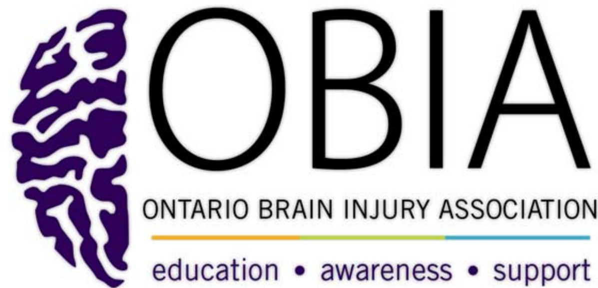

DEVELOPING A LOW-COST BRAIN INJURY REHABILITATION PROGRAM: GUIDELINES FOR FAMILY MEMBERS

The day you waited for with such mixed feelings finally arrived: your family member was discharged from rehabilitation after sustaining a head injury. Contrary to the predictions you may have heard the night of the accident, he did survive; he woke up; he began to talk, to eat, and maybe even to walk. Each time you met with members of the rehabilitation team, they told you about his progress over the past several days. You saw his progress each time you visited and when he was home on weekend passes. Family members and friends visited in the hospital, the rehabilitation setting, and even during trips home on weekends; they all offered to help once he was home for good. You knew things would work out, that he would continue to improve, that you could handle it all. But now that he's been home for several weeks, months or maybe even years, the situation is very different from what you saw in the rehab setting and very different from what you expected. He didn't continue to improve; in fact, his skills and behaviours may even have deteriorated. He did less and less each day and demanded more and more from you. No one comes to visit him or you, including family members. It breaks your heart to see him struggling to accomplish simple tasks. But at the same time you get angry when he behaves inappropriately. You realize that unless the situation changes, he may survive but you won't.

At this point, you're ready to try anything which might make things better. Unfortunately, insurance benefits have usually been totally exhausted; if local head injury programs exist, you have already discovered that he is not eligible or that the programs cannot meet his special needs. You may decide to design a program for him using free or low-cost resources which exist in your community. The steps listed below may serve as a guide if you wish to develop a program to continue rehabilitation after discharge to the community.

Content © 2011 • The Ontario Brain Injury Association

STEP 1:

Obtain Detailed Objective Information About:

The injured individual: Since research has clearly demonstrated that the most disabling consequences of head injury are cognitive and behavioural, information about the individual's current level of functioning in these areas is essential if a realistic program is to be developed. To obtain such information, neuropsychological evaluation should be completed. Those with limited funding may be able to receive evaluation at reduced rates through their community mental health center or from a local hospital or clinic setting. Neuropsychologists in private practice may be willing to provide this service on a sliding scale. You need specific information on such things as how much he can learn, what is the best way for him to learn, what activities are most likely to present problems, what limitations he may have perceptually, and how you can set things up to maximize his abilities. Your rehabilitation program must also take physical limitations into account. In addition to general information about the individual's medical status and physical abilities, thorough evaluation of both visual and auditory systems should be completed. Management of medical needs must be an integral part of the rehabilitation program. Adaptive equipment such as a wheelchair, braces, and communication devices, must be appropriate to the individual's current needs and in good repair.

Your support system: Before undertaking a rehabilitation program, family members must objectively decide how much time, money and emotional energy they will be able to commit and how long they will be able to do so. This includes such factors as who will provide transportation to activities, supervision in both the home and the community, and what materials will be needed. Some of the support which will be needed may not be provided directly to the injured person: perhaps a family member who does not drive can do the laundry or cook meals while you transport the injured individual to a recreational activity or a class. It is critical that your assessment of your support system be accurate; otherwise you may find that you are the one who is being rehabilitated, whose behaviour problems are being managed, and whose cognitive abilities are deteriorating. An organized program requires the effort of more than one individual unless it is undertaken in extremely small and manageable steps.

Community resources: This is definitely the time to "let your fingers do the walking." A wide range of community services, many of which are paid for by your tax dollars, are available in most communities and are appropriate for individuals who have sustained head injuries. Most of these agencies do not advertise; many are not aware of the special needs of those who sustain head injuries and how their agency's services might be utilized by this population. Contact your local and/or state head injury support groups for a list of community resources, talk with professionals working in local head injury programs, and work your way through the local phone book. At a minimum, you should contact the public transportation system, local library, community colleges and universities, public schools, and parks/recreation departments; you should also routinely check radio/television listings for appropriate offerings, especially those on public broadcasting. Read your local newspaper to identify activities and organizations which may be useful and appropriate. If a caseworker has been assigned by an agency, discuss your needs with that person, making sure you emphasize the injured individual's strengths as well as needs and deficits. Involve your physician in program development to ensure that the individual's medical needs are being met; on a more practical level, the physician should be contacted if a disabled parking permit or handicapped bus pass is needed and has not yet been obtained.

Content © 2011 • The Ontario Brain Injury Association

STEP 2:

Develop / Implement Your Specific Rehabilitation Program:

Once you know what you have to work with in terms of the injured individual's strengths and weaknesses, commitments by family members, and community resources, you are ready to set specific rehabilitation goals. Since you are designing your own program, you are free to include only those activities which you feel will be helpful to the injured individual and for which you have the time, resources and energy to follow through. If you and your family members are couch potatoes, for example, you may choose to avoid addressing areas which would require you to put forth significant physical effort. Although each individual who sustains a head injury is unique, the deficits which result and the rehabilitation goals which will be most appropriate share certain common features. Certain problems occur often enough that the broad areas which must be addressed can be identified even though specific activities must be decided by family members. Among these common areas, and in chronological order of importance, are:

Survival skills goals: Those activities which have the highest survival value (management of daily routines such as showering, grooming, toileting, dressing, sleeping and eating) should receive concentrated attention in the initial phases of your rehabilitation program. Goals should address the mechanics of completing the task as well as the amount of time required. Goals in this area have been accomplished when the individual is able to awaken on his own, independently complete his morning hygiene routine, and prepare and clean up after eating; he should be dressed as if he were going out in the community each day, i.e. in clean clothes which are pressed and in good repair. These routines should be completed by a reasonable time each day (such as 9 a.m.). The individual should be continent during both day and night, with awakenings mid-evening if necessary.

Basic cognitive goals: At the most basic level of cognitive functioning, individuals who have sustained head injuries are frequently extremely distractible and have limited ability to attend to and concentrate on tasks. Until attention and concentration are improved and the individual is able to function in at least moderately distracting environments, community-based activities may be problematic; therefore initial cognitive retraining activities should probably be conducted within the home setting where the level of distraction can be controlled and the individual's attention span can be challenged for brief periods of time spaced throughout the day. Appropriate activities to improve attention and concentration might include working on craft projects from books in the public library, playing simple board or card games, or playing simple video games. Since pre-injury information and skills are frequently relatively intact, the individual may be able to play games which were learned pre-injury, such as checkers or poker, without having to learn new rules; at this stage, the ability to learn is not being addressed, only the ability to attend and concentrate. Children and teenagers may be able to structure and supervise activities on this level with appropriate guidance. While such activities may initially require a quiet distraction-free environment, the amount and type of distracters should be increased as attention and concentration improve. The amount of consecutive time devoted to such activities should also be gradually increased until the individual is able to continue at the task for at least 30 minutes. With improved attention and concentration, activities designed to remediate deficits in higher level cognitive functions such as memory and learning can be introduced to the program. Activities should be selected which rely as much as possible on the most intact functional areas. If, for example, the individual has field cuts which make reading an ineffective learning tool, you might tape record brief stories on a cassette player or get talking books from the library. These materials can be replayed as many times as necessary for the individual to retain the information; as long as the individual is capable of independently starting and stopping the recorder, the activity can be done without the involvement of other people.

Content © 2011 • The Ontario Brain Injury Association

Basic behavioural goals: When the individual is able, at least at minimal levels, to attend and concentrate, to learn, and to remember, behavioural contracts can be used to reduce the frequency and severity of specific targeted behaviour problems such as verbal aggression, perseveration, or poor social skills. Information about behaviour management strategies can be obtained from your public library, public schools, social service agencies, and local organizations and clubs. It is critical to ensure that behavioural goals are not all negative, i.e., designed to stop behaviours. You must balance behaviours to be stopped with those you wish to see started so that the individual is not left with a behaviour void. Your behaviour management program should utilize appropriate rewards to encourage the individual to behave in more positive ways. At this point in time (if you are not already doing so) you should begin to give honest, objective feedback to the injured individual on specific maladaptive behaviours and your reactions to them. Although such direct oral feedback is not customarily given in most social settings, the injured individual may not understand why he fails to make friends unless he is provided with such information.

Social/recreational goals: One of the most frequent complaints voiced by individuals who have sustained head injuries is the lack of friends and social opportunities. The reasons for this are varied but physical limitations, poor behaviour control, decreased cognitive abilities and poor social skills are usually major culprits. In many cases, the individual lacks insight into the nature, range, severity or even the existence of deficits following the head injury and seems generally unable or unwilling to modify his behaviour even in the face of interpersonal cues which are not at all subtle. Once the individual's behaviour is under adequate control in the home setting, community recreation activities can be introduced in the rehabilitation program. Many communities have recreation programs specifically designed to meet the unique physical and social needs of individuals who are disabled; these resources should be fully utilized before attempting to mainstream in the community. Staff members of these programs are good sources of information on how to mainstream into other community social/recreational activities and which activities are most appropriate. Selection of recreational activities requires that the individual's specific cognitive and behavioural problems be taken into account. If, for example, the individual has difficulty managing aggression, it is probably unwise to take him to a boxing match or hockey game unless you are into self-abuse.

Academic goals: Some individuals who have sustained head injuries may be able to successfully enrol in academic programs once their basic cognitive and behavioural deficits have been remediated or despite remaining deficits. The line between rehabilitation and education begins to blur at this point, especially when the courses or subject areas had not been attempted prior to the injury. If you are considering including a formal academic component in your program, you should avail yourself of televised college level classes shown on local or cable channels before enrolling on campus. These classes can be used to determine whether the individual can keep track of class times, take notes, study for an examination, and learn the information presented without having to simultaneously deal with problems such as transportation to the campus, locating a specific classroom or dealing with distractions in the classroom. If a video recorder is available, you may tape the class so each lecture can be replayed as many times as needed or shown at more convenient times than initially scheduled.

Vocational goals: Some individuals who have sustained head injuries may recover sufficiently to return to either sheltered or competitive employment; others will be able to contribute to their communities in volunteer positions. Many individuals will be unable to pursue vocational goals because their salary would not compensate for government or private sources of disability income and/or benefits. Individuals who are not eligible for benefits may have to attempt to return to work if they wish to live above bare subsistence levels. If and when re-employment is a realistic goal, state Vocational Rehabilitation Division counsellors are an excellent resource for exploring vocational options, obtaining training to qualify for specific positions, and offering incentives to employers to hire an injured individual. They may also be able to provide essential on-the-job support services such as work station modifications to accommodate physical disabilities or job coaching during the training period.

Content © 2011 • The Ontario Brain Injury Association

STEP 3:

Monitor Progress/Update Program as Needed:

As the program progresses, you should find that the individual's cognitive and physical endurance, performance speed, and skills are steadily improving while the demands on your time are steadily decreasing. You must be able to fade yourself from the picture at appropriate times, even when you are not completely sure the individual can perform the activity without your help. As the individual's skills improve, you must make certain that your expectations rise so they are commensurate with his new abilities; when indicated, set goals at higher levels. The myth of the "plateau," which suggests that individuals who sustain head injuries reach a certain point in their recovery and then stop making progress despite the best rehabilitation efforts, must also be challenged as your program progresses. When progress in your rehabilitation program appears to be levelling off, it may be useful to think of that time as a period of consolidation of newly-acquired skills, a time for the repeated practice which is required to integrate the new information and skills with the old until they become as routine as possible.

At some point in time the injured individual and/or family members decide that they no longer wish to pursue rehabilitation. On rare occasions this occurs because all goals have been met; usually other factors such as extremely slow progress, the wish to pursue other activities, or burnout account for this decision. The fact that a structured rehabilitation program is no longer in place does not necessarily mean that the injured individual will stop acquiring or refining skills or that deterioration will occur, although both are certainly possible. The long term success of your program may be contingent upon continued effort on the part of all family members, especially the injured individual.

Author: Judith Falconer, Ph.D.

Content © 2011 • The Ontario Brain Injury Association