



Family guide to a low cost rehabilitation program

Your family member is discharged from hospital and you are ready to continue their rehabilitation. The steps listed below may serve as a guide if you wish to develop a program using free or low-cost resources which exist in your community.

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- Step 1: obtain detailed aim information
- Step 2: develop and implement your program
- Step 3: monitor progress and update as needed

Step 1: obtain detailed objective information

The injured person

Information about the person's current level of cognitive and behaviour functioning is essential to develop a realistic program. Specific information is needed on factors such as:

- how much can be learnt,
- what is the best way to learn,
- what activities are most likely to present problems,
- what limitations there may be perceptually,
- how the environment be set up to maximise abilities.

The rehabilitation program must also take physical limitations into account. In addition to general information about the person'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 person's current needs and in good repair.

The support system

Family members must realistically determine how much time, money and emotional energy they can commit, and for how long. This includes consideration of who will provide transportation to activities, supervision in both the home and the community, and what materials will be needed. An organised program requires the effort of more than one person - unless it is undertaken in extremely small and manageable steps.

Community resources

This is definitely the time to start ringing around. A wide range of community services are available in most communities and are appropriate for people who have sustained brain injuries. Most of these agencies do not advertise; many are not aware of the special needs of those who sustain brain injuries and how their agency's services might be used by this population. Think outside the box and don't be afraid to approach these community services for assistance

Step 2: develop and implement your program

Now 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 person and for which you have the time, resources and energy to follow through. 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 (daily routines such as showering, grooming, toileting, dressing, sleeping and eating) should receive concentrated attention in the initial phase. Goals should address the mechanics of completing the task as well as the amount of time required. These goals are accomplished when the person is able to awaken on their own, independently complete morning hygiene routines, prepare and clean up after eating, and dress appropriately to go into the community.

Basic cognitive goals

Concentration and attention can be particularly challenging for people who have sustained a brain injury, and this can negatively impact on community-based activities. Initial cognitive retraining activities should probably be conducted within the home setting. Appropriate activities might include working on craft projects, playing simple board or card games, or playing simple video games. Since pre-injury information and skills are frequently relatively intact, the injured person may be able to play games which were learned pre-injury without having to learn new rules. At this stage, the ability to learn is not being addressed, only the ability to attend and concentrate. While such activities may initially require a quiet distraction-free environment, the amount and type of distractors should be increased as attention and concentration improve. The amount of consecutive time devoted to such activities can also be gradually increased until the person is able to continue at the task for a realistic amount of time.

Basic behavioural goals

When the person 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 social skill issues. Information about behaviour management strategies can be obtained from your brain injury association.

It is critical that not all the points are negative, e.g. Designed to stop behaviours. You must balance behaviours to be stopped with those you wish to see started so that the person is not left with a behaviour void. Your behaviour management program should utilise appropriate rewards to encourage the person to behave in more positive ways.

At this point in time you should begin to give honest, objective feedback to the injured person on specific behaviours and your reactions to them. Although such direct oral feedback is not customarily given in most social settings, the injured person may not understand why he/she fails to make friends unless provided with such information.

Social/recreational goals

One of the most frequent complaints voiced by people with a brain injury is the lack of friends and social opportunities. The reasons for this are varied but physical limitations, behavioural issues, decreased cognitive capacity and poor social skills are often major culprits. In many cases, the person may lack insight into the nature, range, severity or even the existence of impairments following the brain injury and may seem generally unable or unwilling to modify his/her behaviour. This could be the case even in the face of interpersonal cues which are not at all subtle. Once the person's behaviour is positively altered in the home setting, community recreation activities are often introduced in the rehabilitation program. Your local brain injury association should have a list of recreation programs set up for people with disabilities.



Don't be limited by disability programs, however. If you feel able, reach out to other recreation programs in your community - try your hand at opening their eyes to inclusive practices, and including your family and loved one in their group. This can take time and education sessions, however may be more advantageous in the long-term.

Academic goals

Some people with a brain injury may be able to successfully enroll in academic programs once their basic cognitive and behavioural impairments 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, you should determine whether the person can keep track of class times, take notes, study for an examination, and learn the information presented. Also to be considered is having to deal with transportation to the campus, locating a specific classroom or dealing with distractions in the classroom. Speak with the campus's disability service. Most will have one and they can generally offer services such as note-taking, recorded lectures and one-on-one tutorials to assist.

Vocational goals

Some people with brain injuries may recover sufficiently to return to their pre-injury employment, perhaps with modified hours or duties, particularly in the short term. Others may find they are able to work, but in a different field, and vocational re-training may be necessary. People who are unable to resume paid employment may be able to contribute to their communities in volunteer positions. If and when re-employment is a realistic goal, disability employment services (des) providers can assist people to find and maintain employment, and in turn help employers put practices in place to support employees.

Step 3: monitor progress and update as needed

As the program progresses, you should find that the person'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 person can perform the activity without your help. As the person'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 people who sustain brain 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 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.

Ending rehabilitation

At some point in time the injured person 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 person 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 person.

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