

# Steps to independence

**Resuming an independent lifestyle safely after a brain injury is an important goal. This goal should be approached in stages based on individual needs and abilities.**

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## Setting realistic goals

For some people with severe cognitive impairments, achieving complete independence may be an unrealistic goal. Determining when it is safe to let go after brain injury can be challenging for carers and families. Frequently families expect that discharge from a hospital or completion of a rehabilitation program indicates the injured person is 'well' or 'cured', but most individuals will experience some ongoing problems. There is a delicate balance between protecting someone with a brain injury from potential harm and promoting independence, and opportunities to learn.

## The role of the family

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

People with a brain injury function best within a structured environment. 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 consistently reinforce those strategies. Ideally, people with brain injury should not use stimulants or depressive agents 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 problem.

Additionally, family members should consider the need for guardianship and familiarise themselves with these protective tools.

## Neuropsychological Assessment

The neuropsychological evaluation is a task-oriented assessment of cognitive functioning. It is the key piece of information that will help determine the extent of assistance a person may need to function in society. Many people with brain injury can experience a range of impacts which increase their vulnerability and inhibit independence and social integration. These include:

- a reduced ability to exercise good judgement,
- poor reasoning and problem-solving,
- socially inappropriate behaviours,
- an inability to organise and structure time,
- an inability to control impulsiveness and
- an inability to follow through with tasks



It is important that these types of problems are identified through an assessment, and strategies put in place to manage these.

If a neuropsychological evaluation was not completed as a part of your 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.

### **Watch for Increased Awareness**

Sometimes as a result of brain injury, people can lack awareness about their impairments and may be prone to taking unnecessary risks. Over time awareness may improve. While this can be a positive sign, it can be emotionally challenging as people realise the impacts of their injury. A lack of awareness can be a buffer to emotional distress, and families must be alert to any changes. If not managed effectively, increased awareness can lead to self-harm, disruption of cooperation and/or increased demands for independence.

### **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. If there is a risk of getting lost, then maps or a record of the person's address should be carried at all times.

### **Dignity of Risk**

Sometimes it can be helpful to support the person in an activity where there is concern about safety. Denial, whether organic denial or lack of awareness of one's deficits, can be a persistent problem. Sometimes it is useful to take risks to reach a goal.

For example, an individual with balance problems who wants to ride a bike again can begin on a stationary bike. If they are able to get on and off the bike safely, they could then progress to a two-wheel bicycle using protective equipment, such as elbow pads and helmets in safe areas with footpaths and grass.

### **Holistic Independence**

Promoting independence among people with a brain injury is complex, and may take many years to achieve. It is helpful to gradually establish some 'safe' activities for the injured person to manage independently.

This could be a program at a local gym where there are staff trained to monitor and provide assistance.

Recreational activities are also good for re-establishing community involvement. Whatever activities a family member decides to participate in, ensure that those in charge are aware of their impairments and the extent of assistance needed to participate effectively.

Gradual re-entry can provide a measure of safety and protection that can move the injured person 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. Finding the appropriate 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.

The focus of rehabilitation typically emphasises regaining lost function; however, there are many other factors to be considered when working towards independence after brain injury. Consensus and clarity around goals and strategies in relation to independence should be reached between service providers, families and the injured person.

An important aspect of goal development activities involves the social relevance of the identified goals:

- where a person lives,
- how they will be occupied,
- how they will relate to others,
- how they perceive their quality of life.

People with a disability must have some interest in interacting with those who can provide assistance to them in promoting independence. When this interest does not exist, it must be established. Promoting independence wisely can increase the injured person's safety, create opportunities to exercise choice, and enhance self-esteem.

In recent years, changes in disability policy have seen shifts away from long-term residential care to community living. Although this constitutes a positive change for people with a disability, community re-integration is complex, and high quality community living arrangements are not always available.

Community knowledge about complex disabilities such as brain injury is poor, which can hamper successful community re-integration. More work needs to be done to prepare communities to understand and integrate well with people who have sustained a brain injury. The major area of difficulty here relates to the accommodation of behaviours that are considered anti-social or 'disruptive'. Obviously interventions designed to support people to learn more acceptable ways to interact are of benefit, but this is not always achievable, and a greater understanding for the general community is needed. Great modifications have been made to create a world that accommodates people with a wide range of disabilities. This needs to be extended to all.

### References

Permission to adapt this article has been kindly granted by the Brain Injury Association of America.

The full version of the original article can be viewed at: <http://www.biausa.org/Pages/related%20articles/article.letting.go.steps.html>