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## *News Release*

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### **Brain disorder leaves lasting legacy of disability, study finds**

Four out of five people with a hidden brain condition that causes limb weakness or paralysis experience lasting physical difficulties.

Research to assess long-term effects of the disorder, called Functional Neurological Disorder (FND), found 80 per cent of patients still had symptoms in their arms and legs 14 years after initial diagnosis.

Experts, who tracked outcomes of more than 100 patients, hope the study – the largest of its kind – will help doctors provide realistic prognoses in future and encourage more work on treatment.

In their initial studies 14 years ago, researchers found that FND is as common and disabling as better known conditions, such as multiple sclerosis. It has, however, suffered from stigma because it cannot be seen on conventional brain scans.

Doctors often describe it as a ‘software’ problem of the brain rather than a ‘hardware’ one – a condition related to how the brain processes information rather than a physical defect in its structure.

For the follow-up study, patients filled in questionnaires to assess their physical and psychiatric symptoms, quality of life and perception of their illness.

Their answers revealed that levels of physical disability and distress remained high, even after 14 years, leading to persistent and sometimes, disabling problems.

Doctors can sometimes be reluctant to give a diagnosis of FND for fear of making a mistake, the researchers say. But the team found mistakes are rare and this should not prevent them making a diagnosis using clinical signs, even if tests are normal.

The study was carried out by the Universities of Edinburgh and Groningen in the Netherlands and is published in the journal *Brain*.

Professor Jon Stone, of the University of Edinburgh’s Centre for Clinical Brain Sciences, said perceptions of FND have changed dramatically over the past 20 years but that doctors are still likely to dismiss patients as ‘imagining’ or ‘putting on’ the condition.

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He said: “Thankfully with better research and treatment those attitudes are changing. This study shows the importance of neurologists staying involved with the long-term management of patients to guide treatment and detect additional neurological conditions, which can rarely occur years after the start of FND.

“It should also help clinicians provide a more realistic prognosis for patients with FND when it causes limb weakness and stresses the importance of active and targeted treatment which many of these patients didn’t have.”

For further information, please contact:

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Further information on FND is available at [www.neurosymptoms.org](http://www.neurosymptoms.org), [www.fndhope.org.uk](http://www.fndhope.org.uk) and [www.fndaction.org.uk](http://www.fndaction.org.uk) or via this short [film](#).

Reference:

Jeannette M. Gelauff et al. The prognosis of functional limb weakness, a 14-year case-control study. *Brain*, 2019.

Link to article after embargo lifts:

<https://academic.oup.com/brain/article-lookup/doi/10.1093/brain/awz138>