

# All-Party Parliamentary Group on Primary Headache Disorders

## Oral Evidence Session

11 December 2013

### **Attendees:**

*Jim Fitzpatrick, MP for Poplar and Limehouse (JF) (Chair)*

*Virendra Sharma, MP for Ealing Southall (VS)*

*Vicky Probyn, Primary Headache Disorder patient (VP)*

*Mike Pollock, Chair, Organisation for Understanding Cluster Headaches (OUCH) (MP)*

*Dr Manuela Fontebasso, GP with Special Interest in Headache (GPwSI) (MF)*

*Professor Leone Ridsdale, Professor of Neurology and General Practice, King's College London (LR)*

*Dr Brendan Davies, Consultant Neurologist and Chair, Association of British Neurologists, Headache and Pain Section (BD)*

*Dr Giles Elrington, Consultant Neurologist and Medical Director, National Migraine Centre (GE)*

*Dr Zameel Cader, Clinical Director, Strategic Clinical Network for the Thames Pathway (ZC)*

*Wendy Thomas, The Migraine Trust (WT)*

## **Introduction**

JF welcomed those present and explained that a recording was being taken of the session. Summary notes of the evidence given would be produced, and would be used in the creation of a report to be released by the all-party group.

## **Presentations**

### **I. Impact of Migraine on Sufferers – Vicky Probyn**

#### **1. Overview**

VP introduced herself and showed some slides illustrating colour and pattern 'auras', as commonly experienced by migraine sufferers. She noted some characteristics of migraine from a personal perspective: an episode could last all night, with symptoms including a 'swirling' in front of the eyes and a feeling of being 'stabbed'. VP would often wake up in the morning with migraine

symptoms. On the days before and after an attack, she would often feel sleepy and ‘fuzzy-headed’. In total, she would be affected by migraines – either pain or lack of alertness – for about 20 days each month. VP said that her family had to make compromises as a result of her condition; for example, family holidays and special occasions had been marred by her headaches. Migraine made her feel that she was always ‘not at her best’; she was a keen cyclist, and migraine affected her enjoyment when taking part in cycle races.

There were also financial and time costs. VP had been a patient at the National Migraine Centre, which had been ‘excellent’, but appointments had cost £100 and involved two hours’ train travel and taking a day’s holiday from work. VP had also used a private physiotherapist to help with her neck pain.

## **2. Impact of poor support**

VP said that she had received ‘inconsistent’ support from the NHS. She had been told by a GP that there was ‘no such thing’ as medication overuse headache, despite her having a permanent headache which was unresponsive to painkillers. She had managed to remedy this after taking different medical advice, but only after two years’ trouble. She had also spent significant amounts of her own time doing research; her GP had expected her to do her own research and ask for a referral, rather than offering support. There had also been trouble transferring her medical notes when she moved to a new GP after moving house; after four months, the new practice had still not received her notes. Eventually she had provided the practice with a summary of her treatment history, but this had still not been incorporated into her records.

## **3. Recommendations**

VP stated that she felt all GPs needed to be consistent in their understanding of migraine and its triggers. They should also offer self-help tips more effectively: for example, on filling in a migraine diary, avoiding having low blood sugar, taking regular exercise, and avoiding caffeine and painkillers. They could provide web addresses which patients could visit for further information. This would involve minimal cost, and might also reduce referrals to neurologists, for which there was currently a waiting list of several months. Finally, VP suggested that there needed to be less mystery surrounding new developments and devices.

# **II. Cluster Headache – Mike Pollock**

## **1. Overview**

MP stated that cluster headache was commonly regarded as the worst pain experienced by humans. It was estimated that more than 200,000 people in the UK suffered from cluster headaches, but despite this there was little awareness of the condition. Of the estimated 200,000 sufferers, only about 20% had been properly diagnosed, and of these only around 50% were receiving the appropriate treatment as recommended by the British National Formulary (BNF).

## **2. Treatment options**

MP outlined three treatments currently available on the NHS.

- Nasal sumatriptan – this was relatively expensive, and sufferers were limited to two treatments per day by the NHS, which was unhelpful for frequent sufferers. It also took around 30 minutes to work, which was not fast enough in the case of cluster headaches. One of the side-effects of cluster headache was blocked nasal passages, which made the treatment much less effective.
- Subcutaneous sumatriptan – fast and effective, but very expensive, and only two treatments daily were permitted on the NHS.
- High-flow oxygen – extremely safe; however, relief would take 20-40 minutes, and there was high potential for rebound attacks.

MP then outlined two treatments which were effective, but which were not available from the NHS. There had been discussion of offering both treatments on the NHS, but it was unclear when this would come to fruition.

- Vagus Nerve Stimulation (VNS) – a small device which stimulates the vagus nerves in the neck. This was relatively low-cost and effective in less than 10 minutes; it was safe and repeatable. There was also evidence that VNS offered a prophylactic effect.
- Ultra-high-flow oxygen – this was very effective and extremely safe, with no side effects.

### **3. Conclusion**

Evidence suggested that less than 10% of sufferers were receiving the correct acute medication, and patients were unnecessarily referred to consultants in up to 90% of cases, extending the wait for treatment to up to a year or more. Research by OUCH suggested that there was currently significant misdiagnosis of cluster headache and inappropriate subsequent management. MP outlined seven action points: specific headache treatment for medical professionals at all levels; correct and speedy diagnosis; effective management; more specialist tertiary headache centres; more GPwSIs, research funding for new treatments; and increased use of more cost-effective treatments.

## **III. Headache Treatment in Primary Care – Dr Manuela Fontebasso**

### **1. Consultation and assessment**

MF stated that she planned to explain her own ‘headache journey’; how she came to become a GP with Special Interest in Headache (GPwSI) and how she had developed a service to respond to the condition. She noted that a 10-minute standard GP consultation was not long enough to properly explore a patient’s headache history. Only around 40% of patients actually spoke to their GP about their headache symptoms; the rest relied on over-the-counter medication. MF observed that she had produced a template to help GPs in her practice take a headache history, although this had been little-used by her colleagues.

Having spent time with a patient building rapport, a detailed assessment must take place. MF said she always gave patients a headache diary, as pattern recognition was important in making a diagnosis. She used a four-category ‘traffic light’ system to help patients record their symptoms daily. MF would then see the patient on a weekly basis for a few weeks. When the headaches were under control, she would see them less frequently; however, she stressed to patients that they should

keep coming to appointments even if their symptoms improved, as they would need self-help advice for when they returned.

## **2. Empowerment of patients**

MF said that as a headache specialist she was able to spend 45 minutes with her patients before making a diagnosis; however, this was often still not enough. Patients needed someone to listen and take ownership of their problem, offer support, and help them understand the barriers to change they faced. The aim was to help patients find ways of improving their own quality of life. She noted that she would only give brain scans to around 30% of patients; of these, only around 3% would have an abnormal result, and most of these had nothing to do with their headache symptoms.

MF continued that it was important to reinforce messages given to patients several times; in order to do this, she had obtained funding for a specialist nurse. The nurse acted as a point of contact in a crisis, offering advice and support to both patients and doctors. The nurse would spend 30 minutes with the patient checking their understanding and making sure they were fully engaged with the treatment process, as well as giving individual written instructions and agreeing a review process. This could be done remotely, as many patients lived a long distance away. The practice also had a physiotherapist to address neck and shoulder pain resulting from headache, and a psychologist to help empower headache patients to make changes in their behaviour.

MF noted that each of the major types of headache – migraine, cluster and medication overuse – required different responses. In addition, every patient needed individually-tailored support, and enough time to discuss the best medication for them. Some patients would wish for fast-acting treatments, others would want treatment regimens which were easy to stick to, and these preferences needed to be taken into account. If a treatment was not working, alternatives would need to be sought.

## **3. Learning points**

MF outlined the main lessons she had learned as a headache practitioner. Patients needed enough time to fully express their concerns, and it was important to listen to the patient when making a diagnosis. There also must be a holistic approach to care, addressing the patient's home, family, work and social life. The patient must be involved in the decision-making process, and treatment must be adjusted until it was optimal; the aim was to minimise the frequency of headaches, not just to medicate the symptoms. Patients needed to feel confident in their medical professional, and be empowered to take control of their own case.

# **IV. Cost-effective Headache Services – Prof Leone Ridsdale**

## **1. Key statistics**

LR stated that while she was now a neurologist, she had also worked both as a GP and an economist. She outlined some key statistics: 4% of the population consulted their GP each year about headache symptoms. 97% of these were treated solely in primary care; 2% were referred to a neurologist, and 1% to other specialists. Less than one in 1000 patients would have a brain tumour; a typical GP would see one new patient a week with headache, but only see one brain tumour in their career.

Headache was the most common neurological reason for Accident & Emergency attendance; 20% of patients at headache clinics had attended A&E with their symptoms in the past six months, and of these, 10% had been admitted. Headache was viewed as being in the top 10 most disabling medical conditions; however, 70% of headache patients attending their GP received no specific diagnosis. GPwSIs diagnosed migraine in headache patients three times more often than non-specialist GPs. Finally, LR noted that between 28% and 33% of patients who had seen a general neurologist had been dissatisfied with their treatment.

It was instructive to analyse the difference between patients whom GPs had chosen to treat in primary care, and those whom they had referred to specialists. The major reasons patients were referred was because they reported other symptoms, or because they were suffering severe worry or anxiety; cost was also a factor, as patients attending their GP more frequently tended to be more likely to be referred.

## **2. Costs to the NHS**

The direct cost to the NHS of headache treatment was estimated at £1 billion a year; however, the cost of headache to the economy in terms of lost productivity was estimated at £5 billion. Services provided by GPwSIs were, in relative terms, slightly cheaper than those provided by non-specialist GPs. Capacity in neurological services was a concern; headache now made up 33% of neurological referrals, and long waiting times were an issue. LR stated that GPs who had not been trained in neurological examination tended to be 'phobic' of doing such examinations; this training needed to be offered to more GPs. There also needed to be more trained GPwSIs.

LR observed that the direct cost of treating a headache patient was around £500 per year, and the societal cost was around £2,000. Training GPs in migraine diagnosis and offering more scans would involve cost; however, patients were less likely to ask for a second referral if they were given a scan. LR noted that patients who had been treated by GPwSIs reported greater satisfaction with their treatment than those treated by non-specialists. LR believed this was because of the holistic approach used by GPwSIs.

In terms of making overall cost savings, LR noted that it was necessary to consider how NHS services were being misused. For example, A&E attendances needed to be reduced, and headache was a common reason for A&E attendance. Giving GPs open access to scans might reassure patients, reducing both A&E attendance and referrals, and this would free neurology services to treat other conditions.

## **3. Action points and questions**

LR noted the current barriers to effective headache treatment: lack of access to training for GPs; lack of capacity in neuroimaging; lack of funding for training GPwSIs. She outlined the benefits of investing in headache services: better diagnosis for the 97% of patients treated in primary care; better drug management, which would reduce the frequency and severity of headaches and reduce chronic migraine and dependence of rescue medication. There would also be less use of A&E, and less pressure on neurology services. Finally, productivity in the workforce would increase.

BD asked whether the publication of National Institute for Health and Clinical Excellence (NICE) guidelines had made any difference to the treatment of cluster headache patients. MP replied that cluster headache patients often had difficulty accessing treatment, and the reasons for this given by GPs were often unacceptable. MF observed that many GPs had not taken the time to look at and

implement the NICE advice. Some GPs were also unwilling to explore a range of treatment options; treatment was offered within a very narrow range, and often only the cheapest options would be considered. LR replied that she felt most GPs welcomed advice from GPwSIs, and tried to implement their suggestions. She suggested that it would be helpful to include migraine in the Quality Outcomes Framework (QOF), as this would motivate GPs to improve their treatment.

## **V. Secondary Care Solutions – Dr Brendan Davies**

### **1. Overview**

BD outlined the different ways patients reached the secondary care environment: via A&E, GP referral, and tertiary referral. The latter type tended to include patients whose condition was proving difficult to diagnose; this was a small number, but they tended to have the greatest level of impairment and were often ‘forgotten’. He noted that 23% of people relied principally on family and friends for advice about headache; therefore, education must be offered on a societal level.

### **2. Solutions: signposting and regional networks**

BD noted that patients were often referred to inappropriate service providers. There were issues with pain clinics, as these did not currently deal with headache; headache care needed to be either integrated with pain management, or clearly separated. GPwSI services need to be developed and networked in order to improve signposting, as currently services were often overwhelmed.

BD showed a map of neurologist-led headache clinics, of which there were 37 in total, and suggested that creating regional headache networks should be considered. These would include primary, secondary and tertiary care services, allowing for holistic solutions and avoiding the problem of patient silos. It would also allow for the sharing of best practice, and clearer patient pathways.

### **3. Learning points**

BD outlined the principal reasons why patients sought secondary care: clarification of their diagnosis; explanation of their treatment; and advice on what to do next. Currently, the tariff for all secondary care headache consultations was the same, regardless of the complexity of the case; this was a barrier to effective care. Some therapies widely viewed as effective were not currently licensed, which made accessing funding very challenging. BD stressed the need for prompt, appropriate access to care, and states that this would involve setting targets. He observed that the ‘jury was out’ on whether open access to neuroimaging was cost effective, and pointed to the example of one Primary Care Trust where open access to scans had not resulted in a decrease in referrals. The issue of medication overuse headache also needed to be addressed, for instance by placing warnings on painkiller packaging.

BD outlined some learning points based on the model for services used in North Staffordshire. GPwSIs needed access to a specialist neurology centre for support. Specialist headache nurses were also imperative in quality care, and could offer services such as telephone consultations and follow-ups; they were also cheaper than doctors, and reduced GP workload. The services of clinical psychologists were also important. BD acknowledged that there were pressures both in terms of resource allocation, and the time required to offer the necessary training.

BD noted the barriers to effective services. There was confusion over whether services were the responsibility of Clinical Commissioning Groups (CCGs) or Specialised Service Commissioning. There was also a need for headache diagnosis guidelines to be made more available. NICE guidelines were useful, but in BD's view they were only a starting point. Finally, research and data collection needed to be integrated in any commissioning plan; without this, it would be impossible to improve services. There was currently no mechanism to capture data on headache diagnosis in secondary care, and this needed to be addressed so that services could be better planned.

## **VI. Brain Scans – Dr Giles Elrington**

### **1. Overview**

GE opened by explaining that in the case of primary headache, a patient's brain scan was generally normal. Whether to routinely offer brain scans was a matter for policy-making, although patients did often push for a scan; GE noted that ruling out brain tumour often received excessive focus. He stated that almost everyone suffered from headache at some point in their lives; perhaps 5% would suffer from daily headaches. The chance of a headache patient having a serious neurological problem was only around one in 1,000. Finding a brain tumour in primary care, therefore, was a case of finding 'needles in a haystack'.

### **2. Usefulness of neuroimaging**

GE stated that he did not feel that routinely offering neuroimaging was useful. The proportion of patients being given MRI scans had increased steadily since 1994. Currently, around 50% of patients GE treated had already received an MRI or CT scan. However, even in people with no symptoms, there would be a one in 40 incidence of abnormal results; it was not, therefore, sensible to offer scans routinely to headache patients.

GE showed a number of abnormal scans ordered during primary care, and noted that each GP would be likely to have a number of asymptomatic patients with neurological problems on their patient list. There had been occasions where patients had received a scan after presenting apparent migraine symptoms, and had been diagnosed with more serious conditions as a result; however, this was rare, and in order to catch them all every patient – even those with no symptoms – would have to be scanned routinely. Therefore, the provision of scans needed to be a matter for NHS commissioners, as the circumstances in which a scan should be offered needed to be clearly outlined.

## **VII. Strategic Clinical Networks – Dr Zameel Cader**

### **1. Overview**

ZC introduced himself as a consultant neurologist; he had also recently set up the Oxford Headache Centre. He stated that Strategic Clinical Networks (SCNs) had been newly rolled out across England, and these offered a real opportunity to bring about major changes in the way headache services were provided. In the NHS, CCGs now held major responsibilities for commissioning services. However, they were not currently responsible for headache or neuroimaging services. This was set to change, although the timeline was currently uncertain.

NHS England had identified five domains in which it would focus on improving outcomes; SCNs would play a role in ensuring these outcomes were achieved. SCNs had been set up in areas where it was felt that changes were needed, and offered an opportunity for improving headache treatment and care. ZC was responsible for the SCN in the Thames Pathway area. The aim was to improve outcomes not via incremental change, but via transformational change. It was hoped that local people would come together to form a consensus on what was needed, and that their input would influence the commissioning process.

## **2. Patient engagement**

ZC advised that patients should engage with their SCN in order to influence change in their locality; SCNs were committed to listening to patients. The Neurological Alliance was also a key voice in neurology, and patients should engage with it in order for their ideas to be channelled back to the NHS. There was currently funding for pilot projects to explore the effectiveness of different schemes, for example the training of GPwSIs and specialist nurses; the best way to access this was via the local SCN.

The national priorities for neurological services were currently the creation of structured neurological networks; improving access to neurological opinions for patients; and improving outcomes relating to A&E. ZC noted that there was little emphasis on headache, which was disappointing. The needs of headache patients needed to be better represented; the voice of patients and third sector organisations was not currently coming through, and was currently ‘crowded out’ by the needs of Parkinson’s disease, Multiple Sclerosis and motor neurone condition patients. CCGs had not set out any priorities for headache care, and this needed to change.

## **3. Action points**

ZC stated that headache care was an important issue in the Thames Valley region. It was a principal reason for outpatient referrals and outpatient attendance, and was a major cause of disability. There was little emphasis on headache care by CCGs, which tended to be more focused on reducing direct medical costs. There was no way of measuring outpatient outcomes for headache patients, and coding for outpatients needed to be implemented as a top priority. However, there was focus within CCGs on reducing emergency admissions and pressure on A&E departments; ZC pointed out that managing conditions such as headache would free up emergency capacity. The Thames Pathway SCN was working to bring about change in acute neurology services, as well as training GPwSIs. ZC stated that NICE guidelines were becoming more and more important in service provision; therefore, NICE guidelines around headache needed to be developed to include additional services such as GPwSIs and specialist nurses.

In summary, ZC noted that headache was a disabling condition, but that services varied widely both nationally and locally. Headache needed to be treated as a long-term neurological condition. SCNs needed to be utilised in order to bring about change; Public Health directors also needed to be involved in this process. A consensus needed to be reached, in consultation with patients, and CCGs needed to be made to realise the benefits of investing in headache services.

## **Questions and Answers**

WT observed that the Neurological Alliance was very conscious of the challenges posed by migraine, and the Migraine Trust had been working with them closely. Patient groups were already putting pressure on the NHS for improved services, but this needed to be ‘ramped up’. A participant noted that there was currently little emphasis on headache in undergraduate medical schools, and this needed to be addressed. LR stated that in her experience, some training was offered in headache treatment alongside stroke and related conditions, but that it could be increased. On the issue of specialist nurses, LR noted that business plans to introduce specialist nurses could be put in place, involving bodies such as this sector groups and pharmaceutical companies; this had been successfully implemented in a past project to supply specialist epilepsy nurses.

## **Conclusion**

JF explained that the All-Party Group on Primary Headache Disorders was one of hundreds of all-party groups. A minimum of 20 parliamentarians needed to endorse a group for it to be allowed to access House facilities; all-party groups were also granted opportunities to network and circulate messages to parliamentarians. The meeting that day had been the first of two evidence collection sessions. These would be used in the production of a report which would be used to influence key decision-makers both inside and outside Parliament, with the aim of putting pressure on CCGs and Public Health England to improve services. JF thanked the speakers and all who attended.

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