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## Headache and migraine disease insight report

Improving the quality of care:

*A 10-point plan for better commissioning*

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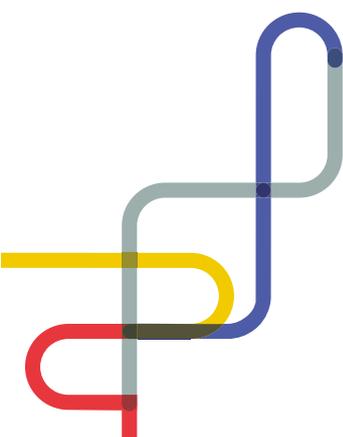
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Improving the quality of care: A 10-point plan for better commissioning

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## Summary

Headache disorders place a huge demand on NHS resources and despite publication of the National Institute for Health and Care Excellence (NICE) Clinical Guideline and Quality Standards on Headache in 2012 and 2013 there are still significant rates of misdiagnosis and mismanagement of people living with headache disorders.

A fundamental lack of understanding about the true cost of headache on a personal, societal and NHS level means that health economies fail to prioritise this manageable, and sometimes preventable, problem. Inequality of access to specialist headache clinics, and barriers to accessing appropriate recommended treatments mean that people living with headache disorders are denied supportive management.

The need for greater awareness of the problem through headache specific data collection and analysis, coupled with improved education of health professionals could support commissioners to improve access to services, thereby improving the lives of thousands of people who live with this disabling condition.

### Recommendations – a 10-point plan for improvement

1. Know your population to reduce unplanned admissions
2. Get smart with data
3. Promote the self-care agenda
4. Educate your healthcare teams in headache management
5. Ensure availability of services to meet the need in both primary and secondary care
6. Develop a local headache pathway so that everyone is aware of management plans
7. Ensure headache disorders continue to be part of local Sustainability and Transformation Partnership plans
8. Promote better medicines management
9. Link into local businesses to ensure a work friendly attitude is adopted
10. Work with the voluntary sector to improve patient outcomes

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## Introduction

This report focuses on headache and migraine hospital admissions to highlight opportunities that exist for service transformation around headache and migraine. Migraine is estimated to cost the NHS in the UK £150 million per year, mostly from the costs of prescription drugs and GP visits. Further, the NHS expenditure on headache disorders is estimated at £250 million per year (APPG 2010). Currently secondary care services consume a significant proportion of expenditure and there is a huge variation in the provision and availability of services that enhance patient care. It is estimated that migraine and headache account for approximately 30% of neurology outpatient appointments.

**The World Health Organization states that:**

***“Migraine, tension-type headache and medication-overuse headaches are of public health importance since they are responsible for high population levels of disability and ill-health”.***  
(WHO, 2016)

It is estimated that around 1 in 7 people in the UK experience migraine, with the condition being more prevalent in women, who are three times more likely than men to have the problem. There are over 190,000 migraine attacks daily in the UK. Migraine can affect people at any age and can last between 4 and 72 hours. It is estimated that 2% of the world's population suffer from chronic migraine, a greater prevalence than that of diabetes (The Migraine Trust, 2017).

Migraine has been identified as the second biggest cause of short-term absence from work and has been estimated to cost the UK economy £2.5 billion annually, resulting from an average of 25 million days taken off work per year (Migraine Action, 2017). In a recent survey, results suggest around 70% of respondents were unaware that migraine can also be classed as a disability, and 60% of respondents did not feel their employers understood the condition (The Migraine Trust, 2017). This appears to indicate a wider lack of understanding of migraine.

Having a migraine can often be a debilitating and distressing experience for a person who lives with the condition. Migraine is complex in nature and comes in a variety of forms and range of symptoms, even with the absence of a headache. Common symptoms include headache, nausea and vomiting as well as a sensitivity to sound or light (The Migraine Trust, 2017). It is estimated that between 10% and 30% of those who experience migraine have migraine with aura (National Migraine Centre, 2017). Aura are temporary neurological symptoms often occurring before the onset of a migraine, and include visual distortions, fatigue and tingling sensations (The Migraine Trust, 2017).

Whilst the exact cause for the onset of migraine is unknown there are a number of associated dietary, hormonal, environmental and even emotional problems that may trigger the condition and although treatment is available to alleviate symptoms the condition itself cannot be cured. Those living with the condition may require medication or prophylactic treatments depending on the type and severity of the migraine (NICE, 2012; Brain and Spine Foundation, 2017).

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A migraine attack is documented to occur across four or five stages. The first is a premonitory stage which describes small physical changes that occur at the onset of a migraine, for example, fatigue. A number of patients may experience aura after the premonitory stage. The main attack then follows, at which point the individual will usually experience painful headaches often with nausea. After the main attack comes the resolution stage where the pain or other symptoms begin to subside. The final stage is referred to as the postdrome stage, which can deliver symptoms like those felt in the premonitory stage. It can take hours or days for a “hangover” type of feeling to dissipate (The Migraine Trust, 2017).

Headache is not usually accompanied by the other symptoms associated with migraine. Primary headache disorders include tension-type headache, cluster headache, medication-overuse headache, *hemicrania continua* and *hypnic headache*. These conditions can vary greatly in their duration and severity. Tension-type headache for example produces a mild to moderate pain which can last from 30 minutes to several days and can become chronic. Cluster headaches are usually experienced on one side of the head and last between 30 and 60 minutes, sometimes every other day or multiple times a day (The Migraine Trust, 2017).



**Around 1 in 7 people in the UK suffer from migraine**



**A migraine can last between 4 - 72 hours**



**25 million days per year taken off work due to migraine**



**Estimated to cost the UK economy £2.5 billion annually**



**Women are three times more likely than men to have migraines**

Understandably the intense pain and distress felt in a migraine attack may prompt a person to seek emergency help, hence the high proportion of sufferers who are using emergency pathways as a source of support. It has also been observed that those who suffer with a migraine or headache disorder are more likely to suffer from depression than those who do not (WHO, 2013).

There are additional reasons why individuals seek emergency care, for example the limited availability of same-day appointments at GP surgeries, long waiting times to see their GP, or lack of information on prevention and management. It appears that there is a lack of training around migraine. This is reflected by the fact that only 25% of medical schools around the UK include teaching about headache disorders, and that there are only 12 specialist headache nurses nationwide (The Migraine Trust, 2017). People with headache disorders often experience the “revolving door” problem: they become frustrated and desperate after multiple visits to primary care and eventually present themselves at A&E. It is estimated that around 60% of sufferers do not seek help from their GP (The Migraine Trust, 2017), and may successfully treat themselves at home using over-the-counter medication.

To ensure that services are utilised more effectively there is a need for the public to be aware of when it is appropriate to seek emergency care and how to effectively manage symptoms.

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## 1. Methodology

Insight into primary care headache and migraine services is problematic due to a nationwide lack of data collection in this area. Hence, only a 'snapshot' is available by looking at patients admitted into secondary care, and no conclusions regarding the use of primary and social care services can be drawn. Secondary care data has greater availability due to Payment by Results activity which incentivises data provision, but it should be noted that the quality of data may vary between trusts for a variety of reasons not discussed in this report.

Hospital Episode Statistics (HES) data, published by NHS Digital, is used under licence to analyse secondary care activity for migraine and headache. All activity within secondary care is recorded by ICD-10 code (International Classification of Diseases Version 10). ICD-10 codes G43 (Migraine), G44 (Other headache symptoms), and R51 (Headache) have been used to define migraine and headache in this analysis. Brain Haemorrhage is also analysed as a comparison: ICD-10 codes I60 (Subarachnoid haemorrhage), I61 (Intracerebral haemorrhage) and I62 (Other non-traumatic intracranial haemorrhage). The HES data analysed is from the fiscal years 2015/16 and 2016/17.

Cost figures mentioned in this report are indicative figures and account for hospital coded activity; we cannot derive the cost of primary and social care. Healthcare Resource Groups (HRGs) are applied to groups of diagnoses and treatments which use similar amounts of NHS Resource, hence patients' diagnoses and procedures are allocated HRG codes, which are used to determine the cost of care (Department of Health, 2012).



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## 2. Analysis

In this section, 2015/16 and 2016/17 hospital admissions data for migraine and headache are split by age, gender and the type of admission (elective and non-elective), and includes the indicative costs of admission. For data from the Diagnostic Imaging Dataset, published by NHS Digital, only data from 2015/16 is available.

### 2.1 Migraine and Headache Admissions

Between 2015/16 and 2016/17 there was a 5.1% increase in total admissions where migraine and headache has been named as the main or secondary reason for admission. As a primary (main) diagnosis there were a total of 98,964 admissions for migraine or headache in 2015/16 and 97,364 in 2016/17 (Figure 1), 82% of patient admissions were as emergencies in 2015/16 and 81% in 2016/17. Hence, elective admissions with migraine or headache as a primary diagnosis only accounted for 18% of patient admissions in 2015/16 and 19% in 2016/17.

As shown in Figure 1, for comparison, there are fewer admissions with the less common diagnosis of brain haemorrhage and these are primarily emergency admissions (Headway, 2017). Figure 1 demonstrates that many migraine and headache patients are opting to utilise emergency pathways for treatment. Both migraine and brain haemorrhage involve an agonising headache, therefore one of the likely reasons for non-elective attendance may be a fear of something more serious than migraine or headache.

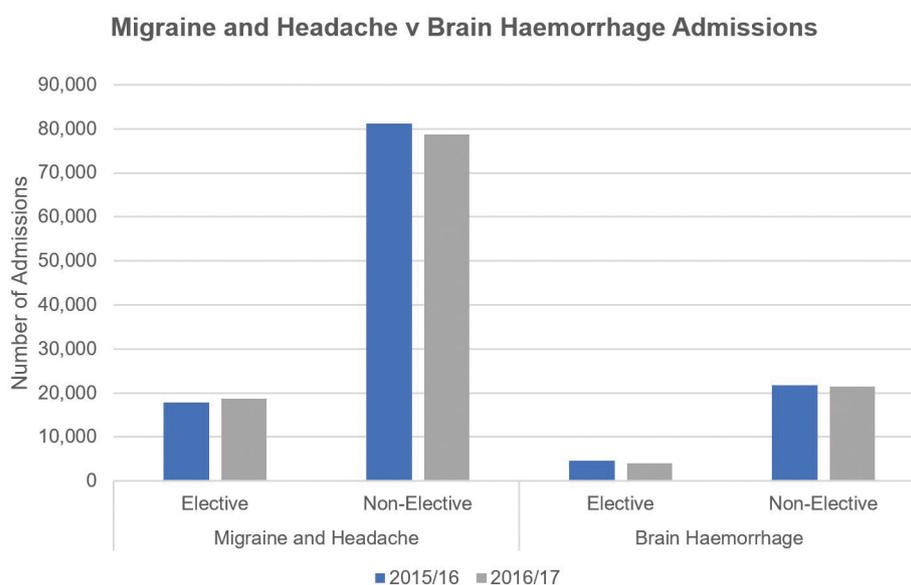


Figure 1: Patient admissions for migraine and headache compared with admissions for brain haemorrhage across the fiscal years 2015/16 and 2016/17

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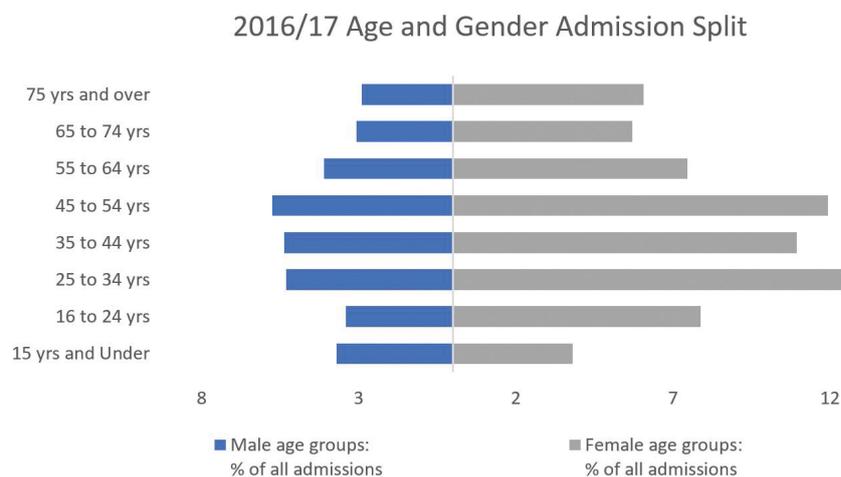
### 2.2 Admissions by gender and age

To gain a better understanding of the types of patients accessing treatment in secondary care, the headache and migraine admissions have been analysed by age and gender (**Figure 2**).

The data shows that a sizeable proportion of patients being admitted for headache and migraine are female, this may relate to hormonal triggers whereby fluctuating levels of oestrogen and prostaglandin can trigger a migraine attack, referred to as a menstrual migraine (The Migraine Trust, 2017). This may offer some explanation as to why females are more likely to suffer from migraine, but does not offer any rationale as to why they are finding themselves in secondary care instead of utilising GP services or self-treating at home.

In terms of age, most female admissions occur in the 25 to 34 years age group closely followed by the 45 to 54 years age group. Although there is no specific age of onset, it has been observed that migraine can often begin in early adulthood (NHS, 2017). Referring again to hormonal changes, the average age of menopause is 51 years, which may explain the relatively high number of female patients in the 44 to 55 years age group (Menopause Health Matters, 2017).

For males, admissions were greatest in the age range 45 to 54 years, 19% of all male patients belonged to this age group. There are fewer secondary care admissions for headache and migraine for males (34%) compared to females (66%). Interestingly, the relatively high number of admissions in the 45 to 54 group coincides with the age at which people are encouraged to undertake the NHS 40 - 74 years Health Check (NHS, 2017).



**Figure 2: Age and gender split of all migraine and headache admissions in the 2016/17 fiscal year**

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## 2.3 Indicative costs

### Cost of Admissions

The total indicative cost of migraine and headache admissions in 2015/16 exceeded £64 million, 77% of which was accounted for by emergency admissions. The equivalent indicative figure in 2016/17 exceeded £61 million, with emergency admissions accounting for 78% of costs. The indicative cost per admission for 2015/16 was £655 and £630 in 2016/17. These figures highlight the significant amount of money that might be better utilised for more preventative care, services and education.

2015/16	Migraine and headache	Brain Haemorrhage
Cost of elective admissions	£15,061,795	£22,795,158
Cost of non-elective admissions	£49,773,409	£60,539,410
Average cost per admission	£655	£3,173
Total cost of admissions	£64,835,205	£83,334,567

2016/17	Migraine and headache	Brain Haemorrhage
Cost of elective admissions	£13,331,075	£25,760,588
Cost of non-elective admissions	£48,043,648	£67,415,836
Average cost per admission	£630	£3,643
Total cost of admissions	£61,374,723	£93,176,424

Table 1: A breakdown of indicative costs for migraine and headache as a primary diagnosis for the fiscal years 2015/16 and 2016/17 in comparison to the indicative costs for brain haemorrhage as a primary diagnosis



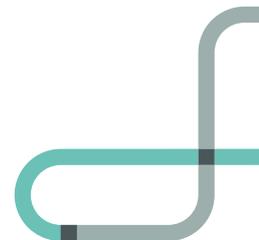
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### 2.4 Length of stay

In total, migraine and headache accounted for 73,638 bed days in 2015/16 and 65,994 in 2016/17. Additionally there were 55,648 admissions not requiring an overnight stay in 2015/16 and 56,883 in 2016/17. (Table 2 and Table 3)

Overall, across 2016/17, 67% of all admissions did not result in an overnight stay. The total indicative cost of these admissions across 2016/17 was over £30 million, which accounts for nearly 50% of the total cost of admissions for the fiscal year. (Table 3)

2015/16	Migraine & headache	2016/17	Migraine & Headache
Total elective bed days	5,723	Total elective bed days	5,979
Total non-elective bed days	67,906	Total non-elective bed days	60,015
Total bed days	73,638	Total bed days	65,994
Average length of stay	0.74	Average length of stay	0.68
Average length of stay (Non-elective admissions)	0.84	Average length of stay (Non-elective admissions)	0.76

Table 2 : Bed days and length of stay for Migraine and Headache Admissions

	2015/16	2016/17	Total
Number of zero-day admissions	41,638	42,801	84,439
Indicative cost of zero-day admissions	£20,173,076	£20,770,200	£40,943,276
Number of day case admissions	14,010	14,082	28,092
Indicative cost of day case admissions	£11,607,232	£10,068,845	£21,676,077

Table 3: Zero-day admissions (Non-elective) and Day case admissions (Elective) for migraine and headache, and the related indicative costs

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### 2.5 Diagnostic testing

Patients who have been admitted with a migraine or a headache may be referred for a magnetic resonance imaging (MRI) or computerised tomography (CT) brain scan. Brain scans may be undertaken to exclude more complex reasons for the headache or migraine.

Within the cohort of patients who have a primary diagnosis of migraine or headache and present as non-elective admissions, 71% were referred for a scan in 2015/16. This leads to an indicative cost of over £39 million to the NHS. Of migraine and headache patients who had undertaken a scan 68% were referred from A&E in 2015/16. This cost the NHS approximately £29 million. (Table 4)

2015/16	Admissions Count	Patient Count	Indicative Cost
Elective admissions	7,388	5,959	£6,591,786
Admissions from A&E	47,267	44,833	£29,512,580
Other non-elective	15,981	15,225	£9,897,534
Total admissions	70,636	62,771	£46,001,901

Table 4: Migraine and headache patients referred for a brain scan, via method of admission, in 2015/16

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## Call for action

This report has identified the cost of migraine and headache and from the analysis outlines 10 points for action that might support better service provision.

## Recommendations – a 10-point plan for improvement

### 1. Know your population to reduce unplanned admissions

Profiling your population is the first step to understanding how to commission effective headache and migraine services. Once you know roughly how many people are living with the problem in your health economy and what demand exists you can plan accordingly.

The prevalence of headache is 14,000 per 100,000 therefore if you are a CCG of 250,000 patients this means that its likely approximately 35,000 of individuals in the area will be living with a headache disorder. (Based on 1 in 7 people suffering from migraine, The Migraine Trust, 2017)

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### 2. Get smart with data

Hospital activity data can help you to understand how local services are performing and provide an indication of current costs of admissions which might be offset with more appropriate service provision. Check out your current performance:

- What are the admission rates, length of stay and readmission for headache and migraine?
- How do your figures compare with the national average and other CCGs?

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### 3. Promote the self-care agenda

Check that sufferers have local access to self-management programmes and condition specific information to increase their ability to self-care. The Migraine Trust has useful information about self-management on their website (The Migraine Trust, 2017).

Encourage patients to understand the importance of keeping a headache diary, which not only tracks the frequency and severity of their attacks, but also other factors such as their menstrual cycle and lifestyle factors such as periods of stress, sleep deprivation, weather or exercise. Recording this information is a key way that patients can work together with health professionals to both make a firmer diagnosis and to monitor whether treatments are working. The Migraine Trust has a diary template on their website (The Migraine Trust, 2017).

Pharmacists and opticians can provide a key resource in managing headaches in the community and offer a valuable channel for dissemination of information and enhancing public awareness, although they may not initially be considered as part of a management pathway. It is by using innovative approaches such as these that public awareness can be improved.

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## 4. Educate your healthcare teams in headache management

The level of headache education and knowledge amongst non-specialist health professionals in England is inadequate (APPG Headache 2014). Poor awareness, particularly amongst GPs, threatens to undermine the implementation of the NICE headache guideline and the quality of care received by patients. Greater GP training on headache should be prioritised as many headache patients are likely to visit their GP.

However, initiatives to improve headache training are needed to address poor knowledge and awareness amongst all health professionals who are likely to provide clinical support, for example, nurses and general neurologists. Training can be sourced from [www.neurologyacademy.org](http://www.neurologyacademy.org).

Encourage healthcare professionals to share expertise and good practice amongst themselves. If a headache specialist nurse or GP with a specialist is available, it is useful for colleagues to be aware of who this individual is so that they can discuss and refer patients if needed.

## 5. Ensure availability of services to meet need in both primary and secondary care

It is essential to support local services to develop an integrated approach to the management of individuals with headache disorders as clinical and support services will span the breadth of health, social and voluntary care. Additionally, the workplace environment should be considered as context for the development of supportive headache networks. Commissioning plans should encompass all aspects and ensure accountability for the full patient pathway.

Headache patients comprise about 30% of appointments at neurology outpatient clinics. It is essential that these clinics are well resourced in order that GPs can refer patients to an expert, and crucially that patients do not experience long waiting times for investigation. Well provisioned secondary care helps support patients and helps divert them away from unnecessary presentation at A&E.

Other services can also help alleviate the burden of patients with headache disorders on emergency pathways. These include GPs with a special interest in headache and headache specialist nurses. Such services give patients fast access to expert care, and importantly help support them by providing the right help early on. However, there are only around 12 trained headache specialist nurses for the whole of England which represents a significant shortfall in the face of such a large problem.

Depression is three times more common in people who suffer with migraine or severe headaches compared to those who do not (WHO 2012). In an NHS that has parity of esteem for mental health high on the agenda, adequate psychological support for migraine and headache patients should also be part of the care package. It is vital too that professionals understand the nature of migraine and headache which often sits at the intersection of physical and mental health.

The debilitating nature of migraine can have a detrimental impact on mental health, and it is worth noting that in many cases underlying mental health factors may be an exacerbating or sometimes sole cause of the migraine condition. Some patients benefit from cognitive behavioural therapy (CBT), and for those with intractable migraines experiencing more than 10 days of headache per month this type of therapeutic support is likely to be a worthwhile investment helping to reduce reliance on emergency care. For more information see a review of CBT management (Harris et al., 2015).

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### 6. Develop a local headache pathway so that everyone is aware of management plans

The lack of clearly defined pathways within the NHS leads to inefficiencies in the system and poor outcomes for patients. It is essential that local integrated pathways are developed.

The problem of the “revolving door” for patients with migraine and headache who keep returning to their GP and do not receive adequate treatment may be driving patients towards A&E in sheer desperation for a resolution. It is essential that GPs are equipped with a pathway to follow for patients who are making repeated visits about headache and migraine including how to escalate their care, and who to refer to. It is estimated that 3% of GP consultations are for headache (Kernick and Goadsby, 2009), so it is vital that GPs have a clear idea of the pathway to follow.

Thames Valley Strategic Clinical Network provides an initial outline of current and legacy pathway work in the management of patients and services to people with headache disorders that is still a useful resource (see References).

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### 7. Ensure headache disorders continue to be part of local Sustainability and Transformation Partnership plans

Migraine and headache represent the most common neurological reason for A&E attendance, and comprise about a third of neurology outpatient appointments (The Migraine Trust, 2017). It is essential that this patient population is considered in local STP plans.

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### 8. Promote better medicines management

Migraine is estimated to cost the NHS in the UK £150 million per year, mostly from the costs of prescription drugs and GP visits (APPG 2010), hence development of algorithms for prophylaxis and increasing awareness of medication overuse, which can exacerbate the issues, are essential.

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### 9. Link into local businesses to ensure a work-friendly attitude is adopted

Chronic headache disorders are disabling and require the same flexibility and understanding that all people with disability are entitled to in the workplace. Stress is a huge component of migraine and headache disorders, whether caused by the chronic, intermittent disruption to a person's work, to their social and family commitments or to the distress of having a chronic condition that seemingly cannot be resolved.

Stress is known to be an exacerbating factor in headache disorder, so in order for people to manage their condition it is essential that they receive support and understanding from their employer and colleagues. Workplaces can do a lot to not only support employees with a headache disorder, but also assist by ensuring they are managing their work demands, have time and space to take regular breaks and meal times, and receive an ergonomic assessment in their workspace. Simple steps towards promoting staff wellbeing benefit all staff, particularly those with a headache disorder.

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### 10. Work with the voluntary sector to improve patient outcomes

Charities, such as *The Migraine Trust* offer resources for people living with headache disorders such as workplace advice and information regarding what benefits a sufferer may be entitled to. More recognition of the value of this support is due.

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In 2016/17  
**65,994**  
bed days were utilised



Migraine and headache  
cost the NHS nearly  
**£61 million**

### Conclusion

From this analysis migraine and headache reveals itself as a major challenge for our health services and its patients. In 2016/17 alone, migraine and headache cost the NHS nearly £61 million in admissions and utilised 65,994 bed days.

Headache disorders place great pressure on secondary and emergency care which are struggling to cope, especially in winter when admissions to A&E are higher. Whilst it is recognised that emergency care is appropriate in some cases, especially if there is an underlying condition, improved alternative provision will help alleviate this burden.

This calls for the availability of improved education in the diagnosis and treatment of headache disorders for clinicians and education in prevention and management for individuals with the problem. Additionally, there is a need to ensure services are sustainable for the future and provide the care required for those living with this distressing problem.

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