



## LIVING WITH BRAIN INJURY: POST-REHABILITATION RECOVERY

You survived the physician telling you he would not live through the night. You survived waiting for him to wake up from a coma (and maybe being told that if he did, he would be a vegetable). In the rehab center, you watched him struggle to re-learn the simple things we all take for granted: sitting up, walking, eating, bathing, talking. When he was discharged from the rehab center, you re-arranged your schedule to take him to therapy and all those medical appointments. You noticed that his rate of progress was slowing down but you could wait; you'd do whatever it took to make him like he was before.

But no more therapy is scheduled and there doesn't seem to be any progress; maybe he's even lost some of the skills he learned during rehabilitation. There are times when you see a glimmer of the person you used to know: that wry sense of humour, the winning smile, maybe he even remembers an incident from before the accident. Other times he is an unlikeable stranger masquerading in the body of the person you knew: he has angry outbursts, messes up the house, repeats the same stories, asks the same questions, forgets things from one moment to the next, and never gets things done unless you're there every minute.

You ride an emotional roller coaster: guilt, depression, anger, frustration, regret, and hope. It dawns on you that your whole family has been injured, not just one person. You've all had to change your lives. You can't even remember what it used to be like. You wonder if things will ever return to normal, if there's anything you can do to change the way things are now. You're willing to try anything but don't know where to start. You're afraid to "rock the boat," fearing anything you try might make things worse. If only there were a magic wand you could wave, a miracle pill you could take. Where's that fairy godmother when you need her?

When you reach that point, you may be ready to start your own program to make things better. The following information may help guide you in your quest for a more normal life for you and all members of your family, including the injured individual:

## OBJECTIVELY ANALYZE THE STRENGTHS/WEAKNESSES OF THE INJURED PERSON:

Physical and medical limitations are generally quite clear-cut and can be explained by physicians and therapists who have been involved in the rehabilitation process. As most family members soon learn, however, physical and medical limitations are relatively easy to understand and work around. It is cognitive and behavioural deficits which prevent return to a normal life for the injured individual and it is these deficits which cause stress for family members on a daily basis.

Two of the most common reasons for problems after a head injury are (a) overestimating or underestimating the cognitive and behavioural abilities and limitations of the injured individual and (b) failure to understand the practical implications of deficits. Expecting too much from the injured individual frequently causes significant behavioural problems; expecting too little may also cause behavioural problems but, more importantly, limits recovery and the acquisition of new skills. At either extreme, the stress experienced by family members is exacerbated and increases over time.

Neuropsychological evaluation is useful in determining which cognitive functions are intact (or nearly so) and which are impaired. Unfortunately, family members only occasionally have an opportunity to discuss test results. When such discussions do occur, the words used by the neuropsychologist may be quite technical and family members may not understand how things like “impaired initiation”, “left neglect”, or “apraxia” might be observed in daily life. If you are able to discuss results with the neuropsychologist, make sure you ask for specific examples of how you might see the deficits in daily life. If you don’t understand (or you don’t agree), ask for additional examples. Make sure you have a clear picture of how the test results apply to daily life before you leave the office. Ask what specific activities the injured individual should be able to do independently, which can be done with assistance, and which are probably totally beyond current ability levels. Ask how you can structure activities to maximize independence. Get the information you need to develop a reasonable plan to maximize recovery.

In addition to (or instead of) neuropsychological evaluation, use your own behaviour observations to understand what the injured individual is capable of doing. Watch him try tasks throughout the day and take notes on what you see. Ask other family members and friends to do the same. Get a good picture of what he does, when he does it, how he does it, and where he does it. Observe the impact your behaviour has on his abilities. Don’t make assumptions about the meaning of what you are seeing; just make observations.

It is especially critical that you observe and understand the individual’s limitations in the broad area called “executive functions”: attention and concentration, distractibility, initiation, planning and sequencing. These are the skills which must be developed before you begin to address more specific areas such as memory, learning, and perception. You must discover how long he can attend to each specific type of task: you may observe that he is able to process verbal information for only 5 minutes but visual or motor information for 15 minutes. He may do well on certain activities if the room is quiet and he is well rested but totally lose that ability if the slightest noise occurs. You may observe that once he starts a task he can finish it easily but appears unable to get that first step going. Or you may observe that he consistently stops at the same step or leaves the same step out each time he tries a certain task.

Although it is relatively easy to understand the injured individual’s limitations in physical endurance, limitations in cognitive endurance are more difficult to observe and to understand. It is important that you keep track of time as well as activities as you observe the injured individual: how long the individual can work with words, with visual information, and on motor tasks and see how abilities in these areas deteriorate over time.

One of the hallmarks of head injury is performance variability: the individual can do something with apparent ease one day and appear totally confused and unable to do the same activity another day or at a different time the same day. In analyzing the individual's abilities, therefore, it is important to understand the circumstances under which each ability is seen: (a) environment variables (e.g., who else was present, other activities occurring at the same time); (b) variables within the injured individual (e.g., fatigue level, how long the activity went on, what else the person has done earlier in the day, mood); (c) interpersonal variables (e.g., the mood of family members involved in the activity).

Memory problems are extremely common following head injury and account for a large percentage of the problems experienced by injured individuals and family members. Unfortunately, many people do not understand that attention and concentration must precede memory: if information didn't get in the first place, you can't remember it later on. We also tend to evaluate memory by verbal reports (i.e., what the person says) rather than behavioural observations (what the person does).

Generally the problems are in remembering information since the injury. It is important to observe what kinds of information the individual is able to remember and under what circumstances. Is he more able to remember something he did than something you told him? Does he remember things he heard better than things he saw or read? Does he remember things that happen in the morning better than things that happen at night? Have you observed him doing things even though he says he doesn't remember how to do them? Can he remember things in one location and not another? If you understand the circumstances under which he is most likely to remember things, you have a good handle on how you can retrain his general ability to remember important information.

After you have carefully observed the injured individual's current abilities for several weeks, all family members should meet to share the information collected and make sure you agree on what you have observed. The more you all understand about the individual's current abilities, the more able you will be to help him develop appropriate skills and to continue the family's recovery from head injury. At the end of the observation period, you should have a pretty good idea of which family member can work best with the injured individual on certain tasks.

#### CREATE A PLAN TO DEVELOP THOSE SKILLS WHICH ARE IMPORTANT TO THE INJURED INDIVIDUAL AND TO OTHER FAMILY MEMBERS:

As more individuals survive head injuries it has become clear that recovery continues as long as the environment is structured to maximize remaining abilities and the person is provided with opportunities to re-acquire skills. These two broad areas provide the framework for your recovery program. Far too often the lives of head injured individuals are incredibly disorganized: they go to bed and awaken at different times each day, nap throughout the day, eat meals at random times, and have no regularly scheduled activities. Such a pattern is grossly atypical of most adults and almost precludes productivity at even minimal levels.

Therefore, the most important first step in any program is to develop a daily schedule which is reasonable for both the injured individual and other family members. With a schedule, the injured individual is required to make fewer decisions throughout the day and family members can plan their own lives. Just being on a schedule makes the injured individual's life and that of all family members more normal!

One of the most common deficits following head injury is significantly decreased performance speed: the individual is capable of completing a wide range of tasks but requires excessive time to do so. Rather than spend the extra time, family members choose to do the task for the individual; this may temporarily make life easier for the family members but almost guarantees that the injured individual will not develop that particular skill.

Therefore, if morning hygiene requires 2 hours, schedule that much time initially. But at the same time, watch the individual do the routines and try to figure out how you can decrease the amount of time required and the amount of supervision or assistance you need to provide. If, for example, he forgets to brush his teeth, store his toothbrush and toothpaste on the sink rather than in the medicine cabinet so that seeing it can jog his memory. Train him to use a list in the bathroom, checking off each step as he completes it.

If his attention span is limited to 5 minutes, it is useless to schedule work on developing new skills for 10 minutes: the last 5 minutes may undo what you accomplished in the first 5 minutes. If distractibility is a significant problem, you need to make sure the environment is “neutral” when you are presenting new information (e.g., make sure he doesn’t need to go to the bathroom and the TV is off; sit still while you are talking).

It is especially important that you take both cognitive and physical endurance into account when planning the daily schedule. All of us perform best when we are well-rested; most of us can engage in certain activities for limited periods of time (e.g., no matter how much you wanted to finish that last chapter, you fell asleep without doing so). Schedule the most difficult activities for those times of day when the individual is well-rested and switch activities before the particular system you are working with becomes fatigued (e.g., alternate reading with working on crafts or playing games).

Once you have decided upon a reasonable schedule, you can introduce specific activities designed to improve the injured individual’s cognitive abilities. Almost any task can be used for cognitive retraining from dressing in the morning to playing checkers or taking college level classes. Before deciding on a specific activity, however, you need to make sure the activity is appropriate and that YOU will be able to follow through.

Try to select activities which minimize your involvement (transportation, travel and waiting time, supervision) while building the injured individual’s ability to work independently. Use community resources (public library, parks and recreation department programs, public school programs, etc.) whenever possible: they are generally inexpensive and provide opportunities for social contact. If you plan to buy equipment to use at home, make sure it is safe, sturdy, an appropriate size, and can be repaired. Check out educational supply and craft stores for things such as rubber puzzles, reading programs, craft projects, games, and simple recreational activities. Avoid supplies that, while at appropriate cognitive levels, were clearly designed for young children: adults are insulted by cute little frogs commending them for doing a good job.

Typically, learning occurs at an extremely slow rate after head injury: it may take thousands of trials to acquire new information and to be able to retrieve it reliably. Few family members have either the patience or the time to present the same material thousands of times. This is one of the reasons why computers are increasingly used in cognitive retraining: they will present the same material in exactly the same way as many times as is necessary without becoming frustrated, angry or bored. Try a variety of ways to teach the individual new information and use as many ways as you can simultaneously. Use activities which the individual knew how to do before the injury if possible.

No one likes to spend prolonged periods of time working on activities they do not do well. Make sure your cognitive retraining program includes activities which the individual can perform well and enjoys doing; guarantee success as much as possible to keep motivation high. Be creative and flexible but don’t change an activity until you are certain it won’t work or the individual has mastered it and is ready to move on to the next step. When family members have a well-organized plan to re-build skills after head injury, the injured individual is more likely to continue to recover and to maximize his abilities while minimizing family stress.

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