

West Berkshire Neurological Alliance

Representing all people in Berkshire West affected by a neurological condition

Report for Berkshire West Long Term Conditions Board

Findings from a focus group held at Padworth on 29th September 2014

Living with Migraine

Purpose

Migraine and headache are identified by the NHS, nationally, regionally and locally as a significant issue, with high care costs attaching. This has led to initiatives locally and regionally, seeking to improve future service delivery. Therefore the Alliance convened a focus group on 'Living with Migraine and Headache', to provide a local patient perspective and inform these developments.

Findings

Those at the focus group were all Migraine sufferers, such that there was minimal discussion about headache. Therefore this report and its recommendations are only about Migraine.

The impact on an individual of having Migraine can be immense, many sufferers being unable to do anything other than close down completely, putting their lives on stop, sometimes for several days at a time, affecting work, studies, leisure and family life in a drastic way. In addition to the unbearable and relentless, debilitating pain, sufferers report embarrassment at what others may regard as unpredictable behaviour, leaving Migraine sufferers having to explain they are 'not making it up'.

The triggers mentioned in the focus group for the onset of Migraine included; stress, hormones, hereditary factors, food and diet, light, noise, odours and eyesight issues. No doubt a larger gathering would have listed other triggers. Sufferers referred to desperate thinking and measures to identify and avoid likely triggers and all had experimented to find prevention, avoidance, treatment and recovery strategies.

The lack of information on the subject, across all aspects of need, was identified as a concern.

Those living with Migraine are rarely seen by a clinician while at their worst time of suffering, such that the focus group attendees felt that many clinicians have little understanding of the impact and debilitation arising.

Attendees were of the view that GPs generally have a poor understanding of how to respond to patients with Migraines, offering investigations of varying perceived merit, limited information, advice and support, with a perceived inconsistent approach overall. However, some helpful treatments are sometimes offered to some individuals by their GPs.

The group discussion included time spent exchanging a wide range of self-help ideas, a clear indication of the lack of certainty about self-management, despite the long passage of time since onset in most cases.

For some, it has been a chance meeting with a clinician that has been helpful, stumbling across ideas or actual treatment.

Sufferers reported a spectrum of things that had helped, ranging from taking a few aspirin, through to having a brain scan. Most had been offered, or perhaps tried on their own initiative, various drugs. Beta blockers, sumatriptan, zomig, neproxin, amytryptin, NSAIDs and morphine were mentioned; not a very comprehensive list compared to what is available and benefits only partially successful.

Migraine sufferers identified several effective or partly effective alternative therapies. These are not routinely suggested by clinicians. Massage, acupuncture, hot & cold therapy, peppermint tea and Botox injections were among ideas exchanged.

When given a range of options as to how any new Migraine-specific service might be structured and operate, sufferers appeared unanimous that any form of condition-specific service would be one they would welcome and use. GP clinics, nurse specialists, a Migraine service, etc were all seen as good ideas.

When prompted, there was only limited interest in the idea of setting up a local support group for those suffering from Migraine. Noting that the prevalence is high, the interest could be sufficient to form and maintain a viable local support group.

Recommendations

1. Migraine (and headache) sufferers need access to good quality information.
2. GP Migraine-awareness and care-needs training are needed.
3. A care pathway should be established for Migraine sufferers, to be followed consistently
4. An accessible, condition-specific Migraine service should be established.
5. Establishing any reasonable type of Migraine service model quickly would be more important than taking a long time to identify a 'best' model.
6. A more systematic approach to Migraine assessment and safe prescribing is needed.
7. Advice and support for those affected by Migraine should include self-help, prevention and alternative therapies.
8. Care management for Migraine should be ongoing.
9. The development of a specialist Migraine service is an opportunity to kick-start a local support group.

About the focus group attendees

The event was publicised widely through the voluntary sector network, but only four people living with Migraine/headache attended, a fifth, disabled sufferer sending a representative to speak for her. All were female and all were in the age range 30-65. Onset age was between 17 and 50. Three were in work, two whose general health prevents them from working.

Format of the Focus Group

A convener without any personal experience of Migraine led the discussion. There were two independent note-takers. Minimal prompts were used, allowing delegates to determine their own priorities for discussion.

Limitations of this Focus Group.

The experiences raised at a two-hour focus group with only five participants cannot cover comprehensively the experiences of living with any condition. The themes identified should not be taken to represent the full extent and nature of what it is like to live with these conditions. This report provides pointers for reflection and further work.

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Appendix. Consolidated record, based on two sets of notes.

K: regards her Migraine as stress-related and is *'only ever given tablets, which I do not want to take.'* She has *'never received any advice on other therapies, diet, lifestyle etc.'*

C: has regular headaches/Migraines. The Migraines knock her out completely and stop her from working and are *'often triggered by fatigue, stress, etc.'* Recently her GP has treated her with beta-blockers, which have made a huge difference, but there are side effects.

G: has MS as well as Migraine and has had a Migraine at least once a month since the age of 35, which *'knocks me out for 2-3 days'*. She has tried beta-blockers but they didn't work for her. She takes tablets morning and evening and now on Sumatriptan and the symptoms pass within half an hour and then she feels fine. Migraines really disrupt her life – *'I make plans and then have to cancel them at the last minute.'* Her trigger is stress and she is *'now having head, back and neck massage, which helps a bit'*. It has taken her 'years' to be prescribed Sumatriptan but has now heard that it is available over the counter!

E: has suffered from Migraines since she was 17, usually triggered by stress, fatigue and anxiety. Her sight goes first but now she is on Zomig and has also tried amitriptyline. If she takes Zomig when a Migraine starts, within 10 minutes her sight returns, but there are nasty side effects. Recently, she saw a locum GP when suffering a Migraine and he referred her to Eye Casualty at the RBH. A special machine there identified two old tears in her retina and one new one, all of which subsequently have been repaired by laser treatment. This has reduced the number of Migraines that she suffers but she would like her eyes checked regularly. She wishes her GP had one of the specialised machines that can identify problems with the eyes. She would *'like a service that could give me a really thorough check for all aspects of my Migraines'*.

C: thinks there should be a plan or protocol listing all the treatments that can be tried, so they can be investigated and eliminated systematically. *'People vary in their response to different medication and other treatments.'*

K: her first Migraine came about two years ago then she had eight within twelve days, so was sent for a brain scan, which revealed no useful information. She was prescribed Naproxen but told that it might trigger a Migraine – she was advised to take strong aspirin if it did. She observed that *'different treatments work for different people and I would like GPs to work through a hierarchy of drugs to see what is best for which patient'*. When she starts a Migraine she gets a feeling of fuzziness across

the bridge of her nose and a sickness at the back of her throat and she becomes very sensitive to sounds.

K: *'My son now suffers from Migraines and his triggers are strong emotions.'*

E: problems with light sensitivity herald a Migraine and she knows she needs to *'avoid orange juice, bananas and chocolate because they can trigger an attack'*. Others mentioned bananas, chocolate, cheese and orange juice as foods to beware.

Prompt: *'What is the difference between headache and Migraine?'*

E: a headache is something you can live with but a Migraine affects the whole body and you feel very sick.

All agreed that the difference between a headache and Migraine is in the degree of debilitation. Different triggers often combine in starting a Migraine. *'Doctors don't see you getting a Migraine which is often the reason why they don't react particularly. Either you have to go to the surgery in the middle of a Migraine (not easy) or you have to be very pushy (assertive) about what you need.'*

J: represented on behalf of a person with MND, severe gastric problems and Migraine. *'When she gets a Migraine it feels as if her head is going to explode. If she takes a Zomig tablet she starts to feel better after a bit. Recently she went to see a neurologist who told her that those tablets are the problem and that she needs to come off them completely. She couldn't understand the logic of that because the tablet is the only thing that helps her when she has a Migraine. The Consultant told her to go and see her GP who would give her 'something' for 5 days, which should help, and that also, she should keep a 'headache diary' – the Consultant wouldn't see her again. She hasn't been to see her GP yet because he only sees patients on Mondays and Fridays and she hasn't been able to make an appointment. Keeping a headache diary isn't particularly easy for her as she has so many conditions to cope with.'*

G: her GP *'considered my hormone situation'* as part of his treatment plans, and sent her to a Gynaecological clinic, but the treatment given, first a coil, later some surgery, *'didn't really help'*.

C: *'My husband had a Migraine, went to A&E, and was checked for a brain tumour.'*

K: had a "sit and wait" hospital appointment. She had to be put in a side ward, as she *'could not stand the noise being made by a child'*. She is *'left exhausted for days and sleeps a lot'*.

The question was posed by a sufferer *'How long do you take medication for?'* The responses included *'Zomig should not be taken more than 10 a month'*. *'Aspirin works but you have to drink a great deal of water.'*

C: before coming to the focus group, she had looked up the Migraine Trust website, something she had never previously thought to do, and then read out that:

- *More people in the UK suffer from Migraines than epilepsy, diabetes and asthma sufferers put together.*
- *There are 190,000 Migraine attacks in UK every day*

- *Depression is 3 times more common amongst Migraine sufferers than healthy individuals*
- *Migraine is the least publicly funded of all neurological illnesses relative to its economic impact*
- *8 million people in the UK suffer from Migraine.*
- *Migraines run your life. A recent programme on TV concerning foods and Migraine found that trigger foods can be bananas, pineapple, oranges, chocolate, coffee and cheese – combined with stress and fatigue. There are also genetic factors.*
- *So Migraine is one condition but has different triggers, and treatments seem to be painkillers, triptans and preventative precautions.*

E: *'some investigation has made some difference'.*

C: saw a locum who did more for her, including she had a scan.

K: *'my face swells and I have to take my glasses off'.*

J: She feels that *'a whole range of investigations should be done'.*

Prompt: *'Are clinicians working systematically?'*

The group's emphatic response was *'NO' – 'solutions to the problem were clutched from the air'.*

In another person's case, *'4 different GPs suggested 4 different tablets.'*

'Paracetamol is useless, aspirin is much better (if you are not allergic to it) but you need to drink lots of water with it.'

G: managed to keep a diary of her attacks for 10 months, then she saw a Neurologist who decided she needed morphine and so was put on morphine patches. *'The side effects were awful, they stopped everything'.*

'GPs are reluctant to accept what an impact Migraine can have on your life. You need to know your limits.'

C: said that over-exertion can trigger her Migraine. Interruption of her daily work is significant. Massage over her shoulders and neck helps.

E: *'Perfume and incense can trigger Migraine.'*

C: *'Botox has not been suggested by my GP. Might this help?' I feels sick but am rarely sick.'*

G: has *'tried acupuncture but it did not help me.'*

K: has been offered acupuncture for tingling in her arm.

G: *'The Times' had an article about the benefits of taking peppermint tea.*

Prompt: *'Would a GP with a special interest in Migraine or a specialist nurse be useful?'*

Anon: *'Does the CCG have an interest in providing a better service?'*

J: *'A large amount of money must be spent on treating sufferers in the acute services. There should be more attention given to prevention.'*

G: *'There is not enough information at the surgery.'* *'There are no leaflets.'*

C: mentioned cold strips and Tens machines. She would like a system (protocol) which you could progress through even if it took time.

'Massage can help. Temperature and pressure manipulation on the head can also help as a preventative measure.'

'Botox is mentioned on the Migraine Trust website but has never been suggested medically. Peppermint tea can be good.'

'Not only does stress and fatigue cause Migraine, but sometimes, relaxing after a very busy week or at the start of a holiday, Migraines can occur.'

K: *'At the moment it feels as if we are fumbling around in the dark. You need the GP to agree that you have a Migraine.'*

E: *'We need a Migraine clinic that can understand the numbers affected and can work to understand the condition better and help treat the condition preventatively at community level, because Migraine is costing the NHS at hospital level.'*

C: *'You need to be able to see the same health care professional so that they can get to know you and how you are affected by Migraine.'*

K: *'A clinic specialising in Migraine would be really helpful – it could look at talking therapies and alternative therapies. For example a TENS machine helps me with the pain I suffer at the back of my neck and shoulders.'*

E: *'A full assessment at a specialist clinic is what is needed. Those who are light sensitive should have regular eye checks at a specialised clinic My eye tears were not found at the optician checks.'*

C: *'I want my GP to go through a full assessment and have a systematic plan which would eventually lead to me seeing a Specialist.'*

K: thinks that the underlying causes should be investigated. *"GPs never invite you back"*.