New migraine treatments on the horizon

Meet headache nurse Jill Murphy

Amanda Ball on living with chronic migraine
It is now a full year since I started here at The Migraine Trust and I want to thank each and every one of you for the warm welcome you have given me and for the continued support you have shown for the charity in this last year.

So many of you have been busy fundraising for us recently – we don't have space to fit you all in! Have a look at pages 16-17 to see what others have been up to and hopefully this will inspire you to do more for us! Another way of supporting us is to consider leaving a gift to the Trust in your Will. Many of you will have suffered greatly from migraine and you will know the help and support we have been able to give you. In this way, with your ongoing support, we can continue to help even more people that need us.

I've spent a lot of the year going round the country to meet you and hear about your migraine stories first-hand – you really are an inspiring bunch. Please read Amanda's story on pages 8-9 where she writes to her 'migraine,' sharing her experience with us in a really unique and interesting way.

I've also met a lot of the GPs, nurses and neurologists who provide care for you, and I have been super impressed with their passion and empathy for what they do. On pages 12-13 Jill Murphy tells us what it's like to be a headache nurse, Dr Fayyaz Ahmed answers some of your questions on pages 14-15 and Professor Peter Goadsby tells us about some of the new treatments that are close to becoming available to you on pages 6-7.

I'd like to share some of the interesting results from a survey that we carried out in advance of Migraine Awareness Week in September. The YouGov poll was commissioned with Migraine Action and the National Migraine Centre; the very first time that we have all joined forces for such an initiative. Among the worrying findings were that almost two thirds (64 percent) of those quizzed believe employers don't understand very much or at all about the nature and impact of migraine on their workers; a very depressing picture. Overall the results confirm the urgent need for better understanding of the reality of migraine and its disabling impact as well as for the condition to be taken more seriously. At the Trust we are committed to changing this, with your help.

I'd like to thank you again for the warm welcome you have given me. It is a great honour to work here at the Trust and I am looking forward to doing everything I can to raise the profile of migraine and ensure that it is taken much more seriously.

Best wishes

Arlene
Migraine postdrome MRI study

In May 2017, The Migraine Trust’s Clinical Research Fellow, Dr Pyari Bose, was invited to present his research work from King’s College Hospital at the Association of British Neurologists’ conference in Liverpool. The project is sponsored by The Migraine Trust and supervised by Professor Peter Goadsby. Dr Bose explains, “We scanned the brains of volunteers during the postdrome (recovery) phase of a migraine attack using a specialised type of MRI brain scan called arterial spin labelled MRI. The scan has shown for the first time, that when migraine sufferers are in recovery mode, there is a reduction in brain blood flow. It is as if the brain is ‘re-booting’ itself following a migraine attack and this explains why some migraine sufferers complain of various symptoms like tiredness and sleepiness in the recovery phase.” The research team hopes that this knowledge will lead to better treatment options for migraine sufferers in the future.

Safe in Schools Campaign

We are campaigning, along with over 30 other charities, health professional groups and trade unions, to ensure that children with medical conditions receive the care they deserve in school. The Safe in Schools Campaign has launched a video for schools and parents explaining more about the statutory requirements on all schools in England to ensure that medical conditions policies are in place. You can download and share the video with your child’s school via The Migraine Trust website by visiting www.medicalconditionsatschool.org.uk

Mental health report

On 6th July the Neurological Alliance launched its report “Parity of esteem for people affected by neurological conditions” which shines a light on the distinct cognitive, emotional and mental health needs of neurology patients. The report highlights the need for better diagnosis and specially designed services to overcome the current patchy service provision. To mark the launch of the report, our Policy Manager attended an expert meeting to consider the key themes in the report and how the health system can work together to address the current issues. The meeting, which brought together patient groups, clinicians, public sector bodies and other stakeholders, was the first step in implementing the recommendations within the report. You can read the full report on our website.

Managing Your Migraine events

We have been travelling across the UK, bringing together people with migraine and their local specialist health professionals at our Managing Your Migraine information events. We recently held very well attended events in Hull and Birmingham (pictured below). Here’s what one attendee had to say: “This event was fantastic, so informative. I have suffered for more than 20 years and the advice given in these four hours has been the best advice I have had over the past 20 years. Thank you so much.” Our upcoming events, including one in Exeter on 4th November, are listed in the events section of our website.

For more news visit our website: www.migrainetrust.org/news/
Migraine care ‘falling short’
Our analysis of the neurology patient experience survey

Why patient experience matters

There are approximately nine million people with migraine in the UK. Around four percent of adults see their GP each year for headache or migraine, and headache is the most common reason for neurology outpatient appointments. While it is important that the NHS and the government recognise these figures, they can only ever reveal part of the story. They don’t demonstrate the experiences of people with migraine, from the moment they seek support, obtain a diagnosis and receive treatment to manage their condition. The experience that people have of their treatment and care is intrinsically important to them. Improving that experience is considered a key aim of the NHS.

Falling short

Earlier this year the Neurological Alliance published the results of its second patient experience survey in a report: “Falling short: How has neurology patient experience changed since 2014?” The report, based on the experiences of over 7,000 neurology patients, reveals that services to diagnose, treat and provide ongoing care have seriously deteriorated since 2014. Patients are being failed across the spectrum of neurological disorders.

What the findings reveal

Over 1,300 people with migraine responded to the survey, giving a snapshot of the experiences of patients who access services for this debilitating condition:

• 64 percent of people with migraine are restricted in their activities frequently, most or all of the time

• 73 percent of people with migraine say their condition causes them severe or extreme pain or discomfort.

The research highlighted that the way in which diagnosis is communicated, and the quality of the communication between people with migraine and their health care professional, is an important factor in their overall experience of health care. Over half of patients are more satisfied than unsatisfied with the way their migraine diagnosis was first communicated. However, the survey reveals that more must be done to provide sources of additional support and information when diagnosing:

• 76 percent of people were dissatisfied with the sources of emotional support (such as patient support groups or counselling) provided by their health professionals that they received when diagnosed with migraine

• 67 percent were dissatisfied with sources of information they received from their health professionals, such as signposting to charities, when diagnosed with migraine

• 32 percent of people with migraine believe their diagnosis should have been communicated more appropriately.

as few as 17% of people with migraine who received specialist neurological care had access to a headache nurse
The results also revealed the difficulties people can have in accessing appropriate health services for their migraine:

- Only 30 percent of people with migraine described the health services for their condition as ‘good’ or ‘excellent’
- As few as 17 percent of people with migraine who received specialist neurological care had access to a headache nurse
- Only 14 percent of people who received specialist neurological care were offered a care plan for their migraine
- 19 percent of migraine patients – almost one in five – had attended a hospital accident and emergency department at least once as a result of their condition in the past two years.

Our commitment

We are encouraged that some very positive experiences were reported and we know from listening to you that there are some excellent health professionals and clinics providing support. However, the overall results are very disappointing and highlight the unacceptable variation in migraine care across the UK.

With NHS resources becoming tighter, it’s clear that the system is struggling more than ever to provide the timely support needed to ensure the best possible outcomes and experience for people living with migraine and other neurological conditions. We are working with people with migraine, health professionals, health charities, NHS decision makers and influencers to drive forward improvements in the standard of care for migraine. It is essential that we all work together to understand and learn from these results and turn around poor experiences within the health service. While there are a number of positive initiatives underway already across the UK, it can take time for these to translate to change on the ground. We are committed to drive forward this work, to continue to campaign for and support real change for patients and to ensure that the voices of people with migraine are central to the process.

What to do if you have a bad experience?

Visit our website – the ‘Living with migraine’ section has information on seeking medical advice, navigating the health service and what to do if an issue occurs.

Contact us – our support services team can support you via phone and email to overcome issues you have in accessing and receiving appropriate care from the NHS.

Contact the NHS directly – if you want to give feedback or express concerns about an NHS service, ask the service for a copy of their complaints procedure, which will explain what you need to do.

Write to your MP – your local elected representative may be able to support you to challenge poor experiences of care. You can write to your MP or visit their local surgery to discuss your concerns.
New treatment update

A wave of new preventive migraine medications are on the horizon

Around nine million people suffer from migraine in the UK. Experts say that just under half of those could benefit from a new class of treatments called calcitonin gene-related peptide (CGRP) pathway monoclonal antibodies, which aim to reduce the number of migraine days per month that an individual will experience. Here we talk to Professor Peter Goadsby about these new treatments and why we should be excited by them.

Why do we need these new treatments?

Migraine is a complex condition with a wide variety of symptoms. For many, the main feature is a painful headache. Other symptoms include disturbed vision, sensitivity to light, sound and smells, feeling sick and vomiting, fatigue, and concentration impairment. The symptoms will vary from person to person and individuals may have different symptoms during different attacks. Attacks may differ in length and frequency. The headache phase of a migraine attacks usually last from four to 72 hours and most people are free from symptoms between attacks, although many patients have disabling symptoms for hours before and after the pain phase. Migraine can have an enormous impact on work, family and social lives.

Whilst many medications exist for the effective treatment of migraine, they can also be problematic for some individuals. Many simply don’t work; some people may suffer side effects; for those with other health conditions, different drug interactions are a major problem; those of childbearing age may choose to avoid medications; and those with heart disease are advised not to take triptans. People will often stop taking their medication because of one or more of these issues. Currently, there is no preventive treatment that was actually developed for migraine. All currently used preventive drugs used today were originally approved for other diseases, such as high blood pressure or epilepsy, and noticed to work in migraine.

This shows that new drugs are needed to treat migraine in patients in whom the current treatments are not working, or are not safe or tolerated. Moreover, we want to develop new treatments specifically to target migraine.

What have we discovered?

Back in the mid-1980s and 1990s, myself and Lars Edvinsson were researching the pain of migraine to try and improve understanding and treatment approaches. We discovered that a molecule called CGRP was important in a migraine attack. We showed that CGRP levels increase during an acute migraine and decrease during effective treatment of the attack.

Focusing on CGRP offers an entirely new approach to treat migraine. CGRP is an exciting treatment target since such medicines would be the first preventive treatments designed specifically for migraine.

Having shown CGRP was important, the race was on to find a way to prevent CGRP from working in migraine and thus to develop a new treatment specially targeted at migraine. We hoped for a treatment that would be effective, as the triptans often are; yet better tolerated and safer to use. Initially research focused on the development of small molecule drugs that were designed to block CGRP receptors. However, while these were effective in the acute and preventive treatment of migraine, the lead drug failed because of liver problems. This idea is now again being pursued.

“Focusing on CGRP offers an entirely new approach to treat migraine.”
Most recently attention has focused on the new monoclonal antibodies (MABs) against CGRP, or its receptor. Currently, four MABs are being developed. Trials, which have been encouraging, suggest that they may offer clinicians the opportunity to reduce the number of migraine days per month that an individual will suffer and significantly improve the care of patients with migraine. They have consistently demonstrated significant reductions in frequency of migraine in both the episodic and chronic forms. Extensive clinical trials are ongoing to confirm the efficacy and evaluate the safety of these new treatments.

Is this treatment right for you?

This is the first preventive treatment designed specifically for migraine which is very exciting. The positive results in preliminary studies should give you hope. There are however a few important things to note:

1. They won’t be available this year. Of the four, one has been submitted to European and U.S. regulators, and we expect to hear their views in 2018. One is about to be submitted and the others are not far behind.

2. They are delivered by injection. The MABs can’t be taken orally; they have to be given by injection, which won’t suit everyone, although auto injectors are being developed to make the task simpler. The injections can be performed at relatively low frequency, every month or even quarterly, which may enhance patients’ compliance.

3. We don’t know about the long-term effects of these medications when administered for more than a year. Longer administration periods will be needed to assess these effects. CGRP is widely distributed throughout the body – in the kidney, lungs, eyes, liver, and gastrointestinal tract – as well as the brain. But the results so far obtained are promising. The most common side effect appears to be reactions at the injection site.

4. Not everyone will respond to this treatment. It is unlikely that any of the drugs will be a cure-all but some will do very well so we will chip away at the problem with research and investment.

5. The monoclonal antibody drugs are likely to be very expensive, which could be an impediment to getting the treatment to people who need it the most.

These treatments won’t be around for a few years, what should you do in the mean time?

• Keep your migraine diary

• Find a GP who is interested in the condition; persist until you find one!

• Keep going back to the GP until you find a treatment plan that works for you

• If you try many medications, and they aren’t working, ask to be referred to a headache specialist

• Contact The Migraine Trust!
Migraine stories

Amanda Ball shares her experience of living with chronic migraine

“When you are absent I feel so happy and unbelievably lucky with the life I have. So why do you have to return, become such a blatant presence and cast that all aside?”
Dear Migraine,

I feel it’s time to write to you. You have been a part of my life for so long, causing me pain ranging from a slight ache to unbearable agony. I have known you from the age of 13 and despite a hiatus for several years, we suddenly seem to have developed an unsettling, formidable, and hugely influential relationship that is having an enormous effect on my personal and professional life.

Despite not materialising much during my 20s and early 30s, I guess you were always there. Watching and waiting to rear your (apologies – as I know you extremely well and know you deserve much respect but I must say it) ugly head once more. Most times I beat you and you know it. At times I can handle you and control you, regulating my physical and emotional pain. It exhausts me, but it makes me feel fantastic too. I love life and the people I have in it. I so just want to enjoy them and to show them happiness too.

However, you recognise the difficulty I have in keeping control at other times and my inability to cling on to and use all the wonderful and happy things in my life to keep me afloat. You use this against me, and to full effect. When you are absent I feel so happy and unbelievably lucky with the life I have. So why do you have to return, become such a blatant presence and cast that all aside? You creep like a mist floating through my very reason, cast moments of doubt and leave me feeling as if a dark cloud is about to descend. It inevitably does. Despite my resistance, I feel like I am being pulled under water for the umpteenth time. My mind becomes vague and my thoughts unclear. I embarrass myself time and again when speech becomes difficult: the simplest of words balancing precariously on the tip of my tongue. My inability to express myself, with the vast vocabulary within my possession, is torture. You make me feel foolish. I doubt my own intelligence. Those close to me become the enemy, as if you want me all to yourself. Despite desiring escape to the very core of my body, and the avoidance of putting my loved ones through this, I feel helpless. I feel you take control over my desires, my ability to communicate, show affection and just be my normal happy self. You knock me and smash me until my strength has gone and then you know when to strike that final blow to make my life feel utterly pointless and hopeless. I can’t do anything but admire your strength and persistence, despite its effect on me. I only wish I could transfer that strength to my ability to fight you.

When I say ‘you’, I no longer refer to the ‘headaches’ and sickness I used to bear. It’s the weekly and often daily tirade of auras, neck pain and sheer exhaustion. An old symptom of numbness has also returned and scares me willy nil. At times, a numb arm and garbled speech have convinced me that I may be having a stroke.

‘You’ are also now no longer just physical pain, but the blackness that takes over my thoughts, my reason and my emotions: the blackness that causes hurt to my family and to my loved ones. I sometimes no longer know who I am. I no longer know what I’m doing or what I think at times. The thoughts that materialise in my mind during this time scare me so much. At times I daren’t even speak or look someone in the eye for fear of them being discovered. I often don’t even recognise myself: a stranger to my loved ones. It’s as if I can see them but they can’t hear me screaming for help. I feel like a shell has enveloped me and I am an insignificant version of myself right in the hollow of my body. Like a Russian doll, it feels like layer upon layer has built up around me and inhibits me from telling people exactly how I feel, despite the screaming that goes on inside ‘little me’.

However, the one silver lining is that you don’t last forever. But during your agonising presence, I can’t express to my loved ones that they mean the world to me, that I need them so much; that I need their touch, for them to hold me when I push them away, their reassurance when the tears fall and their love to wrap around me and ease the pain that you inflict on me. To tell them that this blackness has nothing to do with them. Nothing. I want to desperately apologise for the pain I inflict on them because of the pain you inflict on me.

I’m almost 43 and now have the joy of facing an even closer relationship with you through the imminent arrival of the menopause; my neurologist informs me that it will get a lot worse before it gets better. I am hoping and praying that the medication she has prescribed will ease some of your regular visits; the visits that affect my teaching career in a way that is hard for me to bear in a class of sixty children. It’s hard to explain to my children why a dark shadow casts over my face and why I can’t bear being touched or spoken to, often three or four times during the school week.

I long to wake up each morning without the first word in my head being ‘migraine.’ I long to fall asleep each night without the last word in my head being ‘migraine.’ I long for the day.

Yours respectfully (but bitterly),

Amanda
How we can help you

The Migraine Trust offers support services for people with migraine, their families, carers and others with an interest in migraine.

Our support services include the information service, which responds to enquiries about migraine, research evidence, treatment options and health services, and the advocacy service which can help with workplace issues such as disability discrimination or obtaining reasonable adjustments so that a person with migraine can continue to hold down a job. It also offers help with access to health services as well as issues for children and young people with migraine in education.

In an age of easy access to information via Internet searches and social media, it is more important than ever to know that sources are reliable, evidence-based and authoritative. This is especially true where a person’s health and rights in the workplace, healthcare or education are concerned. All of the Trust’s information is based on the best available research and clinical experience of specialist health professionals in the field and, in the case of advocacy, the latest legislation.

It is really important to be aware that at the Trust, we are not health professionals or lawyers and so unable to make a diagnosis of someone’s symptoms, or provide medical or legal advice; this should only be done by a person’s own health or legal professionals. However, many people who have used the service have said that it is very useful to have access to a resource that can provide evidence-based information to shed light on migraine as a chronic health condition which needs self management, and guidance on issues such as migraine as a disability, as well as the rights of employees, patients and pupils when they have migraine.

Frequently asked questions to the advocacy service about migraine and employment include issues around whether migraine is a disability, migraine and sick leave, and reasonable adjustments in the workplace. Parents contacting the Trust’s advocacy service are often worried about how their child’s school can provide more support and better facilitate their child’s access to education. Universities and higher education students have contacted the advocacy service about completing courses and taking examinations for those who have migraine.

Many enquirers ask about symptoms and signs, evidence for different treatment options, worries about any risks of having migraine or of long term treatment, any links between having migraine and developing other health conditions.

Some comments from people who have used the support service are:

“A very reassuring and helpful response – thank you so much.”

“Reply to my enquiry was thorough and provided further contact facilities which I can and have used. Many thanks.”

“Thank you for the invaluable information I was given.”

“Thank you for forwarding the information. In the process of going through it and keeping a diary to take to a consultant.”

“Many thanks for your kind and helpful reply.”

“As a result of the information emailed to me following phone calls, I now have sufficient information to help me understand the nature of botox treatment for migraine.”

If you would like to contact The Migraine Trust’s support services, you can use the contact form on our website (www.migrainetrust.org/contact-us) or telephone: 020 7631 6975 (migraine information) or 020 7631 6973 (advocacy) – leave a voicemail message if necessary and we will call you back. Or, as above, write to information or advocacy at the address on the back page of Migraine News.
After taking care of your loved ones, please consider leaving a gift to The Migraine Trust in your Will.

A gift of just 1% will make a real difference to supporting our charitable work.

Most of The Migraine Trust’s work is funded by individuals – people just like you – and our most vital income comes from people leaving gifts in Wills. We couldn’t do what we do without them.

You don’t have to be wealthy to leave a gift in your Will to help us, nor do you need to exclude loved ones. Whatever the amount – big or small – we’re extremely grateful for any gift that is left to The Migraine Trust, after you have looked after family and friends.

Your gift will help us to continue supporting the millions of people in the UK who suffer from migraine, educating the public and health professionals, as well as funding research to improve treatment and find a cure.

More information can be found at www.migrainetrust.org/legacy or you can call us on 020 7631 6977.
I work at York Hospital in the neurology out-patient department four days a week. I have five headache clinics a week which includes a weekly Botox clinic for patients with chronic migraine.

The majority of people I see have a diagnosis of migraine, often chronic migraine, but I also see people who have medication overuse headache, tension type headache, and other rarer headaches belonging to the group of headaches collectively known as trigeminal autonomic cephalalgias, which includes cluster headache and paroxysmal hemicrania.

Most of my patients are seen by a neurologist first and then followed up by me.

If the diagnosis is uncertain or complex, I will take another headache history to try and gain a better understanding of the symptoms, including the duration, the frequency, severity and the level of burden experienced by the individual. I will make a diagnosis and discuss the treatment options with my patient and then provide a treatment plan.

My aim is to educate and empower people to feel confident in managing and treating their headache type.

The four areas I encourage people to work on are:

- Improving their diet and lifestyle
- Rationalising their acute treatment frequency
- Aiming for a therapeutic dose of preventative medication
- Introducing complementary therapies.

I work within a team of two physiotherapists who provide acupuncture and physical therapy and a psychologist who can help people to understand and deal with the complexities of pain.
What difference does having a headache nurse make to your headache patients and the clinic you work in?

I can be the first point of contact for my headache patients. This is often quicker than waiting for an appointment to see their GP. I follow up with people more regularly and have longer appointments than the doctors. This can ease the burden for the neurologists too. I am able to instigate medication, alter the dose, instigate treatment plans and withdraw treatment; I can advise GPs to refer my patient to other agencies or hospital specialist as required. I work with the patient and aim to provide a positive outcome.

It would be fair to say that most people don’t like taking medication; this is generally because of side-effects. I explain side-effects and try to tailor the medication to suit the individual, using the side-effects in a positive way, as well as taking into account the headache diagnosis.

I provide information leaflets which explain the different types of headache, treatment and management. I write letters to employers and educational establishments explaining the burden of migraine with the aim of improving the work or study environment.

Local GPs can and do contact me for advice about treatments for different types of headache.

Are there any frequent or common concerns or worries that your headache patients express to you about their health condition?

Most people I see have had their headache or migraine for many years. People will generally consult their GP, or attend an Accident and Emergency (A&E) department within a hospital if there are new headache symptoms or their headaches become more severe. This causes worry and concern for the patient who in turn will seek reassurance. If this need is unmet, my patient will ask me if I think there is something sinister or worrying going on inside their brain. It can be difficult for people to believe that they can suffer so much pain and not have something seriously wrong with their brain. I will take another headache history about the new symptom or worst ever headache, and if I cannot reassure myself or my patient, I will discuss the patient with their neurologist to decide on the next steps. This may result in a review with the neurologist.

What are the greatest challenges of being a headache nurse?

There are not enough headache clinics and headache specialist doctors and nurses. People have to travel long distances to access the care that they need. I have a lot of patients who come to my clinics from out of the area; this places a greater burden on me to keep waiting times acceptable.

I can’t cure headaches but I can help to improve them. I don’t have a magic wand; my patients have to work with me, and we are a team.

Other challenges include:

- **Managing people’s expectations** – most people have very low expectations based on their previous experiences. It can take time to get the treatment plan right; this will take perseverance by the patient to find the drug that works for them and may require regular visits in the initial stages to get the right treatment regime.

- **Overcoming barriers to care** – misunderstanding familial beliefs; people often feel that they haven’t been taken seriously in the past; undoing learned negative behaviours.

- **Poorly managed migraine** – getting the right treatment at the right time for it to be effective, but not taking acute treatments too often. I feel that getting this right can help to reduce A&E attendances.

What’s the most rewarding part of your job?

Meeting lovely people and being able to help them make a difference in improving the quality of their lives.

Working with people who are willing to do whatever it takes to improve their condition.

Empowering and educating people and their families to regain control of their headache and migraine, allowing them to live life the way they want to.

I am able to discharge people from my clinic when they feel better equipped to manage their headache and migraine.

Being part of a group of professional people all working towards the same goal, raising the awareness of the burden of headache and migraine and improving headache services.
Question: Is there a link between migraine and Meniere’s disease?

Answer:

Meniere’s disease (MD) is a condition of the inner ear characterised by vertigo, tinnitus, pressure in the affected ears and/or hearing loss.

Vertigo as a symptom of migraine has been recognised for around 50 years and was known with different names – migrainous vertigo, migraine associated dizziness, or benign recurrent vertigo. Vertigo is also a recognised feature of basilar migraine and may be an aura symptom in other forms of migraine.

“The considerable overlap of symptoms between migraine and other conditions of the ear and brain made it difficult to separate or differentiate the two.”

The considerable overlap of symptoms between migraine and other conditions of the ear and brain made it difficult to separate or differentiate the two. The term vestibular migraine (VM) was introduced following the work of Dr Hannelore Neuhauser in 2001 and was recognised later by the International Headache Society. In VM, patients may have episodes of vertigo, imbalance and dizziness that may last from seconds to days and may or may not be temporally associated with migraine headaches, with or without aura.

As described above, VM and MD have identical symptoms making it difficult to distinguish between the two disorders. One study found that patients diagnosed with VM or MD had symptoms that could meet criteria for either disorder. Of patients with VM, 38 percent had hearing loss and of those with MD, 49 percent presented with photophobia and headache. MD patients have been found to be twice as likely to have migraine compared to those without MD. Similarly those with migraine who also develop MD, are more likely to have hearing loss at a younger age than usual and loss of hearing in both ears from MD.
The pathophysiology of both conditions remains unclear with the diagnosis totally reliant on history. There is not enough evidence to definitively link VM and MD, but considerable overlap of symptoms make it difficult to differentiate the two.

**Question:**
Is hyperacusis a migraine symptom and if so, is there any treatment?

**Answer:**
Hyperacusis is an abnormal sensitivity to sound and in the context of migraine, it is often called phonophobia. Sound that is neither threatening nor uncomfortably loud to a typical person is perceived as exaggerated and unpleasant by someone affected.

Hyperacusis may be caused by structural disorders of the inner ear (Meniere’s disease), damage to the nerve taking signals from ear to the brain (vestibulocochlear nerve) or those with temporal lobe disorder (epilepsy). However, in migraine this is a result of hypersensitivity rather than a structural disorder. Increased sensitivity to light (photophobia), smell (osmophobia) and touch (allodynia) co-exist in such patients. Increased sensitivity to otherwise normal stimuli is also seen in disorders like fibromyalgia, complex regional pain syndrome, depression and post-traumatic stress disorder where there seems to be an increased central sensitivity to sensory input. As migraine is extremely common, 90 percent of all hyperacusis are caused by migraine. There is evidence that the serotonin pathway (brain nerve cells that communicate with serotonin) is implicated in both migraine and hyperacusis.

There is no definitive treatment for hyperacusis caused by migraine; however, treating migraine has been shown to improve hyperacusis. Wearing ear plugs may help although frequent use may worsen the sensitivity. It is also suggested that people avoid stimulants such as caffeine and nicotine, and migraine triggers. Preventative treatments for migraine are helpful as well.

“There is no definitive treatment for hyperacusis caused by migraine; however, treating migraine has been shown to improve hyperacusis.”
How you have supported us

Star fundraiser
An extra special thank you to Laura, aged 11, who took part in the Edinburgh Marathon Festival Junior 2K event on 27 May and raised over £190 for The Migraine Trust. Congratulations Laura!

“My name is Laura and I ran the Edinburgh Marathon Festival 2K run. I wanted to raise money for The Migraine Trust because my mum has suffered from migraine since she was five. For the last six years, my mum has been unable to work as she suffers from a constant headache and she doesn’t know when she will have a migraine attack. I also wanted to help the other eight million people in the UK suffering from it. Hopefully the money that I have raised will help to find out more about this very complicated neurological condition.”

London Marathon
Our amazing supporters Debbie, Paul, Zoe, Brittany and Ben all completed the challenge of running the Virgin Money London Marathon on Sunday 23rd April. They have raised a fantastic combined total of over £7,300. Well done marathon runners!

“"I hope along the way I have educated a few more people about this dreadful disability.""

Brittany: “We absolutely loved the day. Despite the pain and the blisters and the trapped nerves, it was an incredible experience.”

Debbie: “I had a great run, really enjoyed myself and so glad the weather was good. The crowd support was amazing.”

Paul: “Running the London Marathon was something I had thought about for over 20 years but I never really thought I could do it. One day at work someone told me life is short, stop thinking about it and just do it – so I did! I chose to run for The Migraine Trust because my wife suffers from chronic migraines and I see the human misery of this condition on a daily basis. The six months of training were painful and gruelling and the big day itself amazing and humbling – I have never experienced so much positive energy in one place before in my entire life. Raising funds for The Migraine Trust was a fascinating experience. I was met with both ignorance and understanding about migraines. On the day I was very proud to wear the blue shirt of The Migraine Trust and I hope along the way I have educated a few more people about this dreadful disability.”
We are incredibly heartened by the efforts of our enthusiastic and inspiring fundraisers. Thank you to each and every one of you who has raised money for The Migraine Trust over the past six months. We really appreciate all the hard work and effort you put in, and the money that you raise really does make a difference to lightening the burden of migraine.

Hellebore garden open days

Committed supporter, Valda, has been organising fundraising open days to her hellebore garden for a number of years in support of our charity and this year raised a further £1,100. Thank you Valda!

Can you lend a hand? Valda is now seeking local volunteers to help organise and run these popular events. If you live in North Yorkshire near Hilton and are interested in helping, for example, collecting donations on the day from cake and plant sales, please email fundraising@migrainetrust.org.

Thank you to:

- **Alison**, a chronic migraine sufferer who completed her ‘March on Migraine’ in April, walking 10,000 steps a day for a month and raising £230
- **Ian and Sue** who chose The Migraine Trust for their charity of the year
- **Lisa** who organised an afternoon tea and raised £217
- **Sian** who ran the Chester Half Marathon in May
- **Tom and Demi** for collecting over £500 in lieu of gifts at their wedding in June. Congratulations Tom and Demi!
- **Sheeva** for collecting donations in lieu of gifts on her birthday
- **Alice, Jackie and Victoria** for running the British 10K in July
- **Jill** for taking on the Great Aberdeen Run in August
- **George** for fundraising via the Strathpuffer 24 Mountain Bike Endurance Event
- **Sally** for her continued community fundraising.

And to everyone else who is fundraising for us this year – we really appreciate your support!

Interested in fundraising?

There are lots of ways you can get involved, from challenge events to coffee mornings.

For inspiration and more information, please visit www.migrainetrust.org/fundraising
How you can get involved

For more information about any of the events below please visit www.migrainetrust.org/events

September

**03-09: Migraine Awareness Week**
An annual campaign to draw attention to migraine, educate the public and reduce stigma. Visit our website, Facebook and Twitter to follow the activity and get involved.

October

**31: Virgin Money London Marathon team chosen for 2018**
While the application deadline for our limited London Marathon 2018 charity places was 31 August, we will notify applicants whether or not they have been successful by the end of October. Check our website to see if we have any last minute places available.

November

**04: Managing Your Migraine, Exeter**
Tickets are now on sale for our next information event, to be held in Exeter. Aimed at people living with migraine, the event is organised in association with the British Association for the Study of Headache. It offers the opportunity to learn more about migraine with presentations from experts, the chance to ask questions and meet other sufferers.

March

**Managing Your Migraine, Edinburgh (Date tbc)**
We plan to visit Edinburgh in early 2018 to hold another of our migraine information events for the public, organised in association with the British Association for the Study of Headache. Further details will be available on our website once confirmed.

April 2018

**22: Virgin Money London Marathon**
Our Migraine Trust marathon team will take on the 26.2 mile route through London today, raising both awareness of migraine and funds to support our work.

September 2018

**06-09: Migraine Trust International Symposium**
The 17th biennial Migraine Trust International Symposium will take place in London in September 2018, continuing our commitment to migraine research and education.

Our next Managing Your Migraine event is in Exeter.
Yes, I want to help The Migraine Trust invest in crucial research and find a cure for migraine. Please find enclosed a donation of:

- £20.68, which could pay for an hour of specialist migraine research by our pioneering neuroscientists.
- £62.03, which is enough to pay for half a day of research into headache disorders.
- £144.74, which could pay for an entire day of dedicated migraine research.
- My own preferred gift amount of: £____________

I enclose a cheque/CAF voucher payable to The Migraine Trust OR

Please debit my credit/debit card

Card type: [ ] Maestro [ ] Visa [ ] Mastercard [ ] Delta [ ] CAF

Card holder’s name: ____________________________

Card number: ____________________________

Valid from: ______ / ______ Expiry date: ______ / ______ 3 digit security number: ________

Issue number (Maestro only): ________ Signature: ____________________________ Date: ________

Your details

Telephone: ____________________________

Email: ____________________________

I am happy for The Migraine Trust to contact me by email [ ]

For every donation we receive, we send a letter acknowledging receipt and thanking the giver. We are delighted to do this, but if you would prefer us to not send an acknowledgment, please tick the box. [ ]

Please return to
Freepost RSRB-ZYSK-GGCC, The Migraine Trust, 52-53 Russell Square, London, WC1B 4HP

Gift Aid declaration. Please treat as Gift Aid donations all qualifying gifts of money made. (Please tick all boxes you wish to apply)

[ ] In the past 4 years

[ ] Today and in the future

Signature: ____________________________ Date: ____________________________

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities or Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 25p of tax on every £1 that I give.

Funds raised will be used in accordance with the aims of the charity as set out in its governing document, namely to help improve the lives of people with migraine in the UK and work towards our vision of a world where people can live free of migraine. The Migraine Trust will keep your name and contact details on our database and use this information to inform you about events, news (such as our journal Migraine News) or ways to support The Migraine Trust that might be of interest to you. We will never sell or pass on your details. If you do not wish to receive further communications from The Migraine Trust please tick this box. [ ]
The Migraine Trust was founded in 1965 primarily to promote medical research into migraine.

We

- Provide a comprehensive information service to the general public, health professionals, employers and the media. We have a comprehensive website and produce the Migraine News journal.
- Hold the Migraine Trust International Symposium every two years for leading experts in migraine from all over the world to meet and exchange research results and ideas.
- Fund research, fellowships and studentships in hospitals and universities.

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