

# Tired of being tired

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## Impact paragraph

Worldwide millions of people sustain a brain injury each year. These can have external causes such as falls or traffic accidents leading to traumatic brain injury or internal such as problems with the blood supply causing a stroke. These brain injuries are a major cause of mortality and long-term disability, which places a high burden on society. Sleep disturbances and fatigue are amongst the most disabling symptoms following brain injury. Sleep disturbances may include trouble falling asleep or staying asleep. Fatigue has been compared to having a phone with an old battery that is easily out of supplies and needs longer times to recharge. In addition, the more you ask from it the faster the battery runs empty. Living with accelerated fatigue and prolonged periods of time to recover can be considered a handicap. People with a brain injury might therefore not be able to perform the same number of activities or tasks as a person without a brain injury. This can have a large negative impact on daily functioning, for example, a person might not be able to return to work, visit social events or perform leisure activities, which might lead to a reduced quality of life. Furthermore, some of the consequences of a brain injury, including fatigue and sleep disturbances, are not directly visible to the environment, for example, there is no need for a wheelchair or other physical aids. Therefore, the environment might struggle to acknowledge and understand these symptoms.

Despite this large impact and the high frequency of symptom reporting among patients, the experience of fatigue and sleep disturbances following brain injury is still poorly understood. This thesis, therefore, explored fatigue and sleep disturbances following brain injury. Sharing our results via diverse routes (see activity section), might raise more awareness of the high prevalence of fatigue and sleep disturbances following brain injury and the consequences of these symptoms. This is important for *people with a brain injury* because it will give rise to better treatments, help their *environment* understand these symptoms, and might increase support. Furthermore, *clinicians and caregivers* such as the partner or family might start exploring or help recognise which situations trigger sleep disturbances or fatigue, for example, social occasions, stress, or busy environments with many stimuli. This way these symptoms could be controlled and possibly minimized.

In addition, a better understanding of the underlying factors associated with fatigue and sleep disturbances might aid the development of new treatments aimed at reducing

fatigue and sleep disturbances following brain injury. The results of this thesis can therefore be relevant for *researchers* and a broad range of *clinicians, people with a brain injury, and their social environment*.

#### Objective measure of fatigue

Questionnaires used to assess fatigue often ask about a period in the past such as 'how fatigued were you feeling the last month'. This might be difficult to answer, particularly for people with a brain injury who have trouble with their memory. In addition, people could think back about the worst fatigue they had in that period or the most recent experience and might therefore over- or under-report their symptoms. Objective measures of fatigue are thus recommended. As an objective measure of fatigue, we tested a reaction time task, in which participants had to respond as fast as possible by pressing a button every time they saw a visual stimulus. We found that people with a brain injury who responded slower also reported more fatigue and related symptoms such as depressive symptoms and daytime sleepiness. This finding is relevant for other *researchers and clinicians* such as *neuropsychologists and occupational therapists* who want to include objective measures of these symptoms in their assessment in addition to subjective self-report. Objective measures are also important for *people with a brain injury*. Task performance can be used to provide insight into their own performance or might be a way for people with a brain injury to show their environment that there is a problem since only self-report is sometimes not taken seriously. Furthermore, to provide insight into the symptom dynamics the clinician could for example show a person with a brain injury their own reaction time to indicate if it is within a normal range or not and thus, whether the consequences of sleepiness or fatigue are as threatening as the person might think. In addition, task performance could also be used to demonstrate the effect of a treatment. Feeding back the person's own data can be a meaningful way to give people more insight and control over their own complaints. However, future research is necessary to examine if a specific decrease in reaction time is associated with an improvement in symptoms including fatigue and sleepiness.

### The role of the environment

We found that people with a brain injury recovered from a demanding task at the same rate as people without brain injury. However, people with brain injury reported higher levels of fatigue at the start of the experiment. This suggests that fatigue following a brain injury might be better explained by incorporating the demands and influences from the environment. These could be external factors such as trying to focus attention (for example reading) in a noisy environment or having to perform multiple tasks at once (dividing attention) or internal factors such as emotional reactions, feeling anxious for an assessment, or constantly thinking about how fatigue or sleep problems might affect daily life. For example, people with a brain injury could have been more fatigued at the start of the experiment because they had to drive to the research institute or take public transport, which could be more exhausting or stressful when you are easily overstimulated. It is thus important to take the environment and other factors into account when examining fatigue and sleep disturbances.

*For people with a brain injury*, this finding is important to help them better understand their fluctuations in levels of fatigue. For *clinicians* trying to help people with a brain injury who experience fatigue, it is important to be aware of possible tasks, situations, or other symptoms that could contribute to fatigue. They could for example recommend the use of a registration system (for example a diary) to explore when a person with brain injury gets fatigued and which situation or emotional state preceded this fatigue.

*Researchers* who are comparing people with a brain injury to people without a brain injury should take into account fatigue levels at the start of assessment since these might influence performance. In addition, researchers could also try to minimize these baseline differences, for example by performing assessments at the home of the person with a brain injury to prevent fatigue from travelling to the research institute.

### Sleep and physical activity

In the general population, sleep and physical activity are thought to be related to each other. We examined this relationship in people with a brain injury and showed that physical activity during the day is not a good predictor of sleep quality the following night. However, sleep was a predictor of physical activity the next day. Therefore, sleep may have more of an influence on physical activity than physical activity has on sleep in people with a brain injury. This finding

is important for *clinicians* treating people with a brain injury, including *(neuro)psychologists, psychiatrists, physical therapists, and occupational therapists*. It indicates that treatment should focus on improving sleep first because sleep affects physical activity and not the other way around. For *people with a brain injury*, this is important since improving sleep might thus lead to increased physical activity. This might also lead to increased societal participation because more energy to be physically active could mean that a person could perform leisure activities again or start working.

#### Future treatment options

*People with a brain injury, their environment, and clinicians* would benefit most from effective treatment for fatigue and sleep disturbances following brain injury. At the moment, there is still a lack of proper treatment for these symptoms. The existing treatments consist of psychoeducation / psychological treatment, which provide insight and strategies to cope with fatigue and sleep disturbances. In addition, sleep medication or alerting substances might be used but these often have side effects and cannot be used for longer periods of time. Some studies suggest that light therapy could help alleviate fatigue. However, knowing which factors might enhance or maintain fatigue and sleep disturbances over time might provide new opportunities for treatment. To better understand these possible factors, it is necessary to follow people with a brain injury for a longer period of time to examine whether changes in mood or participation might maintain or enhance fatigue or sleep disturbances. These relationships are currently explored in an ongoing study. Better treatment options for fatigue and sleep disturbances could significantly improve the quality of life of *people with a brain injury* in the future.

#### Activity

The knowledge collected with the research described in this thesis has been and will be communicated in several ways. First, via publications in international and national journals to share our knowledge with other researchers. Chapters two, five, and six have already been published, and two of these chapters are in open access journals, so accessible for everyone. Second, the results are communicated via presentations at national and international conferences such as the Limburg Brain Injury Centre symposium and activities during the

brain awareness week, meeting of the Dutch Institute of Psychologists, and the Conference in Neuropsychological Rehabilitation of the Special Interest Group of the WFNR. These conferences are visited by clinicians as well as researchers. Furthermore, the online version of the Limburg Brain Injury Centre symposium is also followed by people with brain injury and people of patient associations thereby spreading the results to a broad audience. Findings have also been shared via online platforms such as LinkedIn, Twitter, and Facebook. Furthermore, results are shared directly with colleagues via research days and informal interactions. In addition, the results could be shared at informal low threshold events such as “brain cafes” where people with a brain injury and their caregivers could be informed about the results.