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Welcome from the Chief Executive

This is a really difficult one. In any other edition I would want to talk enthusiastically about how many inspirational people and stories there are in this magazine. We are so grateful to all of you who do extraordinary things to raise more awareness about migraine and much needed funds to support our charity’s work.

But, with the greatest respect to you all, there is really only one person I’d like to talk about today. Susan Haydon, our Information and Support Services Manager, dear colleague and friend died on 12 July 2019 after a short illness.

For many people who sought our help, Susan was The Migraine Trust. She had dedicated 17 years of her life not just to our organisation but to people affected by migraine. Day after day, year after year, she was the gentle, knowledgeable, caring voice callers heard when they rang our helpline. They were often calling in immense pain and feeling lost. But everyone who called knew immediately that Susan really wanted to help.

After the shock and lots of tears, the conversation amongst the staff and trustees has turned to how to remember Susan. We’re still thinking about an appropriate and fitting tribute. We’re starting with a few pages in this magazine.

Perhaps most importantly, everyone at The Migraine Trust is even more determined to build an even better charity. A charity that reaches more people, helps more people and changes more lives for the better.

We miss you Susan and we will make you proud.

The Migraine Trust is the largest charity dedicated to leading the fight against migraine in the UK. We exist to transform the lives of people who get migraine. We do this by funding and promoting research, providing support and information, and campaigning for people affected by migraine. Visit our website to subscribe to email updates and news, access migraine information and to learn more about The Migraine Trust including our support services, research and events.

Trustees
Michelle Walder (Chair)
Jenny Mills (Hon Treasurer)
Dr Brendan Davies BSc MB BS MD FRCP
Dr Fayyaz Ahmed MD FRCP MBA
Dr Shazia Afridi MCRP PhD
David Cubitt
Sir Denis O’Connor
Sir Nicholas Stadlen

Chief Executive
Gus Baldwin

The information and views given in this journal are not necessarily those of The Migraine Trust nor endorsed by The Trust · ISSN No. 0544-1153
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Cover: Gail Emmerson gives her top training tips after running the London Marathon. Read her article on p22
There have been several developments in relation to the availability of the new calcitonin gene-related peptide (CGRP) antibody migraine preventive medication.

A NICE technology appraisal process is to assess whether a treatment can be available on the NHS and the terms of this availability. We hope that both processes conclude quickly and that Aimovig and Ajovy are soon available via the NHS throughout the UK. You can find out more about CGRP antibody medication and how it works on our website, go to migrainetrust.org/calcitonin-gene-related-peptide-pathway-monoclonal-antibodies

We have been informed by Johnson & Johnson, the manufacturers of Migraleve, that they have resolved their supply issues with one of the ingredients of their Migraleve Pink tablets and that they are now available in the UK again.

The National Institute for Health and Care Excellence (NICE) technology appraisal process for Aimovig (erenumab), which is produced by Novartis, was suspended in the Spring but has recently restarted again. While, Ajovy (Fremanezumab), which is produced by Teva, is now available privately in the UK, and is due to commence a NICE technology appraisal process this Autumn.

gammaCore, a handheld medical device that enables cluster headache patients to self-administer non-invasive vagus nerve stimulation (nVNS) therapy is now available via the NHS. It must be prescribed by a specialist healthcare professional, typically a consultant neurologist. You can find out more about nVNS therapy and how it works at migrainetrust.org/transcutaneous-vagus-nerve-stimulation

They said that:

“We originally had a supply shortage issue with an ingredient in Migraleve Pink tablets, which has since been resolved. However, to begin selling Migraleve Pink tablets again, we had to work through both Johnson & Johnson and the Medicines and Healthcare products Regulatory Agency requirements, which unfortunately did take some time, but was an essential process that every over-the-counter medicine has to go through”.

We have been informed by Johnson & Johnson, the manufacturers of Migraleve, that they have resolved their supply issues with one of the ingredients of their Migraleve Pink tablets and that they are now available in the UK again.
Lisa Plotkin has been appointed as our new Policy and Research Manager. Lisa joined us from the policy team at the Faculty of Public Health at the end of July. She will lead on all aspects of our UK-wide policy influencing and research agenda.

Speaking about her new role, Lisa said: “I’m absolutely thrilled to be joining The Migraine Trust team at what feels like a transformative time for our organisation and for migraine research, treatment, and care. I look forward to working with people affected by migraine, our partners, and health professionals, to ensure that together we can make the most of it and make lasting, positive change happen for the entire migraine community.”

“Over the coming months you’re probably going to be hearing from me and/or the team with some requests for your help and feedback on our latest thinking, so thank you so much in advance for any time and insights you may be able to lend us!”

Here are three questions to help you get to know Lisa:

Where did you work before joining The Migraine Trust?

“Prior to joining The Migraine Trust, I worked in health policy roles at the Women’s Institute and the UK Faculty of Public Health and in academia where I worked on a PhD in the history of medicine.”

What do you like doing in your spare time?

“Outside of work I enjoy reading, going to museums, and spending time with my partner, Kav.”

If you were sent to a desert island and could only take one book, film and piece of music, what would they be?

“They would have to be Catch 22, because it makes me laugh a lot; the English Patient, because I think it’s beautiful; and Bach’s Goldberg Variations because they put me to sleep (in a good way!).”

WANT TO KNOW THE LATEST MIGRAINE NEWS?

Stay up to date with the latest news about The Migraine Trust, and migraine research, treatments and best practice, by subscribing to our monthly ebulletin. You can subscribe by filling in the short form at the bottom of our website migrainetrust.org
There are a range of ways to get involved with the charity, from learning more about migraine and its management at a Managing Your Migraine event, to using your experience of migraine to inform our work by joining our Volunteer Forum, or raising crucial awareness and funds during Migraine Awareness Week or by taking part in a challenge event. Here are upcoming opportunities to get involved.

1-7 September 2019: Migraine Awareness Week
A week of activity aimed at raising awareness and increasing understanding of migraine. This year we are focusing on migraine in the workplace and tackling isolation through Meet-ups. Find out more and how you can get involved on pages 16 and 17.

15 September 2019: Kiltwalk Edinburgh
Choose from a 6 mile, 13 mile, or 26 mile walk in a kilt. Thanks to the support of The Hunter Foundation, all of the fundraising will be topped up by 40%. Find out more about it at migrainetrust.org/kiltwalk-edinburgh

21 September 2019: Serpentine two-mile swim
The Serpentine Swim festival is held in and around the beautiful Serpentine in Hyde Park. It is a challenging two-lap swim set in a beautiful location. Find out more at migrainetrust.org-serpentine-two-mile-swim

28 September 2019: The North Downs 50
Take on 50km from Farnham to Reigate in this Area of Outstanding Natural Beauty, and wonderful Surrey countryside, including the climb up the impressive Box Hill with fantastic views to the south. Find out more at migrainetrust.org/the-north-downs-50

19 October 2019: Managing Your Migraine Cardiff
An event for people living with migraine or with an interest in learning more about the condition. The programme includes presentations by migraine experts, with opportunities to ask questions and meet other people living with migraine in your local area. There will be a focus on new treatments and the management of children in migraine at this event. You will also be able to learn more about The Migraine Trust and talk to staff. See the full programme and book a ticket at migrainetrust.org/events

26 April 2020: Virgin Money London Marathon 2020
The London Marathon is now established as one of the major events in the sporting calendar and the biggest annual fundraising event nationwide. Over 35,000 people run the famous 26.2 mile route through central London, from Blackheath to The Mall. Find out more about it and how to take part at migrainetrust.org/virgin-money-london-marathon-2020

Ongoing: Volunteer Forum
The Volunteer Forum works with our staff and trustees, and is a crucial part of the charity. Members of the forum volunteer their time and skills, acting as a resource pool and critical friend to The Migraine Trust by keeping the charity informed of the views and needs of people affected by migraine. The Volunteer Forum is open to anyone with migraine or a carer of someone with migraine. Find out more about it and how you can join at migrainetrust.org/volunteer-forum
Amylin is a neuropeptide that is known to have similar mechanisms to calcitonin gene-related peptide (CGRP), a neuropeptide that is released during migraine attacks and can increase the activation of the nerves that relay headache and facial pain signals to the brain. The new generation of migraine treatment that is currently becoming available is focused on blocking the activity of CGRP. This project will commence shortly and will look at if amylin and CGRP may act on common receptors in the pain processing pathways. Specifically, the research aims to demonstrate if:

1. the receptor target of amylin is present in headache and facial pain relevant brain regions
2. targeted inhibition of amylin can modulate headache and facial pain pathways
3. there is a potential migraine-relevant functional interaction between amylin and CGRP

Together, the above aims will determine the role of amylin in migraine and have the potential to develop a novel therapeutic target for the one billion people with migraine globally.

We are very excited about this project and what it could mean for furthering the understanding of the mechanisms behind migraine and developing new treatments for it. We will be interviewing the researchers in the next edition of Migraine News.

**Save the date – The 18th Migraine Trust International Symposium (MTIS)**

We host an international symposium every two years to bring together migraine scientists and clinicians from around the world to present and discuss the latest research findings.

The event includes a day where people with migraine get to learn about these findings and meet the people who are leading this research. The next event is taking place in London from 10-13 September 2020, so save the date if you are interested in attending, and sign up to our ebulletin for more details.

**Meeting our international partners**

The team from The Migraine Trust will be travelling to Dublin to attend an international conference that’s taking place there between 5-8 September. As well as meeting with a range of migraine researchers, we will be meeting with our fellow members of the European Migraine & Headache Alliance. We will be discussing plans for an international campaign to raise awareness and increase understanding of migraine.
For so many people living with migraine, seeing a headache specialist can make a real difference. From diagnosing your particular type of migraine to formulating a treatment plan and reassuring you of the realistic positive outlook, your headache specialist can be invaluable. While not everyone will need to see a specialist, here are some good reasons to be referred:

1. **If your diagnosis is not clear.** Getting the right diagnosis is the first step to creating a management plan that works for you. For example, if you feel your symptoms have changed or you have been misdiagnosed or you have more than one type of migraine.

2. **If your migraine becomes more frequent and changes in character.** It is normal for migraines to fluctuate over time and sometimes without any obvious change in your activity or treatment. It is important to keep a migraine diary to capture just a few pieces of information daily: the severity e.g. on a 0-10 scale, how frequent they occur and painkillers used.

3. **When your treatments are not working.** It is frustrating to keep taking medicines without benefit or adequate benefit, often with undesirable side effects. If you feel you have exhausted the options and have used adequate doses over an appropriate length of time, it may be time to consult a specialist.

4. **If you have a complicated medical history.** While a person with migraine’s headache history and symptoms may vary, some may have other medical conditions or may develop sudden onset headache that is out of their usual pattern and this may be adequate reason to see a specialist. Often identifying and treating another coexisting condition can improve migraine and manage the other symptoms simultaneously.

5. **If you have an unusual form or presentation of symptoms.** For example, some rare types may present with physical weakness, numbness, problems speaking, prolonged or persistent aura and visual change. Headache specialists can recognise and also offer treatments that require specialist prescription and supervision.

At present in the UK there are a limited number of specialist clinics and as such waiting times can vary. However, do not hesitate to seek a referral if it is medically appropriate to do so. Please always discuss this with your GP.

We recommend that you take the following to your visit:

- Your headache diary
- A list of current and past medicines and doses taken
- Your medical history – such as a list of any operations or procedures you have had, other conditions or family history of headache

The Migraine Trust has two Support Services – an **Information Service** (for questions about migraine and its management) and an **Advocacy Service** (for support accessing healthcare, overcoming issues at work or in education) which can be reached via our website migrainetrust.org or by calling 0203 9510 150.

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**SEEKING SPECIALIST HELP FOR YOUR MIGRAINE**

[Image]
OUR PLANS TO INVOLVE YOU IN THE DEVELOPMENT OF OUR NEXT FIVE-YEAR STRATEGY

BY GUS BALDWIN

We are so grateful to the hundreds of people affected by migraine who got involved in our recent consultation about the future of our charity.

At the end of June we drew together all the feedback we received into a series of ‘headlines’ (go to migrainetrust.org/our-three-new-draft-strategic-goals).

Perhaps the most important bit of feedback you gave us was your enthusiastic endorsement of our three new strategic goals. At the time of writing I’m still describing them as ‘draft’ because they haven’t yet been formally signed-off by our trustees. The latest version is:

1. Help find a cure – play a major role in encouraging new research and treatment to alleviate the symptoms and impairment caused by migraine and ultimately to find a cure.

2. Ensure every single person with migraine – no matter who they are or where they come from – gets an accurate, timely diagnosis, and access to the best possible information, care and treatment and has the same legal protections as other disabled people.

3. Build an active and supportive community of people affected by migraine (PABM) – this community would act as both a source of support and a movement for change.

I believe these three new strategic goals demonstrate that we are taking our new responsibilities as ‘The’ UK migraine charity extremely seriously. They are sufficiently ambitious and aspirational to set the direction of travel for our organisation for at least the next 30 years, while still feeling real and achievable enough for everyone to get behind them and to direct our charity’s day-to-day work.

They also give us the opportunity to ‘dial up’ and ‘dial down’ different aspects of this portfolio of goals as opportunities arise over the upcoming decades. But it is worth stressing that all three are equally important to us.

We are taking all the feedback you gave us during the consultation as the starting point for the development of our new five-year strategy. We plan to launch the strategy in February next year which means we’re going to be busy over the Autumn and Winter.

Your ideas, feedback and experience

We want to continue to engage as many people from the migraine community as possible in the next stages of the strategy’s development. So far we plan to:

• Undertake a major survey of people affected by migraine and others in October
• Host a number of small focus groups of people affected by
migraine around the UK. We would particularly like to visit local migraine support groups so please do invite us to your next meeting feedback@migrainetrust.org

• Seek the views of attendees at our ‘Managing Your Migraine’ event in Cardiff in October. There are still places available so please do come along. You can book a place at migrainetrust.org/event/managing-your-migraine-cardiff

• Work closely with our Volunteer Forum to see what they think

• Seek the views of ‘GPs with a specialist interest’ in migraine

• Seek the views of headache nurse specialists

• Encourage as many of you as possible to email your thoughts and ideas throughout this process to feedback@migrainetrust.org

I hope we can take our inspiration from the mental health community and the journey they’ve been on. Mental health has gone from a largely hidden, very misunderstood and stigmatised condition to Royal family endorsement and widespread acceptance that mental wellbeing needs to be a positive part of everyday conversation among family and friends and in schools and workplaces.

Imagine if we could be even half as successful in changing the narrative and transforming awareness and understanding for people living with migraine. It is from this transformation that better access to treatments, new money, new services, less discrimination and better life chances will flow.

Given where we’re starting, we aren’t going to get there over the course of the next five years. We may not even get there in 20 years. But I would like our next five-year strategy to take the first important steps on our journey of a thousand miles. We would love for as many of you as possible to walk with us, side-by-side.

Our monthly e-bulletin is the best place to find out in more detail about all these opportunities to get involved. You can sign up at the bottom of our website migrainetrust.org
TAKING MIGRAINE SERIOUSLY: A HISTORICAL VIEWPOINT
BY KATHERINE FOXHALL

Our knowledge of migraine can be traced back to Galen, the most famous philosopher and physician in the second-century Roman Empire. Galen described hemicrania as a very painful disorder affecting half the head, caused by the ascent of malign vapours from the stomach.

Medieval sources reveal how seriously people took migraine. The German abbess Hildegard of Bingen (1098-1179), explained that migraine seized only half the brain at a time because it was such a powerful bodily force that would be unendurable if it affected the whole head. In the thirteenth century, the Franciscan monk Bartholomaeus Anglicus described “hammering and pounding in the head. Sound or talking is unbearable, as is light or glare… one feels piercing, burning and ringing”.

Throughout the sixteenth and seventeenth centuries, many recipes for home-made remedies suggest a widespread common knowledge of migraine. Approaches to treatment range from simple recipes using common garden and kitchen ingredients to complicated preparations that took time and financial outlay to make, but would last for twenty years.

If, for hundreds of years, migraine had been taken seriously as a painful, common disorder, the question is when did this change?

Migraine seems to have begun to lose legitimacy in the late eighteenth century. In 1782, for example, a flamboyant quack graced a London masquerade, introducing himself as “Le Sieur Francois de Migraine, Docteur en Medicine”. In 1787, a London newspaper described how “half of Paris had the migraine”. Migraine was becoming something to joke about. By the nineteenth century, physicians talked of migraine as an illness of female “martyrs”, particularly mothers whose minds and bodies were weakened by childbearing, exhaustion and anxiety.

This history is important because it sheds light on a key problem in our own time: although migraine affects around one in seven people globally, of whom around two-thirds are women, it (along with other headache disorders) has a credibility problem, and is under-funded, under-diagnosed and under-treated.

If the beginnings of a tendency to dismiss and minimise migraine can be seen in the eighteenth century, taking an even longer view offers hope. It shows that this situation is relatively recent and, most importantly, that it can be changed.

Katherine Foxhall is a medical historian, and the author of Migraine: A History. She can be followed on Twitter @historikat.
Take Sage Rosemary and of Pellitory of Spain, the roots of three a like quantity, and boil them in a part of Vinegar upon a shalving dish of coales, until half be consumed, then put thereto two good spoonfulls of Mustard being made with good Vinegar, and so let it boile a while and then take a little of it, as bott as you can suffer and hold it in your mouth as you shall find occasion and then spitt it out, and take more and this doe five or six tymes every morning, so long as you shall fynde occasion or seeeth your sufferance.

A Plaster for the same griote to be applied after you have taken the Gargas.

Take sixe Spoonfulls of the gall of an Axe or Cowe, put thereto two spoonfulls of the powder of the Lower Wormes of the Earthe and the powder of half a Nutmeg grated. Boyde all these together upon a Chafing dish of coales un-til it be so thick as you may spreade it upon a cloth, then take a double Lynnen cloth and cutt it fitt for your forehead and as it may cover the temples, spreade this upon it, and lay it to your forehead late warme, and let it lay untill it do fall of of itself, you shall knowe the Megreeme by this it lyeth in your Browes, or in the Noddle, or in the one side of your head.

The Migraine Trust is mourning our longest serving team member, Susan Haydon. Susan ran our Information and Support Services Team and had been with the charity for 17 years.

As someone who lived with migraine herself, she was dedicated to helping people understand their condition and treatment options, and to giving them the highest quality clear and evidenced-based information.

Susan was the heart of The Migraine Trust for so many years. She was a trusted source of support for both people with migraine, their families and friends, and everyone who worked at our charity.

We are heartbroken she has gone and want to pay tribute to her.

We asked people who have worked with her for their thoughts and stories about Susan.

If you have been helped by Susan and would like to pay tribute to her too, we would love to hear from you.

You can send your thoughts to Una Farrell at ufarrell@migrainetrust.org or The Migraine Trust, 4th Floor, Mitre House, 44-46 Fleet Street, London EC4Y 1BN.
"I first met Susan nearly 14 years ago. It took quite some time to get to know her and even longer before I could call her a friend. Like most worthwhile relationships it didn’t happen overnight but I can honestly say that despite Susan being a very private person, we were friends.

Susan had a capacity for detail that I always admired as that was not really my forte. She was meticulous in her research in order to give a patient or carer the best evidence-based information for which The Migraine Trust is justly proud.

Over the years I met many people who had spoken to her on the phone and said how kind and helpful she was. She knew so much about migraine but always wanted to learn more. She enjoyed coming to our Symposia and also EHMTIC meetings when they were in the UK so that she could continue her professional development.

She taught me how to listen properly and I will always be grateful for that.

She had lovely hair and lovely clothes too.

She was approaching retirement and I’m so sorry she didn’t get the chance to enjoy her life after The Migraine Trust having dedicated so much of her working life to our charity.”

Wendy Thomas, former Chief Executive of The Migraine Trust

“I was Susan’s line-manager for the last five months of her life. She used words sparingly but that meant that when she spoke up you knew you needed to listen.

What she spoke about most and most passionately was the helpline. Or rather she spoke about helping people. The people at the end of the phone, and increasingly at the end of a computer, were everything to Susan.

No question or query was too challenging or too complicated for Susan to answer. If she needed to do a morning’s worth of research or to speak to three neurologists to find the answer then that’s just what she did.

I think she was motivated by three things. Firstly, a sense of duty to help people with migraine. Secondly, a sense that the people asking for our help were often in huge amounts of pain who already felt no one was listening, that no one cared. She was determined to show them that they mattered to us. And, thirdly, the simple ‘thank you’ she got in response to a job well done. Thank you Susan.”

Gus Baldwin, Chief Executive of The Migraine Trust

“Joining the Migraine Trust 14 years ago in June 2005 and Susan was already a well established member of staff.

My recollections of Susan are of an enormously private person who worked long hours helping people affected by migraine. She was usually surrounded by piles of journals and books that were so high that it was difficult to know whether she was there or not!

Susan was extremely dedicated and would often stay very late in the office to help people, so much so that she became responsible for setting the alarm!

I know that Susan was starting to plan for life after The Migraine Trust and was thinking about moving back to her roots in Kent when she retired. I’m so sorry she didn’t get a chance to fulfil her plans.”

Adam Speller, Chief Operating Officer of The Migraine Trust
“Susan was a dedicated and committed member of our Information and Support Services team.

She cared deeply about the quality of information that enquirers received and made sure that enquirers were happy with our service. Susan was also conscientious, ensuring that her work was research-based, precise and thorough.

She was caring and supportive of her Information and Support Services colleagues, whenever I approached her with an enquiry she would put aside her work and make sure the problem was resolved.

The Migraine Trust will not be the same without her, she will be greatly missed.”

Helen Balami, Advocacy Officer at The Migraine Trust

“I never had a bad, silly or uninformed question from Susan; an email from Susan meant pause and think because it will be well thought through.

Susan quietly, surely and carefully helped thousands; we are less for losing her.”

Dr Peter Goadsby, Professor of Neurology, King’s College London, and Trustee of The Migraine Trust

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She cared deeply that people with migraine got the most up-to-date information and worked tirelessly to provide complete answers to enquirers.

I really enjoyed working with her, she was supportive and I admired how she put her heart into her job.”

Ria Bhola, Headache Nurse Specialist at King’s College Hospital and The Migraine Trust

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Dr Peter Goadsby, Professor of Neurology, King’s College London, and Trustee of The Migraine Trust
“She was always so professional and dedicated to helping those with migraine.”
Shazia Afridi, Consultant Neurologist at Guy’s and St Thomas’ NHS Trust and Trustee of The Migraine Trust

“My thoughts go to the small, dedicated team at The Migraine Trust for whom Susan’s absence will be keenly felt.

For many years Susan was our internal expert on migraine, our first port of call before asking medical professionals. Her knowledge of the condition, the NHS, and the health sector, made her a great sounding board for ideas and approaches as we were thinking them through.

Thousands of people would have had their questions answered and their concerns eased with Susan’s input. She was a great support to me personally during my time with the charity. I owe her my thanks.”
Christine Davies, former Senior Fundraiser at The Migraine Trust

“My memory is of someone who was energetic, consistently happy to help, and always focused on the mission.”
Sir Denis O’Connor, Trustee of The Migraine Trust

“Susan was an asset of The Migraine Trust. I have been a trustee for nine years and have had many personal and professional interactions over email and face to face when I used to come down for a board meeting.

She was a very dedicated member of the staff who would be the very quickest in responding to email and returning your call. She organised staff teaching sessions on various headache topics just before the board meetings for many years. She was great in compiling responses for any media queries and above all she was a very friendly person to talk to with a good sense of humour and fun to chat to when I used to arrive early for the board meetings.”
Dr Fayyaz Ahmed, Consultant Neurologist and Hon. Senior Lecturer at Hull and Yorkshire Hospitals NHS Trust and Hull York Medical School, and Trustee of The Migraine Trust

“She cared deeply that people with migraine got the most up-to-date information and worked tirelessly to provide complete answers to enquirers.”
Ria Bhola, Headache Nurse Specialist at King’s College Hospital and The Migraine Trust
While there is an increasing awareness of migraine and understanding of what it is, not many would disagree that we are nowhere near the level of awareness and understanding that we need to reach. And we do need to reach it because lack of awareness and understanding of migraine seriously impacts our lives, with too many people not fully realising what it is like to live with this condition.

That’s why it is so crucial for us to maximize the opportunity that Migraine Awareness Week gives us. Running from 1-7 September this year, it is a moment when everyone affected by migraine and everyone working to help those affected work together to raise the profile of migraine as a complex neurological condition and dispel any ideas that it is ‘just a headache’.

We have two focuses for this year’s Migraine Awareness Week.

One is to build on last year’s workplace activity. The aim of this is to create workplaces that are ‘Mindful of Migraine’. By mindful of migraine we mean for employers to be aware of the high numbers of people who get migraine and that it is a complex, varied, and often debilitating neurological condition. We would then like employers to make reasonable adjustments once they become aware that they have an employee who gets migraine.

This is quite a simple message and one that all employers should integrate into their management of those working for them. It is also a win-win situation as mindful of migraine workplaces help employees who have migraine work better, which is good for them and the organisation.

We are delighted that the Civil Service, which employs tens of thousands of people from across the UK, has embraced...
this message. They are working with us on a campaign to increase understanding amongst their employees of what migraine is and how it can be managed effectively at work. While this activity launches this Migraine Awareness Week, it will be an ongoing project that aims to ensure that everyone working for the Civil Service is aware that their employer takes their condition seriously and wants to help.

Despite potentially reaching large numbers of people through this campaign, there is still far too many people working in environments that aren’t mindful of migraine. If you would like to help change that, please get in contact with us to talk about how we could work with your organisation on becoming mindful of migraine.

Meet-up for Migraine Awareness Week

The second focus of this year’s Migraine Awareness Week is tackling the isolation that people with migraines can face and encourage them to talk to their friends and family about it.

It has been wonderful that so many people have held Meet-ups since they launched. We love seeing the pictures from your Meet-ups and hearing about them, particularly how they have helped you talk about migraine. Many of you have also used them as an opportunity to thank your friends and family for supporting you with your migraine.

We also love the recipes that you have been sending us!

If you haven’t held a Meet-up yet, Migraine Awareness Week is a great time to hold one. If you don’t have time to hold one this year, you could also take time during the week to set a date for one and start to organize it. We have a range of resources to help you, including a Meet-up pack with tips to keep you organised, baking tips, a quiz, cake flags, bunting and a menu poster. Get in contact with Sean at skendall@migrainetrust.org or 0203 9510 150 to find out more about our Meet-ups and request a pack.
You might recognise some of these feelings. They, amongst many others, are the downside of migraine. However, there is an upside. I didn’t choose migraine and I certainly wouldn’t recommend it, but its presence in my life is not entirely bad. Your experience will be different from mine but I think there will be some positives we have in common.

Never knowing when you will feel well and when you will feel terrible alters your habits. A natural procrastinator, I find myself packing for holidays in advance. The thought of trying to do it right before a flight, mid-attack, is just too awful to contemplate. I try to seize opportunities when I’m having a good day. I don’t know if I’ll get another chance. Effective prioritising is another welcome by-product. Nobody wants to waste a migraine-free day.

Trying to manage your health gives you a very useful skillset. How often have you been looking for triggers when you notice you’ve been working too hard or not eating properly? You might have overlooked these things if you didn’t get migraine. Having noticed them, you can act accordingly. At the very least they will likely increase your general wellbeing. In addition to this you get to know yourself really well. You may not have all the solutions but your research skills are excellent. You are your own specialist subject.

Migraine stigma is something we all have to deal with, whether we notice it or not. Sometimes it slaps us in the face, like the poorly placed joke in our favourite sitcom. Other times it is much more subtle. Either way, this experience makes us more compassionate. We take notice of the way others are treated, by the media and individuals. We modify our own behaviour and stick up for our friends where we can.

There is, however, one feature of migraine I favour most of all.

The morning after that wintry Tuesday, I woke up feeling fantastic. I had an inexplicably clear head and energy to burn. In another life this might have gone unnoticed but the contrast with the day before, and the way I had expected to feel, felt magical. I was happy and healthy and knew how precious both these things were. Dancing around the kitchen that morning is one of my favourite memories of the past few years.

We lose many things to migraine but we gain a depth of knowledge, empathy and appreciation that is hard to rival. There really is nothing like it.
We have various events and challenges you can take part in; whether you are looking to increase your long distance running stamina, want the adrenalin rush of a skydive or fancy having a go at wild swimming.

You can achieve your ambitions, raise awareness of migraine and much needed funds for The Migraine Trust all at the same time!

For more information visit our website at migrainetrust.org/fundraising-events or speak to Sean on 0203 9510 150 (press option 3 when prompted)

Edwin Price and Helen Reid ran the London Landmarks Half Marathon

Hannah Young walked the South West coast path, a total of 705 miles in just 59 days

Michael Clark was out and about at summer events in West Yorkshire with his vintage fairground organ

Gail Emmerson took on the London Marathon and completed it in a very impressive four hours and 55 minutes. If this inspires you to take on a similar challenge you can read Gail’s training tips on page 22!

During the Edinburgh Marathon festival in May, Nici Thornton ran her first Edinburgh Half Marathon and Paul Johnston ran the Edinburgh 10k

Abigail Berry went retro and ran the 1950s themed Liverpool Rock & Roll half marathon

Vicky Staples ran the Greater Manchester Marathon; you can read more about Vicky opposite

Together they have raised a fantastic £6,889 in support of The Migraine Trust. Congratulations and a huge thank you to you all!

We are pleased to celebrate the success of our fantastic fundraisers:

We are pleased to offer a range of four new Christmas cards for 2019. Packs of 10 cards are just £4.50 each and sending them to family and friends is an easy way to help spread awareness of migraine. We have limited stock so please get your order in early.

To have a closer look at the designs and to place your order visit our website at migrainetrust.org/support-us/shop/christmas or email fundraising@migrainetrust.org

Inspired?

Getting ready for Christmas!
I was on the school bus aged 14 when my friend asked me what I was doing because I was trying to crawl under the seat! I was scared, I had lost the vision in one of my eyes and was starting to lose the feeling in my fingers. The bus was loud and I believed crawling under the seat would help. It wasn’t until later my mum told me that what had happened to me was a migraine.

I have suffered regularly since. I have migraine with auras so I will lose my vision, then the feeling down one side of my body and then lose the ability to speak which is not great when you are trying to tell people what is happening to you. I then will have a severe headache that will leave me unable to function. For a few days after even brushing my hair can be difficult as my head is tender from the swelling.

It has been a difficult journey juggling medication and their side effects. My GP has now put me back on beta blockers and this has been mostly positive as I’ve only suffered three attacks since.

Thank you for reading my story, spreading the word about migraines helps non sufferers understand what happens when an attack happens. I also want to thank my family and friends who have been with me when I have been unable to function due to an attack and looked after me.

Vicky Staples ran the Manchester Marathon for us in April and describes below how migraine has had a dramatic impact in her life:

BEATING MIGRAINE TO THE FINISH LINE

Vicky Staples ran the Manchester Marathon for us in April and describes below how migraine has had a dramatic impact in her life:
Gail Emmerson gets regular migraine and so do several of her family members. She wanted to take it on by raising awareness of the condition and funds for research and support services. This is her marathon story.

“I was super nervous on the morning of. I don’t think I slept much the night before which was a real worry because I know that lack of sleep can trigger my migraines. We’d booked the Holiday Inn London Marathon package which took a bit of the stress out of getting to the start line because they provided an early breakfast and a coach for all the runners. I ended up meeting two really great girls (one who I still keep in touch with now) on the way to the start line which was brilliant because we had a lot of time to kill waiting around!

The marathon itself was incredible. When the three different start lines all came together after a couple of miles, it was a bit of a ‘wow moment’ for me and I could feel myself starting to get emotional! The first six or seven miles was all about people coming out of their houses to cheer everyone on and giving loads of high-fives to children along the route – I loved it!

I got to see my family twice – once just after Tower Bridge along The Highway going one way and then again when you go back along the same road. I stopped to hug them but couldn’t stay too long as I’d have found it hard to get going again. Knowing that I was going to see them twice kept me going!

26.2 miles is a long way! I’d only managed to train up to 20 miles a couple of times and that last 6.2 miles should not be underestimated. At this point, I had developed shoulder and arm pain that I’d not had in training. It made running a lot harder but knowing that so many wonderful people had supported and sponsored me, kept me going.

Running down The Mall with Buckingham Palace behind me was absolutely amazing. I tried so hard to take it all in and somehow forgot about all the pains I was having and managed to run through the finish line with a huge smile on my face!

I would love to thank my family, friends and supporters (a few who I didn’t even know) for believing in me and for helping me raise a lot of money for a great cause so close to my heart (and head). Their support and sponsorship meant the world to me and I’ll never forget that.”

Gail’s top training tips for people with migraine:

• Factor in some contingency into your training schedule – there were times when I couldn’t get out for a run because of having migraines but knowing I still had lots of time to train took the pressure off me.

• Which brings me on to, don’t go out if you’re not feeling it. There were times when I suspected that by going out, I might give myself a migraine so I didn’t run or I’d do a shorter run closer to home just in case.

• Keep well hydrated and eat as often as you can. Try not to let the training impact too much on your usual eating routine if, like me, not eating can trigger a migraine.

• Rest as often as possible. Your body goes through a lot and if tiredness causes migraines then ensure you give yourself enough rest when you’re upping your mileage towards the end of your training.

• Keep remembering why you’re doing this! Training is tough (tougher than the marathon itself) but thinking about my sponsors and supporters and why I was doing this kept me going. I was lucky enough to have amazing support from my family. My husband and the kids were very understanding about my training schedule (we had to cancel tickets to some events like the snooker world championships and avoid booking a holiday in the Easter holidays).
Together we can beat migraine
Please support us and help improve the lives of people living with migraine.

Your details
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First name: _____________________
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Your donation
I wish to make a single gift of £48 – to cover the cost of responding to an enquiry made to our support services.
I enclose a cheque/CAF voucher made payable to The Migraine Trust OR
Please debit my credit/debit card. Complete details below.

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Instruction to your bank or building society to pay by Direct Debit
Service User Number: 838322
Please pay The Migraine Trust Direct Debits from the account detailed in this instruction subject to the safeguards assured by the Direct Debit Guarantee. I understand that this instruction will remain with The Migraine Trust and details will be passed electronically to my bank/building society.

Bank/Building Society name: __________________________
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Account number: __________________ Account Sort Code: __________
Signature(s): __________________ Date: __________

I would prefer not to receive an acknowledgment for my donation today

Together we can beat migraine
Please support us and help improve the lives of people living with migraine.

The Migraine Trust is a registered charity in England and Wales (1081300) and Scotland (SC042911)
Please complete the form below to Gift Aid your donation

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Boost your donation by 25p at Gift Aid for every £1 you donate

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*Please notify us if you wish to cancel this declaration, you have changed your name or home address or you no longer pay sufficient tax on your income and/or capital gains.

Staying in touch

We will securely record the information you have provided to process your donation and to keep you updated with developments in migraine research and treatment. Please select from the options below how you would like to hear from us.

☐ Monthly e-bulletins Email address: ___________________________

☐ Twice-yearly updates by mail (including details of our Managing Your Migraine events)

☐ Biannual journal Migraine News (minimum annual Direct Debit donation of £30 required)

☐ Please do not contact me by email

☐ Please do not contact me by mail

We will process your personal information for these purposes which may include collecting your donation, sending you information you have requested, and ensuring we are working efficiently as a charity that supports people living with migraine. We will never sell or swap your personal information with a third party without your consent. Examples of how we may process your data can be found in our Privacy Policy, which you can access on our website at migrainetrust.org/privacy-policy or alternatively you can request a copy by emailing ufarrell@migrainetrust.org.

You have the ability at any time to request that we no longer process your personal information by emailing info@migrainetrust.org. If you do opt out please bear in mind that this will limit our ability to carry out tasks for your benefit.

To find out more about The Migraine Trust, and to support our work, visit www.migrainetrust.org/support-us.

Please return this form to: Freepost RUAE-EGGG-KXKG, The Migraine Trust, Mitre House, 44-46 Fleet Street, London EC4Y 1BN.