

**P-05-763 Introduce updated stroke advice – B.E.F.A.S.T. – and help save lives and livelihoods – Correspondence from the petitioner to the Committee, 14.11.17**

Dear Kayleigh,

Many thanks for your update, and the correspondence from Stroke Association.

According to their own figures\*, around 80% of strokes are Ischemic in nature (up to 85% depending on which literature you read). Based on their argument in the received correspondence, this is a vast majority, and as such all strokes should be treated with clot-busting drugs or aspirin at the onset of symptoms. However, they are not, because this would make the situation far more life-threatening to the 20% who have haemorrhagic strokes as it would potentially cause a bleed to actually become worse.

Using some more of their statistics:

“1 in 5 strokes are fatal.” – that’s only 20% – should we bother to raise awareness at all?

“For every 1,000 patients who receive thrombolysis, a clot busting treatment, 80 will live more independently.” – that’s less than 1% so why even try thrombolysis?

“For every cancer patient living in the UK, £295 is spent each year on medical research, compared with just £22 a year for every stroke patient.” – maybe an increase in funding and awareness would help?

Out of the UK nations, Wales actually has the highest ratio of diagnosed stroke sufferers (3%)

However, this is only a response to the points made by Mr O’Grady, and not fully relevant to my petition.

The wording of my petition was to improve BEFAST understanding within the professional medical community as well as in other literature. I was seen by several professionals including doctors and a paramedic who was called out regarding sudden onset vertigo, which were most likely Transient Ischemic Attacks (TIAs) which are considered ‘mini-strokes’ or warning signs that an actual stroke could happen. It was the evening of the day I saw the paramedic (who offered me a trip to hospital but recommended against it as most likely a waste of time) that I finally suffered the stroke. This happened as I was actually walking into Mountain Ash hospital to see my GP who was based there at the time. Nobody in the hospital considered the sudden onset as I walked through the door, or the lasting symptoms whilst I was waiting for a lift home – whereas that afternoon they resolved far faster.

There is a section (4.9.2) in the 2016 National Clinical Guideline for Stroke\*\*\* regarding Balance in patients who have suffered stroke, but even though it’s recognised as a common after-effect, it’s apparently not considered as an important symptom by the Stroke Association despite their inclusion of a recent study extolling the benefits of the BEFAST

advice as evidence that as “only” 14.1% of ischemic strokes didn’t present any of the normal FAST symptoms it should not, in fact, be considered. The conclusion of that study even states “If validated in a prospective study, a revision of public educational programs may be warranted.”

Again, I am not necessarily suggesting a public release of BEFAST (though I do believe it would be effective and only improve recognition of more stroke sufferers rather than decrease the identification), but primarily better education of medical professionals. Had a different paramedic come to me with prior experience of my symptoms meaning stroke, I may have had a scan and preventative treatment that morning.

Section 3.4 of the Guideline states “Any person with the acute onset of a neurological syndrome with persisting symptoms and signs (i.e. suspected stroke) needs urgent diagnostic assessment to differentiate between acute stroke and other causes needing their own specific treatments. To maximise the potential benefit from revascularization treatments and the acute management of intracerebral haemorrhage, the Working Party has further reduced the recommended maximum time between admission and brain imaging for suspected stroke from 12 hours to ‘urgently and at most within 1 hour of arrival at hospital’.”

The Guideline also notes in Section 3.2 that “Any person with a fully resolved acute onset neurological syndrome that might be due to cerebrovascular disease needs urgent specialist assessment to establish the diagnosis and to determine whether the cause is vascular, given that about half have an alternative diagnosis.”

You may note it clearly states that alternative diagnoses are possible, and for this reason I believe that relevant tests should indeed be carried out first before submitting for the acute stroke tests. If balance is the issue there are various possible causes, which can be identified in the following methods:

Ear infection – easily noted with a visual inspection

BPPV – a type of vertigo caused by loosened calcium deposits in the ear canal, and can potentially be cured within minutes (or at least diagnosed) using the Epley Manoeuvre.

Hearing tests can also be performed as a deeper ear infection may not be immediately obvious in the ear canal but could affect hearing.

I was showing no signs of an ear infection other than the vertigo (which as we know has multiple diagnoses), and the Epley Manoeuvre was never attempted. However, despite symptoms continuing for nearly a year (though to a lesser degree), my (first) ENT specialist refused me the scan I requested, still didn’t see any signs of infection, no problems in a hearing test, and didn’t suggest the Epley Manoeuvre. It was only the next specialist (who I was only able to see months later) who sent me for an MRI which revealed the stroke suffered.

In previous correspondence you have sent to me, you noted that a symposium of Stroke specialists was asked their opinion on the FAST advice given. The response was that they follow the recommendations made by NICE and have no problem with that. I actually had an appointment with my own specialist the week following that, and he discovered that it was my petition. It was my first appointment with him, and he didn't realise how young I was, or how long it had taken to be diagnosed – I remind you again that it was 15 months before diagnosis of a cerebellar stroke, as it affected only my balance. He was surprised I had suffered a stroke because of my physical condition and age. He explained the cerebellum deals with balance, and it's perfectly obvious to him that was the cause of my vertigo. However, due to my physical condition and age, it wouldn't have been his first thought.

This exactly what my GP said after diagnosis during follow-up treatment. 25% of diagnosed strokes are suffered by those under 65, but I wonder if that would be higher if diagnosis was more effective?

I do understand this is a slightly jumbled response, but I hope you have been able to make sense of it. My point is that I simply believe that medical professionals should consider stroke as a possibility when there are balance issues, and BEFAST should be recognised by them. Do the standard tests – ear and throat examination, Epley Manoeuvre, hearing test – and if they don't come up with anything, stroke is the next possibility. This should be recognised and then tested for as per the guidelines mentioned above. I have discussed this with all my doctors, and they do agree with me.

The importance of correct diagnosis is more important now even than when I submitted my petition. In July a new study highlights the “substantial long-term morbidity and mortality” risk\*\*\*\* of Stroke and TIA sufferers for up to five years from the incident date. Correct diagnosis and treatment at the soonest possible time can help much more in the long-term – therefore decreasing costs for the NHS in Wales.

For such a high ratio as 14% of *diagnosed* strokes that do not present with FAST symptoms, it is well worth educating NHS Wales staff to identify these correctly, before they turn into strokes that *do* display FAST symptoms which could have been prevented by earlier diagnosis.

In a recent article by Wales Online\*\*\*\*\* , The Stroke Association suggests that stroke survivors in Wales may increase to 100,000 – an increase of 50% on their current estimation – with spending potentially trebling in the next 18 years. This is currently living stroke survivors – though around 7,400 people in Wales have a diagnosed stroke each year\*\*\*\*\*, with 2,317 diagnosed stroke deaths in 2014 (ONS figures used). Over 30% of diagnosed strokes in Wales are deaths. Shouldn't we be doing as much as possible to prevent this?

There are multiple posters in my GP's surgery regarding Sepsis and Meningitis. One that always catches my attention goes as follows:

S – slurred speech

E – extreme shivering or muscle pain

P – passing no urine (in a day)

S – severe breathlessness

I – “I feel like I might die”

S – skin mottled or discoloured

It’s amazing that this is promoted by the Sepsis Trust with such a bizarre range of symptoms and no easy acronym, but the Stroke Association don’t trust doctors with two extra words which fit and are actually in the ‘extra symptoms’ advice of almost all stroke advice, which account for 14% of diagnosed strokes.

Finally, I want to reiterate the text of my petition:

“We the undersigned request the Welsh Assembly to review the stroke advice currently **given to healthcare professionals** and in other marketing literature.”

“Had this been recognised by the multiple medical professionals I saw I could have received stroke treatment immediately and the extent of brain damage may have been avoided.”

Throughout this response I have been careful to say ‘diagnosed strokes’ because I do wonder how many incidences of vertigo – especially in younger people – have been caused by stroke but remained undiagnosed.

Thank you for your attention. I am happy to discuss this further. I am sure I can also obtain a supporting signed letter from medical professionals given more than a week to respond.

Best regards,

Phillip Easton