation required to deal with the world. It’s a delicate balance and difficult to

achieve. Congratulate yourself whenever you're successful.

12. Most people are referred for neuropsychological assessment. The person doesn't pass or fail these tests. The tests provide information about the brain-injured person's strengths and weaknesses, in areas such as memory, attention, "mental speed," and learning ability. These tests are useful in helping to determine when and if someone is ready to return to work or school, full or part-time. Returning prematurely can be a major source of frustration.

Additional resources and services available after hospitalization include: Life Skills programs, Adult Day Care, Home Care, training-on-the-job placements, as well as ongoing support, and social and learning opportunities from the Saskatchewan Brain Injury Association.

General Medical Comments

Disabilities

Although coma (impaired consciousness) is the most obvious immediate result of a severe head injury, many brain functions are frequently altered to some extent, temporarily, or longer term. These will be mentioned only briefly here. If any of these problems occur in an individual head injured patient, it is essential for the family to get *specific* information from the health care team treating that person.

1. Movement Disorders

Changes in mobility are probably the next most common result of a head injury or brain trauma and may take many forms. The most deeply comatose patients may not move at all, even in response to pain. As the level of consciousness begins to improve, non-specific, generalized REFLEX MOVEMENTS appear. The movements will be much the same, whether due to pleasurable or painful stimulation. These are *not* under *voluntary* control. The family may worry that these movements are an indication of the patient being in severe pain, but they are not.

Further improvement in the patient's level of consciousness results in more selective and localized reflex movements in response to stimulation, as well as the beginning of some spontaneous movements. However, reflexes still predominate. For instance, stroking the palm of the patient's hand will result in the reflex closure of the hand... this should not be confused with a voluntary squeeze. As the patient begins to move more, it is sometimes noticed that spontaneous movements occur solely, or more often, on one side of the body, which indicates the presence of HEMIPLEGIA (lack of muscle control on one side of the body, either the RIGHT or the LEFT).

As the level of consciousness continues to improve, spontaneous movements increase and eventually the patient will start to produce more specific movements, more frequently, on command (if hemiplegic, he will have normal voluntary movements only one side).

Movement disabilities tend to improve, often dramatically, but sometimes do not return completely to normal.

2. Sensory Impairment

Any and all of the “senses” may be impaired following head trauma. This may be due to localized damage to the sensory organ (i.e. penetrating injury to the eye) or to damage to the area of the brain involved in interpreting the sensory message. However, it is difficult to fully assess sensory function until the patient is sufficiently alert to co-operate with examination.

3. Communication Disabilities

As the patient awakens and becomes more aware of his environment, it will become apparent that there are difficulties with communication. The most common and least significant problem in the early stages of rehabilitation is CONFUSION. This will be present even in patients with mild head injury but frequently clears quickly.

The patient who has been intubated or who has had a tracheostomy will have a weak, hoarse voice when he starts to talk, and this may persist for weeks or months, but in the absence of other problems recovers well.

If the nerves supplying the muscles of the larynx (voice box) are badly damaged, the patient will be APHONIC (unable to make sounds). This may or may not recover. Usually this problem is associated with damage to the nerves supplying the tongue and throat, so that only partial recovery occurs, articulation is poor and speech is slurred (DYSARTHIC). Difficulty in swallowing is usually present in these patients as well.

DYSARTHIA may also result from damage to the area of the brain called the cerebellum, resulting in poor coordination for speech muscles.

The more severe communication difficulties occur when the language centres of the brain (usually the left cerebral hemisphere) are damaged. This results in impairment of language function... APHASIA. The patient may not be able to find words to express himself (*expressive aphasia*) or may also have difficulty understanding what is being said (*receptive aphasia*). Usually, reading and writing are similarly affected.

4. Post-traumatic Epilepsy

There is an increased chance of a patient who has had a brain injury developing epilepsy. Epilepsy may appear early, during the initial or acute phase following the trauma, or may not appear until months or years later. The overall incidence of post-traumatic (after injury) epilepsy is 5%. However, it is much more frequent in more severely injured patients, following penetrating injuries (i.e. gunshot wounds), in those patients with intracerebral haematomas (blood clots), and in those who remain severely disabled. While epilepsy can usually be well controlled with medications, it does interfere with vocational and recreational choices.

5. Drugs and Alcohol

As reintegration into the community occurs, families and patients most often ask about the use of alcohol and non-prescription drugs. We strongly recommend that patients *abstain* from the use of these substances. Mild analgesics, such as ASA or acetaminophen may occasionally be necessary and can be used. All other agents should be avoided. The effects of alcohol and other psychoactive drugs are somewhat unpredictable in a “normal” brain... the effects become much more unpredictable in the damaged brain. In general, the effects of these agents are much more pronounced in the individual who has had a brain injury. The person with impaired emotional and behavioural control will tend to lose even that control with minimal amounts of alcohol or drugs. Additionally, the person’s ability to monitor and control consumption is usually markedly impaired. Finally, the abuse of alcohol and some drugs can produce seizures in anyone, and are more likely to do so in the brain injured person. Because of these considerations, it would seem the best policy is complete abstinence.

6. Stimulation and Coma

Coma is the result of a severe disturbance of brain function from trauma or other factors. The most common result, whatever the cause, is that there is an alteration of biochemical activity within the brain. Recovery from coma depends on recovery of normal biochemical function. There are many things we do to attempt to normalize brain function, some of which we understand well and some of which we do not understand completely. It is agreed by most people that stimulation of the comatose patient (familiar voices, music, touch, taste, etc.) is a good thing, but exactly what this does to the damaged brain is unknown. It appears that stimulation is one of a number of things that may favourably influence disturbed brain function, but there is little or no evidence that stimulation alone could reverse true coma or “undo” brain damage.

7. Long Term Outcome

It is very difficult in the first days and weeks following a head injury to predict accurately the long term outcome. Many factors, such as the type and severity of the trauma, age and background of the patient, and support systems available are all involved in determining the eventual outcome. The injured patient's potential is determined by the extent of the brain damage and the subsequent residual (remaining) abilities of the brain. However, as with a newborn child, the degree to which the potential is achieved depends largely on environmental factors. The patient whose family can provide support, love, and encouragement, as well as stimulation and training is likely to do much better than the patient who is on his own or is institutionalized. Thus, the importance of the home and the family cannot be overrated. The stress is tremendous but the rewards can be well worth it.

Trauma to the brain results in both physical and cognitive (intellectual) disabilities. While physical disabilities are more obvious, the long term outcome is much more closely related to the cognitive disabilities. The person with good intellectual ability can usually do a very good job of compensating for physical disabilities. However, the physically intact person who has severe cognitive impairment and/or an inability to control his emotions and behaviour is left very disabled. Because cognitive and behavioural problems are both the most common and the most disabling, they are the focus of this booklet.

General Suggestions and Summary

1. This booklet is a general *introduction* only. By far your best sources of specific information, suggestions, and help are the staff treating your loved one. Families are usually most familiar with **DOCTORS and NURSES** and their roles in health care. There are some other, very important people involved as part of the rehabilitation team.

PHYSIOTHERAPISTS assess and treat the patient to try to maintain joint flexibility, to help him relearn normal patterns of movement and to improve strength and exercise tolerance.

OCCUPATIONAL THERAPISTS assess and treat the cognitive and perceptual problems. In addition, they work closely with physiotherapists in maintaining functional joints and in muscle strengthening. Dressing, grooming skills, etc. are assessed and practised as necessary.

SPEECH AND LANGUAGE PATHOLOGISTS (speech therapists) also provide cognitive assessment and treatment. As well, therapists deal with the mechanics of both speech and swallowing and the ability to express thoughts in words.

MEDICAL SOCIAL WORKERS work with both the patient and the family to help them deal with the ongoing emotional and practical problems that accompany head injury both during and *after* hospitalization.

2. Please remember that the stages or levels we have outlined are *not* as important as the overall *process or pattern* we're describing. Some of the suggestions are applicable throughout and other suggestions may not be applicable to your family member.

3. Unfortunately, a few people (especially older adults) suffer such a severe head injury that they will never improve enough to be able to respond meaningfully... no matter how much stimulation the family provides or how much therapy is received. There may be only minimal improvement despite maximum effort. It is essential that the family members not feel guilty and blame themselves for brain damage that cannot be "undone."

4. Head injury usually requires temporary, and sometimes long-term role changes in the family. These adjustments can create additional stress. Most people find it helpful to discuss their concerns with staff or another family member.

5. A person who suffers a severe head injury and is immediately unconscious will not remember the accident. Indeed, he may not remember the last few hours or days *before* the accident. This is not psychological denial; this means instead that the injured brain did not "store" these memories. Hypnosis or other attempts to retrieve these memories won't work and aren't necessary for rehabilitation.

6. You will find it a good policy not to discuss any complaints you may have about the therapy program or the hospital in the presence of the head injured person. He may adopt the same complaints, focus on them, exaggerate them, and then use them as an excuse not to cooperate in his rehabilitation program. It is better to discuss your concerns in a staff person's office.

7. People who have suffered a serious head injury are at risk of a future head injury because of potential problems with coordination, judgement, and mental speed. Therefore, swimming, volleyball, jogging, etc. are better for exercise and recreation than motocross racing or trick skiing.

8. Head injury rehabilitation requires patience, love, dedication, and breaks from the responsibility. Go out for dinner, go to a funny movie, maintain at least one hobby. Find a way to spend time alone and to have some time with close friends or family that is *not* focussed on the head-injured person. In the long run, looking after yourself is an essential part of how you can best look after him. Remember, he needs a break from you too!

9. For the head injured person, ALCOHOL, FATIGUE, and EXCESSIVE STRESS can individually have a negative impact on function... when *combined*, the result can be disastrous. Patterns and habits need to be established: No alcohol, adequate rest and avoidance of situations that are likely to be stressful because they're too demanding (i.e. returning to school and a full class load, long before he's ready).

10. In many ways, the cognitive recovery following a head injury mirrors or parallels the cognitive development of childhood. The grasp reflex is seen in babies and in the early stages following a head injury. The ability to *hear* comes before the ability to *understand*. The ability to understand concrete, simple commands like "touch your nose" comes before the ability to discuss feelings, and long before the ability to understand an abstract concept (i.e. democracy).

Early awareness following head injury is like that of a baby... hot, cold, wet, hurt, hungry... all immediate *physical* needs. Then come basic *emotional* needs, and, much later, social/relationship awareness... the needs of *others*. It is common for families to complain that the head injured person is self-centred and/or selfish. Remember that this is a *process* of redevelopment.

Despite the parallels of childhood development and the sometimes childish behaviour, it is essential that you treat him as an *adult*. Do not talk "baby-talk" or "talk down" to him, and do not label him with comments such as, "You're just like a little kid!" This can reinforce childish mannerisms and attitudes and slow down the re-development of his *adult* identity.

11. *Pace* your rehabilitation efforts and remember not to blame yourself when and if progress isn't as fast as you want. No matter how hard you try, you cannot teach a six month old to read... the brain is not developmentally ready. However, a child who is stimulated appropriately at each age and stage will respond to the efforts of the parents and teachers by learning to read, *once the brain is able*. The child who does not experience

organized, progressive, appropriate stimulation is much less likely to read early. So it is with a head injury.

12. Some of you may have heard of Dr. Elisabeth Kubler-Ross's description of the grief process: Denial, anger, bargaining, depression, and acceptance is *not* a useful framework to apply to the head injured. For the head-injured, "denial" of the left-sided weakness or of poor judgment is *not* a psychological or adjustment problem... it is an *organic* problem, a brain injury problem. He may have perceptual and/or body-image problems that hinder his ability to understand his left-sided weakness and its impact on functioning. He's unlikely to have enough insight to realize that he lacks judgement.

Aggressive behaviour is a normal part of the Confused-Agitated Stage (Level IV); it does not represent anger at God or fate for the unfairness of the accident. Longer term, poor frustration tolerance and poor impulse control are common problems experienced by head injured people in stressful situations, particularly when fatigued. This is not "anger" as a "stage" on the way to "acceptance." It is most important to decrease the demands and the overall stimulation and to help him learn "defusing" techniques (i.e. counting 1... 2... 3, *then* speaking).

Depression *is* sometimes seen following a head injury, once the person is well enough to have *insight* into his present limitations and their future implications. This is not usually until the person is functioning very well on a day-to-day basis. Sometimes head injured people at earlier stages of recovery are *mislabeled* as depressed when really they are bored or *under-stimulated*. This is often seen in people who have suffered damage to the *left* side of the brain.

13. This booklet has purposefully emphasized the hard work involved for families committed to the rehabilitation of the head injured member. This effort is a labour of love. No one person can do it all. The rewards vary and are sometimes difficult to predict. Your efforts can make a difference. You are to be congratulated!

K.M. Buchanan, R.S.W.

R.E. Capp, M.D.

To order additional copies of this booklet, please contact:

Saskatchewan Brain Injury Association

230 Avenue R South
St. Paul's Hospital, C Wing, 3rd Floor
Saskatoon, SK S7M 0Z9

Phone: (306) 373-1555
Toll Free in Saskatchewan: 1-888-373-1555

Website
www.sbia.ca