When Get up and Go is Gone. Lack of Initiation and Motivation after Brain Injury

From Changed Lives, New Journey: Tools, Tips, and Insights Blog by Melanie Atkins on August 19, 2014

Not being able to initiate activity and a change in levels of motivation after brain injury can be a challenging and sometimes life limiting outcome to live with.

During a training session for community support workers I asked the group for the number one issue they struggled with, assisting a person living with brain injury.

I had jumped ahead and assumed that number one would be either finding meaningful stuff to do, or challenging behavior.

Surprisingly, the number one issue was neither. It was the ethical dilemma of getting someone to do something they did not seem to want to do. Commonly termed lack of initiation and motivation after brain injury.

How do you push someone to do something if they are not really willing to do it?

How do you know when it is OK to push someone and when it is not OK?

I use the word "push" here because this is how it can seem to a supporter. When a person has low motivation, or difficulty initiating activity it may need physical guidance or strong support to do what is needed.

Definitions: Initiation, Motivation after Brain Injury

There are several terms you might hear in relation to this topic:

Initiation – This is like your starter motor giving you the ability to begin, or to start something. Lacking initiation means difficulty starting activities or tasks. There might be a reduction, or sometimes an absence of "get up and go".

Motivation – This is what drives you to achieve something and follow it through. A lack of or reduced motivation means you are lacking the energy to start and /or to keep going.

Adynamia – Meaning literally no strength. Not being able to do things. It might seem like apathy or lethargy except that it does not go away.

Abulia – a lack of motivation "Abulia is a state of diminished motivation in which an individual may appear apathetic, disinterested, asocial and emotionally remote."
Apathy – I include "apathy" here because it is often used in descriptions about reduced motivation. I believe this word has a more deliberate tone to it. Apathy is about lacking engagement, interest, or feeling whereas loss of motivation is loss of the physical drive. I don't believe it is so helpful to use this word as it sounds like something a person can get over.
Akinetic mutism – is an uncommon outcome and is the most severe form of lack of motivation. A person does not move or speak. Unlike "locked in syndrome" the person is not paralysed, but has no drive or motivation.

What You Might Notice With Lack of Initiation and Motivation after Brain Injury

'Genna' would sit watching television most of the day telling her supporters that she was planning to go back to work. Outlining she would update her CV,sign up for a refresher course and contact her old boss. Genna had been saying this for many months and while she could talk through the plan, she did not get to take the first step. 'Pete' would lie in bed until someone came and guided him into activity. If no-one came he would remain inactive and in bed throughout the day.

The outcomes of reduced initiation and motivation can vary in degree and severity. You might notice any of the following:

- Not able to start things off, but once started you are OK.
- Less drive, or desire, to want to do things. Even interests or activities you were passionate about previously don't happen. Sometimes even with encouragement and support nothing happens.
- Able to explain the plan, including the steps to be taken, but not able to take the first step. You might not even be able to ask for assistance to get started.
- Always talking about the things you are going to do, but never get around to them. Sometimes this gets mistaken for being "lazy". It is caused by damage to the brain.
- Finish one task but not start the next.

Tips and Suggestions for Changes in Initiation and Motivation after Brain Injury:

Remember – it is the brain injury. It is not laziness, or a lack of will to do a task.

Using Motivators:

- Begin with what the person is passionate about. Explore and find things that are of interest and find ways to engage in enjoyable, meaningful stuff.
- Work together to find out what is motivating (and what is not). Look at how to incorporate this into strategies to increase motivation. If music is a passion maybe you could incorporate music into an activity, or as a reward on completion.
- Be prepared to change motivators once they no longer seem effective.

Using Reminders, Prompts and Cues

- You may need to provide physical and/or verbal reminders. This might mean physically guiding a person to begin a task; A volunteer gently lead Pete to the kitchen giving him a checklist to prepare lunch. Or giving a verbal starter “Jim get up out of bed now”.
- You might need to prompt or cue just to get started. Or you might need to do so for each step, every time.
- Use an alarm or timer as a reminder to start something, or change to something else.
- Encourage ways to find cues that work for each person. Work together to review what other people do; look at what has been successful in the past.
- Match the best cues for the person and their life: Visual cues such as checklists, signs, calendars, whiteboard notes. Using phone Apps, or other familiar technology to prompt steps.
- Review, reduce or cease any intervention once it is no longer needed.

Using Goal-setting

- Focus and build on successes. Talk through difficulties / failures as they arise.
- Work to set goals incorporating both what needs to be achieved and what is enjoyable.
- Set goals that motivate the person both short term steps and larger goals. “Finish the housework and we can go to the Mall”. “Keep up your exercise program for 6 months and you will be able to walk further”.

- Work together to set realistic expectations, and agree on ways to overcome difficulties as they arise.
- Provide the amount of support needed to ensure successful participation in agreed tasks / activities.
- Wherever possible give choices and options of what to do, and when. Try and limit the opportunity for the person to say No, or to do nothing.

Structure and Routine

- As much as possible maintain structure, consistency, and a predictable routine.
- Plan days so that activity is spaced and there is not too much time without activity.
- Break tasks and activities down into manageable steps.
- Use the preferred method of recording steps such as in mobile phone, printed checklist, whiteboard list.
- Work out routines that are familiar and link tasks that go together.
  Professional help may be needed to determine whether other factors, such as depression, are causing a lack of motivation.