Final report summary:

What are the important factors associated with fatigue after stroke?

NotFAST (Nottingham Fatigue After Stroke study): understanding the nature of the clinical problem and determining factors associated with fatigue in stroke patients without depression

PROJECT CODE: TSA 2012-04
PRINCIPAL INVESTIGATOR: PROFESSOR AVRIL DRUMMOND
INSTITUTION: UNIVERSITY OF NOTTINGHAM
What are the important factors associated with fatigue after stroke?

What did the researchers do?

Participants were recruited from four different UK hospitals between September 2013 and March 2015. Patients were invited to take part if they:

• had had a first stroke
• were aged 18 years or over
• were able to read or speak English
• did not have dementia
• did not have significant depressive symptoms

In total, 268 participants were initially assessed between four and six weeks after their stroke, using questionnaires and standard tests to find out whether they were experiencing any problems. The average age of people taking part was 68 years old; 63% were men and 37% were women. After six months, the questionnaires were sent out to participants by post for follow-up assessment, with 213 of the same participants completing them for a second time.

The main problem assessed was post-stroke fatigue. This was self-reported by participants using the Fatigue Severity Scale (FSS) which contains nine statements about fatigue to which respondents indicate their level of agreement on a scale of one (strongly disagree) to seven (strongly agree).

Further problems assessed were participant:

• mobility and independence in activities of daily living (e.g. personal care, housework, shopping, social activities)
• mood and emotional factors (symptoms of depression and anxiety, the effect of traumatic events)
• sleep
• cognition (attention, ability to process information)

Why did we fund this research?

Experiencing fatigue after stroke (post-stroke fatigue) can have a significant impact on the lives of stroke survivors, adversely affecting their participation in rehabilitation, their daily occupational performance, ability to return to work and their quality of life after stroke1,2,3.

Post-stroke fatigue is also common, and reported to affect between 23% and 77% of stroke patients4,5,6. These wide variations in reported occurrence may be due to differences in the definition of post-stroke fatigue, as well as methods used to measure fatigue6. The course of post-stroke fatigue over time is also poorly understood7.

Despite being an important clinical issue, there are very few evidence-based recommendations for the management or prevention of post-stroke fatigue. In addition, previous key research has failed to take into account and control for participants having depression, which is known to be associated with post-stroke fatigue2,8.

The aim of this study was to examine post-stroke fatigue in a sample of stroke survivors without depressive symptoms, to determine the frequency of fatigue and to identify associated factors.

Having a clearer understanding of the frequency of post-stroke fatigue, and the factors associated with it, should help us identify the best way to treat and manage this challenging condition in the future.
Twenty-two participants who reported high levels of fatigue at six month follow-up were also interviewed. The aim was to explore their day-to-day experiences relating to fatigue and how it affected them. Open-ended questions were used in order to give participants the opportunity to talk freely about the topics covered, and participants were able to introduce their own topics relevant to post-stroke fatigue. The interviews were analysed using a technique called ‘thematic analysis’.

What did the research find?

Frequency of post-stroke fatigue

Post-stroke fatigue was common, even though most participants had not had very severe strokes. At four to six weeks after stroke 43% of people said that they were experiencing fatigue. This was similar at six months after stroke (51%), although not all the same people reported having fatigue has had done so at four to six weeks after stroke.

For some participants there appeared to be a delay in the onset of their fatigue. About a third of people (38%) who were not fatigued at four weeks said they had developed fatigue by six months after their stroke.

For most participants, fatigue was a new symptom following their stroke. However, around one third (38%) said they had also experienced fatigue before their stroke.

Generally, fatigue was more severe at six months than at four to six weeks after stroke. Many participants had made a good physical recovery from their stroke, but were still experiencing fatigue.

By six months, approximately one third of participants (31%) who had reported fatigue in the early weeks after their stroke had improved and were no longer fatigued.

Factors associated with post-stroke fatigue

Between four to six weeks after stroke, the following factors predicted higher levels of fatigue:

- having had fatigue before the stroke
- having lower levels of independent mobility (walking; moving between lying, sitting and standing; climbing stairs)
- having higher levels of anxiety and depressive symptoms
- having a spouse or partner

At six months after stroke, the following factors predicted higher levels of fatigue:

- being less independent in activities of daily living
- having higher levels of anxiety symptoms

Interviews with participants at six month follow-up

Fatigue had an impact on a wide range of everyday activities, from shopping and housework, to leisure activities, social relationships and work life.

For some people fatigue was present much of the time, while for others it could be variable and was often unpredictable. Fatigue could also be triggered by physical and mental exertion, but also by periods of inactivity.

People attempted to work out how best to manage their fatigue and how to achieve a balance between their energy levels and the demands of life. They did this by having daytime rests or naps, pacing activities (breaking down a larger activity into smaller parts and then spacing out with rest periods), planning or avoiding activities so as to not overdo things, changing their expectations about what they could achieve, accepting help from others, and keeping active or taking exercise such as walking.

Very few people reported having received any information or advice about fatigue from their care teams either in hospital or at home.
What does this mean for stroke patients?

The NotFAST study has identified a number of factors found to be associated with post-stroke fatigue, along with self-devised strategies reported by interviewed participants for managing their fatigue. These represent potential targets for the development and testing of future interventions, including information resources and educational programmes to prepare stroke survivors and their families for the impact of post-stroke fatigue.

The findings from the NotFAST study were published in peer-reviewed articles in three journals:

- The four to six weeks assessment findings were published in the journal Clinical Rehabilitation in March 2017.  
- The six month follow-up assessment findings were published in the journal Stroke Rehabilitation in September 2017.  
- The findings from interviews with participants at six month follow-up were published in the International Journal of Therapy And Rehabilitation in October 2017.

References

2. Yamaguchi, T., Mori, E., Minematsu, K., Nakagawara, J., Hashi, K., Saito, I. and Shinohara, Y., 2006. Alteplase at 0.6 mg/kg for acute ischemic stroke within 3 hours of onset. Stroke, 37(7), pp.1810-1815.  
We are the Stroke Association

The Stroke Association is the leading stroke charity in the UK. We believe in the power of research to save lives, prevent stroke and ensure that people make the best recovery they can after a stroke.

We’re here for you. If you’d like to know more, please get in touch.

**Stroke Helpline:** 0303 3033 100  
**Website:** stroke.org.uk  
**Email:** info@stroke.org.uk  
**From a textphone:** 18001 0303 3033 100

Our research programme relies on voluntary donations.

**Please help us to fund more vital research.**

Call our Donations line on **0300 3300 740**, or visit **stroke.org.uk**

**Together we can conquer stroke**