

## **Briefing for the Public Petitions Committee**

## Petition Number: PE1723

Main Petitioner: Mary Ramsay

Subject: Essential tremor treatment in Scotland

Calls on the Parliament to urge the Scottish Government to raise awareness of essential tremor and to support the introduction and use of a focus ultrasound scanner for treating people in Scotland who have this condition.

### Background

According to the National Institute for Health and Care Excellence (NICE):

**'Essential tremor** is the most common cause of disabling tremor and is distinct from Parkinson's disease. It typically affects the arms and hands, although it may also involve the head, jaw, tongue and legs. The cause is not known but many patients have a family history of the condition. At first, the tremor may not be present all the time. However, it gradually worsens. Purposeful movement, stress, tiredness, hunger, heightened emotions or extremes in temperature make it worse.'

NICE also provides information on some of the current treatments:

First line 'treatment for essential tremor includes medications such as beta blockers (for example, propranolol), anti-epileptics (for example, primidone) or sedatives (for example, clonazepam). Rarely, injections of botulinum toxin may be used.

Surgery may be considered in people whose condition has not responded adequately to best medical therapy. Surgical treatments include deep brain stimulation and radiofrequency thalamotomy<sup>1</sup>.

### Radiofrequency thalamotomy

This procedure is carried out with the patient lying supine inside an MRI scanner. The patient's head is shaved and a stereotactic head frame is attached. Patients are kept awake so they can report any improvement or

<sup>&</sup>lt;sup>1</sup> Thalalotomy means the destruction of a small amount of tissue in the part of the brain called the thalamus. This technique is now only used in rare cases. The procedure is usually done on one side only, because bilateral (both sides) thalamotomy is thought to be much more risky. (Parkinson's UK)

adverse events to the operator during the procedure. However, they may be offered light sedation. Continuous MRI and thermal mapping are used to identify the target area of the brain and monitor treatment. Low power (sublethal) ultrasound is delivered to confirm the chosen location. Then, highpower focused ultrasound pulses are administered to irreversibly ablate target tissue. Chilled water is circulated around the head during the treatment to prevent thermal damage to the scalp caused by the increase in bone temperature. The procedure takes about 3 hours and symptom relief should be immediate.

The potential benefits of unilateral MRI-guided focused ultrasound thalamotomy are that it: is less invasive than the other existing procedures; results in a faster recovery time; and allows for testing of the effects of sublethal doses before ablation. However, it is only done on one side.'

An article in the <u>BMJ Journal of Neurology, Neurosurgery and Psychiatry</u> describes a study and literature review to compare a range of surgical treatments for essential tremor: deep brain stimulation (DBS) and thalamotomy procedures with radiofrequency (RF), radiosurgery (RS) and, focused ultrasound (FUS).

**Deep Brain Stimulation** (DBS) is where electrical stimulation is delivered to specific areas of the brain by one or more electrodes that are implanted in the brain and are attached by a wire to a device which generates electrical pulses and is usually implanted in the upper chest. According to <u>Parkinson's UK</u>, 'Deep brain stimulation is a 'non-destructive' type of surgery. This means that it doesn't destroy any part of the brain. Deep brain stimulation is also reversible in many cases, if no damage occurs during surgery. So, if it isn't successful, the system can be switched off, or removed if necessary.'

#### Radiofrequency thalamotomy (RF) - see description above

**Radiosurgery (RS)** – (<u>Gamma knife radiosurgery thalamotomy</u> – link to video). The Gamma Knife is not a knife in the conventional sense, but uses a focused array of intersecting beams of gamma radiation to treat lesions within the brain. The technique was invented by a Swedish neurosurgeon, Professor Lars Leksell. The intense radiation can be very accurately focused on abnormal tissue, leaving healthy brain tissue at very low risk of damage.

**Focused Ultrasound (FUS)** This is the treatment that the petitioner would like to see provided in Scotland.

This is a relatively new treatment for ET, with a trial begun in 2016. 'Magnetic Resonance-guided focused ultrasound technology uses an MRI to guide powerful focused ultrasound to a very small point in the body. At that point, the ultrasound causes molecules to vibrate extremely quickly, creating an intense local heat. That heat can destroy tissue. MR-guided focused ultrasound allows a very specific focal point to be targeted, ensuring that only this targeted tissue is affected. This non-invasive procedure is used to treat a number of conditions, such as fibroids in the womb. But it has proved much more difficult to find a way to use this technology in the brain.' (Imperial College Healthcare NHS Trust). The procedure has been the subject of a trial

at the Trust since 2016 following a grant of £1 million to purchase the equipment. On 6 June 2019, the Trust put out a <u>press release</u> about the study, where patients received treatment to both sides of the brain, although <u>NICE has approved it as a treatment</u> on one side only since 2018. The full results of the study will be published later this year and the Trust is working with NHS England to make the treatment available on the NHS. The company <u>INSIGHTEC®</u> produced the technology and equipment for the procedure. The company <u>cites a number of treatment centres and approvals for the technology (including EU</u> CE mark) for Essential Tremor.

### **Scottish Government Action**

<u>Draft Neurological Action Plan 2019 - 24</u> and other related documents (2018): https://www.gov.scot/publications/?term=neurological%20conditions&page=1

### **Scottish Parliament Action**

Motion S5M-10550: Rhoda Grant, Highlands and Islands, Scottish Labour, Date Lodged: 20/02/2018 Campaign for Focus Ultrasound Device.

'That the Parliament notes the support for Ninewells Hospital's campaign to raise funds for the purchase of a £1.5 million focus ultrasound device, which it believes would benefit all patients in Scotland, including in the Highlands and Islands; notes that this piece of medical technology can be used with the existing MRI scanning facility to allow surgeons to perform very small incisions within the brain using ultrasound beams; considers that this can be useful for patients with essential tremor and Parkinson's disease, and potentially for people with multiple sclerosis who have severe tremor, and understands that there is only one focused ultrasound device in the UK and that some patients will have to wait until 2022 for this treatment due to the significant waiting list at St Mary's Hospital in London.'

<u>Members' business debate on motion S5M-10550</u>, this debate in the name of Rhoda Grant, on the campaign for a focused ultrasound device, took place on 16 May 2018 and the link is to the Official Report transcript of the debate.

# **UK Parliament activity**

Parliamentary questions on focused ultrasound for Essential Tremor

Anne Jepson Senior Researcher 20 June 2019

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