THE HEADACHE NURSE

Becky Stuckey
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Mercure Exeter
There are currently 30 headache nurses nationally. Approximately 37 Neurologist led headache clinics in England.

Headache should be ideally managed in primary care, but continues to account for 33% of specialist referrals into Neurology.

Also continues to be the most common Neurological reason for attendance to A&E.
My Patch
An estimated population of 5.34 million, so why are there so few of us covering such a large area?
Issues with migraine treatments

- Only 50% of patients with headache are correctly diagnosed
- Only 29% of migraine sufferers say they are satisfied with their usual headache treatment
- On average, only 1 in 10 of those seeking medical help for migraine have received specific anti-migraine therapies

In 2014 a report for the All-Party Parliamentary Group on Primary Headache Disorders stated that...

- “There needs be a sufficient number of adequately trained and well supervised specialist headache nurses in posts across the country to meet the demand of the high cohort of headache patients”
PREVALENCE OF NEUROLOGICAL DISEASE IN USA

Disorders

Patient numbers

Migraine
Epilepsy
MS
Stroke
AD
PD

0
5,000,000
10,000,000
15,000,000
20,000,000
25,000,000
30,000,000
35,000,000
40,000,000

Headache and Neurology
What do we do?
A Neurologist will diagnose the type of headache in the first instance and commence treatment. After this, patients will see me in clinic for follow up or for treatment. I do telephone clinics. For patients who suffer with cluster headache not migraine, I organise home and ambulatory oxygen with demand valve. Emergency 48hr access for cluster headache treatment.

I run ‘around’ 3 Botox/GONi clinics per week. Some people prefer face to face follow up which is done in outpatient clinic. Complete PIP applications/Occupational health queries, from the work place. In times where it is so difficult to get an appointment with a GP or to see a Consultant, I am happy for people both patient and in the community to call email etc so that I can reassure them, explain side effects and so on.
Why Telephone Clinic?

- Patients with migraine often have a poor sickness record, therefore cuts down time out of work.
- There are some very rural parts to Devon and Cornwall therefore avoids unnecessary trips.
- A way of tweaking treatment, or see if recommended treatments have worked and following 2\(^{nd}\) lot of Botox.
- Where patients have a medication overuse headache, I regularly touch base to help them reduce their analgesia.
Most people are anxious about injections especially those we put into your head!

Most common is the fear of pain

People worry about permanent physical changes

Side effects v prophylaxis

Which injections for which phenotype of headache

How long will it take to have 31 injections!

Headache diaries (not essays!)

Aftercare

How long will it take to work?

Shunts

You tube!
80% of migraine sufferers are women, therefore statistically we are more likely to treat women either pregnant or wanting to become pregnant.

Some women only ever experience migraine during pregnancy, whereas some chronic sufferers have no headache during pregnancy.

Don’t just hope that you are one of the lucky ones!

Most of the preventative medications used in migraine can cause serious foetal abnormalities especially sodium valproate (Epilim).

Discuss coming off these with your GP prior to conception.

Triptan’s cannot be used during pregnancy.

We use Botox and nerve blocks for expectant mothers as it stays local to the site it is injected, although Botox should only be used if for a genuine medical reasons as there isn’t enough research to say it can’t cause harm, this is fully explained to patients prior to treatment.
Devices

Cefaly

TMS

GammaCore

Not currently available on the NHS     I lend devices out

I help build IFR’s     Currently awaiting approval for business case
Most common of all is validation. Once someone has a diagnosis and realises you understand their condition is real, there is a genuine sense of relief, this can be a very emotional after years of thinking “this is all in my head”

Nothing is ever going to work- By the time some one has reached my clinic they have usually tried multiple drugs which haven’t worked or had side effects which weren’t tolerated.

“I am told by people often that they suffer with migraine and why can’t I just get on with it like they do”

I’m scared of what Botox will do to me, how I will look- I’m too frightened to admit that

I feel like I am a burden to my family, I can’t make plans socially. I worry about money. I shut myself away sometimes because I’m short tempered, this is not the person I used to be.
Recognising your triggers

Treat your migraines like you treat your pet

Your Pet likes to eat regularly

Your pet needs regular sleep

Photo/Phonophobia and they don’t like storms

They don’t like stress

They don’t like you working shifts

Strong smells

Neither do your Migraines!
If not, your pet won’t be quite so nice

We can’t control all the stresses of life but...

When you are excessively yawning

If you are peeing more often than usual

When you just know it’s coming

When you are sick & stressed

Don’t be the one who says ‘I was just waiting to see if it would turn into an attack’ you already know it is, time is everything take your acute treatment straight away!
Is this you?

BUT I'M AFRAID TO TAKE THEM!!
Most people with chronic migraine will have experienced a lack of understanding from relatives/colleagues and health care professionals, many of you will have experienced the feeling’s of guilt for ‘faking it’ or ‘pulling a sickie’

Compounded by the Bradford score

Employers should make reasonable adjustments to minimise exacerbate poor health

Health and Safety at Work Act 1974: The Act sets out employers’ responsibilities for the health and safety of their employees. Employers should carry out risk assessments of the workplace and take reasonable steps to ensure that workplace factors do not cause or exacerbate poor health. This includes assessing and monitoring stress factors that may impact on individuals in the workplace.

The Equality Act 2010: The intention behind the Act is the promotion of equality and the prevention of unlawful discrimination in the workplace, including unlawful discrimination against those who are “disabled” within the meaning of the Act. More information about the act is available in this document.

The Migraine Trust have a fantastic advocacy service relating to work and education and templates that can be downloaded to assist yourself and your employer

Equally those who have lost their jobs through sickness and are unable to work struggle to access benefits due to a lack of understanding, people will rearrange their PiP appointment for when they have not got a migraine, get someone to film you when you are in the grips of an attack, cluster or migraine. Make sure you have an up to date list of medications and their side effects and a supporting letter from your headache nurse.
Dr Fayyaz Ahmed, a neurologist and trustee of The Migraine Trust, said: “There is no evidence that daith piercing work to help migraine.”

If you are going to daith please go somewhere reputable unfortunately I have seen too many of these and so far only two of my patients are convinced it has worked—?placebo effect? Who knows People unfortunately will pray on your desperation, most people end up having both ears done. Don’t keep handing over your money!
Dear Becky,

When I arrived at the Headache Clinic I was consumed with fear about my future as chronic migraines had taken over my life. However, with the care, support and encouragement I received at the Headache Clinic I managed to return to my doctoral studies and in four days (13th Sep.) I will be submitting my doctoral thesis at the University of Oxford. Words are not enough to express my heartfelt gratitude for all the kindness and care you have offered me, I could not have done it without all of you!
As I watched my husband who was a rugby player and knew pain, crying and screaming with pain and me not knowing what to try or do, all I could do was try to comfort him and try to find medical help. I had no idea where to turn or even where to start.

That help came in the form of an angel “Nurse Rebecca Stuckey”. After all the visits to the local A&E department, after hours doctors, our own GP and consultants she was the one who had the most impact on our lives. Becky was instantly approachable and made us feel that my husband was her only patient. Becky was extremely knowledgeable about the various options and techniques that could be used and made them all available to us. She was the stabiling factor in our life and the “go to person” when all else failed.

Without the skill and knowledge of Becky and her way of explaining everything in terms we could understand, I do not know where we would be. Cluster headaches are really scary, excruciating painful for the person suffering the episodes and even more scary for the person trying to support them through this horrible, horrible time in their life.

Becky may have been extremely tired at times even exhausted but was always encouraging, cheerful and was ALWAYS accessible by phone. Sometimes not immediately but she always got back to us as soon as possible. Becky even called a few days after treatments to see how things were going.

I therefore feel that this is a vital service and more trained nurses would be a real benefit and indeed a necessity to the NHS. Please feel free to contact me if you would like to discuss this experience with me.
To Becky

I just wanted to say a big thank you for everything you have done for me. It really has changed my life having you around and always on the end of the phone when things get tough.

You truly are one of a kind.

Love,

xx.
Moving forward

- There is no cure, we need more treatments
- Developments in non invasive treatments
- Increase in headache clinics and nurses
- Raising awareness and networking, use online forums like the migraine trust for advice and advocacy
- Promising 3rd stage trials in America
- Be kind to yourself
Thank you

Any Questions?