Fighting the FND stigma: the consultant neurologist

Consultant neurologist Jon Stone talks to Kathy Oxtoby about his work to eradicate the stigma around functional neurological disorder

Kathy Oxtoby

When patients enter Jon Stone’s consulting room, he will see fear on their faces which comes from having a complex and debilitating condition. Many will have experienced paralysis, tremor, and seizures, along with chronic pain.

By the time they leave the consultation, Stone’s patients often have a sense of relief that comes from knowing what their condition is and that it is not—as some clinicians may have told them—all in their mind.

Stone, a consultant neurologist at the Royal Infirmary of Edinburgh, and honorary professor of neurology for the University of Edinburgh, specialises in functional neurological disorder (FND).

According to Stone, up to 100 000 people in the UK live with FND, which can be as debilitating as epilepsy, stroke, or multiple sclerosis. The most common misconception about it is that patients are in control of some or all of their symptoms.

“It has been a stigmatised condition,” says Stone. “Many doctors know terms like ‘pseudo seizure,’ or the older term ‘hysteria,’ which suggested there was nothing wrong at all.”

But Stone, a pioneer in the field of FND, has been working to eradicate that stigma. He conducts research, explores new treatments, and hopes to inspire trainees to improve the care of patients with FND.

He lectures globally on the condition, and in 2017 co-chaired a landmark international conference in Edinburgh. In 2014 he was awarded the Royal College of Physicians Jean Hunter Prize for Nervous Disorders, and received the President’s Medal from the Royal College of Psychiatrists in 2017.

Stone still finds it satisfying to help his patients, who are often distressed and may have had bad experiences with doctors in the past. “It takes time to build good relationships and trust,” he says. “Treatment depends on helping people understand their condition and using rehabilitation therapies like physiotherapy and psychological therapy,” he adds. “When I help people get their seizures under control, see them walk again, or sometimes even help blind patients see again, it feels pretty amazing.”

From a young age, Stone was interested in the workings of the brain, and he decided to become a doctor because he “wanted to understand what made people tick.” After graduating from medical school at the University of Edinburgh in 1992, he was torn between specialising in psychiatry or neurology. He opted for the latter.

In 1999, having developed an interest in FND, he began a doctorate at Edinburgh University, studying patients with functional limb weakness. Stone was supported and supervised by two of his own role models, the then professor of neurology, Charles Warlow, and psychiatrist Michael Sharpe.

As well as working as an NHS consultant since 2005, Stone, along with colleagues including neuropsychiatrist Alan Carson, has explored and developed the field of FND. Their work has helped to ensure that it is now a core topic of training for neurologists in the UK. Stone supervises doctoral students, and loves the opportunity to inspire trainees to take an interest in neurology and FND.

As well as a love of travel, outside work he enjoys spending time with his family. He also plays a reed organ, reads Arts and Letters Daily, and has “loads of books—many of them about brains.” He says his interest in the brain “will keep me toiling until the end.”

“I thought FND would be a topic that would last my whole career and one I would never get to the bottom of. I think that’s right, but we’ve got further than I thought we would.”

Nominated by Ingrid Hoeritzauer

“Jon Stone has brought FND into the light after at least 50 years of it being ignored. Along with another role model of mine, Alan Carson, he has led a worldwide renaissance in positively diagnosing FND and creating treatments. He has done all this while working full time as an NHS clinician.”

“He’s also a feminist, supporting many female clinicians with an interest in FND through research and through encouragement when we’ve contacted him out of the blue to tell him about our passion to improve FND care. “Jon is interested in helping both patients and colleagues. He’s humble, too. He’s a mentor, a role model, and now, as a consultant colleague, he’s also a friend.”

Ingrid Hoeritzauer is a consultant neurologist and NHS Research Scotland career research fellow, Royal Infirmary Edinburgh, NHS Lothian

For more information about FND visit:
- FND Action: www.fndaction.org.uk
- FND Hope UK: https://fndhope.org.uk
- FND Society: https://fndsociety.org

You can visit Jon Stone’s website at: www.neurosymptoms.org