The difference an “E” makes in my world

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Very few people know about rare medical syndromes and would certainly not realise that misspelling their names would make such a difference.

As a medical student, I learnt about Meigs syndrome, understanding that is a “benign ovarian tumour associated with ascites and a pleural infusion”. However, until twelve years ago I had never heard of Meige’s syndrome, which is a very different condition.

Both of these conditions are very rare but what makes them unique is the similar spelling with the difference putting an “e” on the end makes!

Although sounding the same, Meige’s syndrome is actually characterised by the combination of blepharospasm and oromandibular dystonia, “a rare neurological movement disorder characterised by involuntary and often forceful contractions of the muscles around the eyes (blepharospam)” (NORD 2019) plus ormandibular spams which causes sustained eyelid closure and twitching or repetitive movements.

I have lived with Meige’s syndrome for over twelve years and have spent a lot of time researching, trying out new treatments but on this occasion it was the first time it has saved me money. I recently applied insurance and provided details of my medical ailments, obviously including Meige’s syndrome. I gave what I thought was a reasonable explanation of the condition and sent off the details. However, when the certificate of insurance arrived, I was apparently credited with a “benign ovarian tumour” for which my travel insurance was indeed triple what I expected it to be. The name “John” clearly did not make them stop and think!..

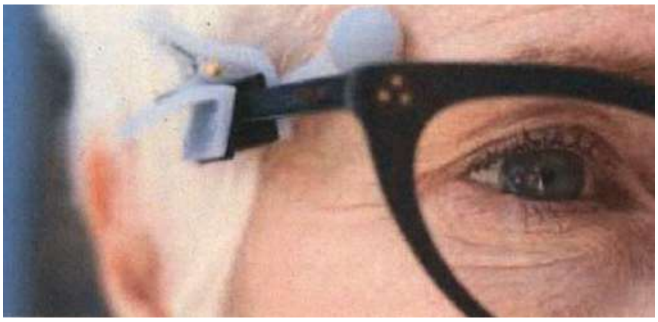
After a very lengthy telephone conversation with the person at the insurance company, they referred it back to their medical advisors who eventually realised their error and sent me new documents adjusted accordingly and the cost was reduced by a third. Clearly, it pays not to have an ovarian tumour……..Whoopee!...

As amusing as this is, the syndrome is very difficult to treat and almost impossible to cure. Back in 2008, I wrote an article, published here in the MBMJ under the title Benign Essentials blepharospasm or BEB. This described my experiences and some of my trails that have since failed to ease of my trails that have since failed to ease the symptoms.

I agreed to have an operation to strip the muscles around my eyes, which healed well but this unfortunately did not solve the problem. I have since been treated with various injections of botulinum toxin but once again no relief…………

Even as a retired GP, old habits die-hard. I am constantly searching for new solutions. During one such search, I found work pioneered at the Oxford Eye Hospital at the John Radcliffe hospital in Oxford. Alexina Fantao, the clinical research nurse Manager and her team developed a novel devise called a Pressop back in 2016 which has proven successful to other suffers of blepharospasm and is now available on the market.

They developed it from the evidence of observational research, that people with the condition find relief when they press a finger firmly on the temporal area on the affected side. Consequently, they created the PressOp. This simply slides onto the arm of any spectacles and the rotational arm provides the pressure point to the temple.



Thus helping to stop the over excitability of the nerve pathway to the moto cortex and controlling involuntary muscles of the eyelids.

Wish me luck, with my own personal trail of the PressOp.

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