



BRAIN INJURY ASSOCIATION OF NEW JERSEY

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Helpline: 1-800-669-4323

No Brain Injury is
Too Mild to Ignore,
or Too Severe to
Lose Hope

Letting Go: Steps to Independence

By *Carolyn Rocchio*

Introduction

As one reaches adulthood, independence is a natural goal. However, to resume an independent lifestyle safely after a brain injury, independence should be approached in stages and based on the individual's recovered physical and cognitive abilities. For some individuals with severe cognitive deficits, achieving complete independence may be an unrealistic goal.

Determining when it is safe to "let go" after brain injury can be a heart-wrenching decision for families. All too frequently, families expect that discharge from a hospital or completion of a rehabilitation program indicates the person is "well" or "cured" and life post-injury will go on as before. Following the acute stage of recovery after TBI, most individuals will experience some lingering and/or persistent problems with cognition (i.e., the way the individual thinks and interacts within the environment). Cognitive impairments can alter personality as well as create unwanted behaviors that interfere with the ability to reenter school, work and/or society successfully. Although recovery after TBI is dependent on many variables, most individuals improve over time and achieve a satisfying, albeit different lifestyle than the one enjoyed before the injury.

Involve the Family in the Rehabilitation Process

It is helpful for family members to witness first-hand how deficits impact on the individual's ability to perform certain tasks. It also prepares the family to assume their role as the support system once rehabilitation is completed.

As you support your family member's pursuit of independence, ask yourself if other family members/friends understand and reinforce the strategies being employed to maintain that individual's safety? Persons with TBI function best within a structured environment and it is important for everyone with whom the individual interacts to be aware of compensation strategies used for deficits, as well as the need to reinforce those strategies on a consistent basis. Persons with TBI often are isolated socially, and when community and/or social opportunities arise, it is vital to have and communicate a clear understanding about the use of alcohol or other addictive substances. Ideally, individuals should not use stimulants or depressive agents after a brain injury due to the exaggerated effect these substances have on the injured brain. It is much easier to monitor and prevent the use of addictive substances than to deal with them after they have become a troubling issue.



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Additionally, family members should consider the need for guardianship and/or conservatorship and familiarize themselves with these protective tools. When impaired cognition contributes to judgment errors and reckless spending of assets by the individual with TBI, it is helpful to have legal means to safeguard funds for the individual's welfare.

The Neuropsychological Evaluation

The neuropsychological evaluation is a task-oriented assessment of cognitive functioning and the key piece of information that will help determine the extent of assistance a person may need to function in society. Many individuals injured as a result of acceleration/deceleration forces experience damage to the frontal lobes, which are essential to higher-level, executive-thinking skills. Damage in this area usually results in a reduction or loss of ability to exercise good judgment, reason things through, problem solve, inhibit inappropriate behaviors, organize and structure time, control impulsiveness and/or follow through with tasks.

If a neuropsychological evaluation was not completed in conjunction with a rehabilitation program, school systems, vocational rehabilitation agencies and other state-supported programs may be a good place to start looking for ways to obtain this information. A neuropsychological assessment is a non-invasive, task-oriented evaluation which measures information processing, attention, concentration, memory, organization, self monitoring and other executive functions to form a comprehensive picture of an individual's strengths and weaknesses. It is a vital tool in determining an individual's dependency or interdependency. In his book, *Interdependence: The Route to Community*, Al Condeluci stresses the importance of focusing on strengths rather than weaknesses.

Watch for Increased Awareness/Insight and Gradually “Let Go”

Some persons with frontal lobe damage lack awareness about their own impairments and may take unnecessary risks affecting safety. Over time this may change and increased insight may create a negative reaction to the new “self.” Although this change in awareness can be a positive sign of improvement, dealing with it emotionally can be quite challenging and often results in behavioral outbursts and/or depression. Families must be alert to these changes to prevent self-injury, disruption of cooperation and/or increased demands for independence.

It is helpful to gradually establish some “safe” activities for the individual to manage independently (i.e., an exercise program at a local gym or YMCA where there are individuals trained to monitor—at least on a short-term basis—and provide assistance to the individual.



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Individuals with TBI and family members should get involved in activities sponsored by BIA or other organizations where people are accepted more readily for their differences. Specifically, recreational activities are good for reestablishing community involvement. County and city recreation departments are open to all residents and some programs have specialized services for individuals with disabilities. Whatever services your family member decides to participate in, ensure the persons in charge know the individual's impairments and the extent of help he/she will need to participate effectively.

The Importance of Appropriate Identification

With each step toward independence, it becomes more important to have proper identification at all times. In the event of seizures, ensure that the individual has information in the form of a bracelet, necklace and/or wallet card that accesses medical instructions. Some BIA state affiliates provide individuals with TBI laminated wallet cards that contain information about the consequences of brain injury.

Plan Failures When Applicable

Sometimes it can be helpful to support the person with an activity for which there is concern about safety. Denial—whether organic denial or lack of awareness of one's deficits—can be a persistent problem. It sometimes is useful to take risks to reach a goal. For example, an individual with balance problems who wants to ride a bike again can start off on a stationary bike. After the individual has been evaluated getting on and off safely, allow him/her to progress to a two-wheel bicycle and—using good protective equipment such as elbow pads and helmets—allow him/her to practice skills in a relatively “safe” area with sidewalks and grass in the event the rider falls. Planned failures can demonstrate to the individual his/her own performance in ways that can help families avoid being labeled “the bad guys” by saying no when an activity is deemed to be unsafe.

Conclusion

It is easier for the family to be in a position of control at the onset of the community reentry phase of recovery rather than experience a sense of failure when the individual with TBI is unable to resume his/her exact pre-injury lifestyle. Gradual reentry can provide a measure of safety and protection that can move the individual from dependence to interdependence and, for many, complete independence. Focusing on what a person does well is an enriching experience for all family members. When letting go is a safety issue, it often is best to err on the side of caution rather than relinquish too much control too early. It is important to keep in mind that independence is not a virtue and dependence is not a vice. Random House New Collegiate Dictionary defines independence as “exemption



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from external control and support.” Finding the proper balance between control by the family and gradual relinquishing of control are the stepping stones to greater independence, with many families finding the journey can be a satisfying partnership.

Reference

Condeluci, A. (1998). *Interdependence: The Route to Community*. Boca Raton, FL: CRC Press LLC.

Carolyn Rocchio is the parent of a son with a brain injury sustained in a 1982 automobile crash. She is the founder of the Brain Injury Association of Florida and a former Board member of the Brain Injury Association.

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*Additional information can be found at: Helpline: 1.800.444.6443
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