CHit CHat

The Official Newsletter of OUCH (UK)

The Organisation for the Understanding of Cluster Headache

Spring and Summer 2024
Liverpool Conference Edition
9th June at Liverpool Medical Institution
Book early to ensure your place

www.ouchuk.org - Advice Line 0800 6696 824

OUCH(UK) Trustees

Professor Peter Goadsby
Patron of OUCH (UK). World authority on cluster headache and is chair of the IHS classification group. Currently conducting research at Kings College Hospital into use of CGRP [calcitonin gene related peptides] for the prevention of cluster headache.

Colin Allen (Vice Chairman)
Colin is an Episodic Sufferer. His long service in the charity as Advice Line Manager and now as Vice Chairman, brings considerable knowledge to the board. Colin is 'retired' and lives in Liverpool.

Dorothy Chapman
Dorothy has been an episodic sufferer for more years than a lady should admit to. She has been a member of OUCH (UK) since the early days of the charity and became a trustee in 2014. Dorothy enjoys liaising with our fabulous fundraisers and promoting their very varied and exciting events.

Dr Nicholas Silver
Consultant neurologist in Liverpool. Clinical and research interests in cluster headache and its optimal management.

Elizabeth Kelly
Liz is the charity's Advice Line Manager. Liz joined OUCH in 2006 and has worked as a volunteer on the advice line since 2007. Liz has helped hundreds of people during that time and she brings considerable experience to the role.

OUCH(UK) Trustees

Valerie Hobbs
Val is a chronic sufferer who joined OUCH in 2002 and in 2003 became an advice line volunteer, taking over the running of the advice line when the original manager retired. In 2006 Val became a trustee, but stepped down in 2010 to take on the administration of the charity and Liz Kelly took on running the advice line. Val has now become a Trustee again, with oxygen for CH in the UK as her remit.

Anne Turner
Anne first joined OUCH (UK) as supporter of a Cluster Headache sufferer and went on to become a Trustee in 2019. She now carries out some administrative work for OUCH, deals with membership and manages OUCH's online shop.

Dale Nolan (Treasurer)
Dale joined OUCH in 2021 after his son Oscar's diagnosis of CH at age 17. Dale is keen to help OUCH support sufferers, support research and build awareness in any way he can. He accepted the position of Trustee and Treasurer in 2022.

Dr. Anish Bahra, FRCP, MD, is a Consultant Neurologist affiliated with Cleveland Clinic London. She completed her neurology training in New Zealand and London, gaining expertise in headache disorders. Dr. Bahra conducted research on Cluster Headaches at University College London Hospital (UCLH) Institute of Neurology.

OUCH(UK) Officers

All the present Officers are sufferers or supporters of sufferers, and provide full support and help to the trustees, sufferers and their families.

Audrey Leng (Advice Line & Membership)
Audrey was diagnosed with Episodic Cluster Headache in 2009 and has been a member of OUCH (UK) since 2011. Over a decade ago, Audrey made a call to the OUCH (UK) Advice Line and through that one call and subsequent emails, she was able to get the right treatment to manage her Cluster Headache effectively. She has been volunteering on the Advice Line since September 2020 and more recently has been dealing with membership administration.

Liz Eden (Advice Line)
Liz is the mother of a Chronic Cluster Headache sufferer. She called the Advice Line once when she was at her wits' end and says she learned more about Cluster Headache from that 40 minute call than she had for the previous two years. Now retired after being a long-term manager at BA, she wants to give something back and help sufferers and their families the same way she was helped.

Vicky Ricketts (Advice Line)
Vicky has suffered with Cluster Headache and also Hemicrania Continua for many years. She says OUCH (UK) has been a lifeline for her and she is very happy indeed to be able to give something back.

Gary Brampton (Advice Line)
Gary suffered his first Cluster Headache attack at the age of 18. His daughter is also a sufferer now.

Rachael Wood (Support for children and young people with Cluster Headache)
Rachael joined OUCH (UK) in March 2020 after her son Frederick's diagnosis of Chronic Cluster Headache at age 11. She is keen to help other parents and children navigate their way through a Cluster Headache diagnosis and to assist with practical advice and support for families living with Cluster Headache.

www.ouchuk.org - Advice Line 0800 6696 824

OUCH(UK) Officers

Jamie Charteris (Artwork, design and humour)
Jamie has been an Episodic Cluster Headache sufferer since the late 1980s and was diagnosed as such in 2014. He considers himself very lucky, as usually he has eighteen months to two years 'off' then has a bout of a few months. Jamie has been a cartoonist, predominantly for the greetings card industry, for over forty years. He also illustrates and writes fiction.

John Poore (CHit CHat Editor) John is a chronic sufferer who joined OUCH UK in 2018 and took on the role of Editor in 2019. As well as helping with OUCH he enjoys building and competing with his radio controlled model boats, playing croquet and generally keeping fit.

OUCH(UK) Membership Report 2024

Please consider subscribing as a full member. Your membership of OUCH (UK) enables us to reach out and help others who suffer the same terrible condition that you do. Our charity will grow as the membership grows and our collective voice gets louder and louder.
All our Trustees and officials are volunteers and sufferers or supporters of sufferers. The charity receives no government or commercial funding but relies entirely on annual membership subscriptions along with fundraising activities and donations by our generous supporters. These enable us to maintain our website, run our all important telephone and online Advice Line, provide printed and online information for the public and health professionals and generally help raise awareness of the devastating pain of this illness.
We have contact with neurologists around the country who specialise in headache, not least our distinguished patron, Professor Peter Goadsby, now at King’s College, London. We are a member of Headache UK, an umbrella organisation of headache charities.

Join OUCH(UK) at: www.ouchuk.org

Membership benefits include -

- the ability to post on the website forum and join in discussions
- a 10% discount on items in our online shop
- a substantial discount on tickets for OUCH conferences
- access to a small number of members only pages of our website
- email updates with news about the latest medical research, surveys, trials and issues of CHit Chat

What does OUCH(UK) do

Our Key Areas of Work	How We Deliver
Advice	• Advice Line • Online materials and links
Awareness & Education	• Informational / educational leaflets, posters and papers • Website and online materials • Social media presence Facebook / X / YouTube • Conferences
Support & Community	• Website forum • Facebook group • Conferences
Research	• Provide access to the OUCH community for research purposes • Directly commission research • Support research done by NHS and other organisations
Advocacy	• **Participation in relevant bodies**: NICE / NHS Trusts / Charity Groups / Parliamentary Groups / NHS Oxygen Safety Group / Chronic Conditions Team • **Working hand in hand with associated charities:** British Association for the Study of Headache / National Migraine Centre / The Migraine Trust / The Brain Charity / The Brain and Spine Foundation and others

OUCH(UK) in Numbers

65,000

estimated Cluster Headache sufferers in the uk (1 in a 1,000)

9,500

members of the OUCH Facebook forum

800

OUCH members

100

attendees at the annual conference

350

calls to the Advice Line per year

130

consultations for CH sufferers by the National Migraine Centre per year

15

Trustees and officers of OUCH, all volunteers

Cluster Headache Awareness Campaign 2024

CLUSTER HEADACHE?

CLUSTER HEADACHE is a rare neurological disorder causing excruciating attacks of pain on one side of the head, centred in and around the eye on the affected side.

Attacks can last 45 minutes to 3 hours (or more) often at the same times of day and night, frequently waking the sufferer from sleep.

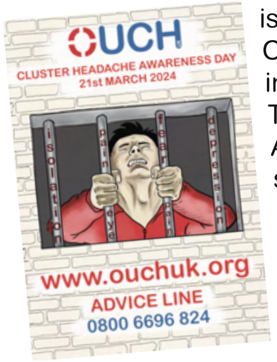
Attack symptoms can include some or all of the following:
- Agonising pain in the eye and surrounding area
- Watering of the eye
- Swelling / drooping of the eyelid
- Runny / blocked nostril
- Changes in the pupil of the affected eye
- Sweating / raised temperature
- Extreme restlessness / pacing up and down / rocking backwards and forwards

Treatment for acute attacks - as recommended by NICE:
- Sumatriptan injections or intranasal sumatriptan / zolmitriptan
- Short-burst high-flow 100% oxygen with non-rebreather mask

There are two types of the condition:
EPISODIC Cluster Headache attacks occur in bouts, or clusters, lasting several weeks or months, after which they disappear, sometimes for months or even years.
CHRONIC Cluster Headache sufferers do not get this relief, and their attacks continue daily for years without a break.

NEUROLOGISTS WHO DEAL WITH CLUSTER HEADACHE HAVE DESCRIBED IT AS ONE OF THE WORST PAINS KNOWN

A key aim of OUCH UK is to raise awareness of Cluster Headache within the medical profession and the general public. We are also keen for CH sufferers to be aware that OUCH UK may be able to give advice and support when they need it most.

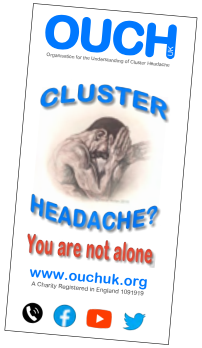


As you may know, March 21st every year is Cluster Headache Awareness Day. OUCH UK makes a special effort to increase awareness of CH on that day. This year, we produced some new Awareness Day posters featuring a CH sufferer as a prisoner of pain, some new posters outlining the symptoms of CH with the NICE approved treatment guidelines, and some new Awareness badges and car stickers. These items are all still obtainable from our online shop. We urged and still urge sufferers to take these posters and some OUCH UK leaflets along to their local GP surgeries, pharmacies, dentists and hospitals.

We also issued a press release focussing on the various treatment guidelines which are available to assist GPs in prescribing for CH sufferers in advance of them getting a confirmed diagnosis from a headache neurologist. This is particularly important nowadays in view of the extremely long waiting times before patients can see a consultant, during which time they may suffer horrendous pain with no treatment whatsoever.

In addition, we are now working to provide all hospitals in the UK with our OUCH posters and leaflets - we would love to know if you spot any of these on your hospital visits. Don't forget - if you would like to help distribute these, you can get them in packs of five from the OUCH UK online shop for a nominal charge. Many thanks for any help you can give!

Raise awareness everywhere you drive with our brilliant car sticker! 100mm diameter

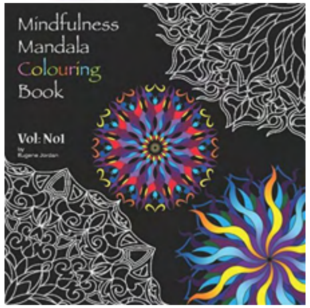


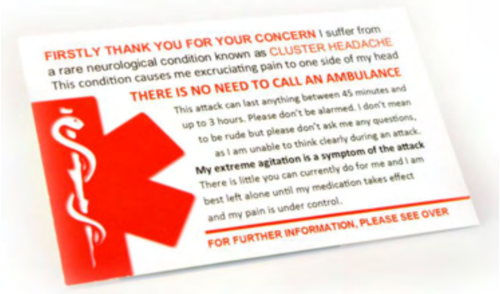
Awareness leaflets, three fold, packed with information

Round Pin Badge
Cluster Head Awareness
38mm diameter

OUCH (UK) ONLINE SHOP

If you haven't visited our online shop yet, have a look on our website at www.ouchuk.org/shop to see OUCH's range of awareness products. These include colourful t-shirts, badges, wristbands and our extremely popular information cards, which can be shown during a CH attack to explain to others what's going on.





FIRSTLY THANK YOU FOR YOUR CONCERN I suffer from a rare neurological condition known as CLUSTER HEADACHE
This condition causes me excruciating pain to one side of my head
THERE IS NO NEED TO CALL AN AMBULANCE
This attack can last anything between 45 minutes and up to 3 hours. Please don't be alarmed. I don't mean to be rude but please don't ask me any questions, as I am unable to think clearly during an attack.
My extreme agitation is a symptom of the attack
There is little you can currently do for me and I am best left alone until my medication takes effect and my pain is under control.
FOR FURTHER INFORMATION, PLEASE SEE OVER

At the Liverpool Medical Institution

Sunday 9th June 2024

OUCH (UK) are pleased to be able to return to Liverpool to present a packed event specifically for Cluster Headache sufferers and supporters.

As usual, the event will be a mixture of talks by the UK's leading Cluster Headache specialists, information sessions and an opportunity to meet and talk with other Cluster Headache sufferers to share experiences and meet and make new friends.

Our medical speakers will take you on a journey through Cluster Headache and other primary headache disorders, telling you about the current treatments available as well as what studies and trials are on-going and what the future holds for Cluster Headache treatment and management.

Confirmed Speakers for the Event:

- **Professor Peter Goadsby**, Professor of Neurology, King's College Hospital, London, patron and chair of OUCH (UK)
- **Dr Nick Silver**, Consultant Neurologist, The Walton Centre, Liverpool
- **Carl Bradley**, Advanced Nurse Practitioner, The Walton Centre, Liverpool
- **OUCH (UK) Trustees and Officers**

Breakout sessions:

- **OUCH Advice Line Breakout Session**, including resources for sufferers and supporters, diagnosis, preventative and abortive treatments
- **Oxygen Workshop**

There will be a quiet room with O_2 available

Throughout the day there will be plenty of opportunities to chat to our speakers, trustees and officers, as well as other sufferers and supporters.

Back by popular demand in the afternoon will be a targeted set of group discussions on various topics that affect sufferers; this is a chance to question the OUCH (UK) team and each other about treatments and employment support, as well as more general questions.

A light sandwich lunch, morning and afternoon refreshments will be provided. If you have any food allergies or special requirements please let us know during the booking process.

Tickets are available securely on our website

As a thank you for past support, we are offering **free tickets** for members this year.

When you book your ticket online you **MUST** be logged into the OUCH (UK) website as a current member to be able to book your free ticket.

Member Adult FREE / Child FREE, Non Member Adult £5.00 / Child £2.50

If you aren't a member already, why not sign up to support the charity and get a range of discounts and benefits.

IF YOU ARE ABLE TO DONATE

If you feel you are able to make a donation to help fund the cost of the conference and other OUCH(UK) activities, it would be much appreciated. Thank you.

If you have difficulty logging into the website or are not seeing your free ticket, please check you have a current membership first and then contact info@ouchuk.org BEFORE completing your purchase.

SUFFERERS IN RECEIPT OF UNEMPLOYMENT BENEFITS

At OUCH (UK) we completely understand how devastating CH can be for a family. Thanks to generous sponsors and fundraisers, we always make a number of seats available to sufferers who cannot afford the ticket price but who would benefit greatly from attending the conference.

If you and a loved one would like to attend the meeting, but are unable to afford the tickets please email dale@ouchuk.org in complete confidence.

We hope to see you there.

Registration from 9.30am with 10.30am start and welcome address.

Venue: Liverpool Medical Institution,
114 Mount Pleasant,
Liverpool, L3 5SR
https://maps.app.goo.gl/VkRYD39DKP5ofoBn6

Directions/Travel Details: https://www.lmi.org.uk/visit-us

Why not join us as a volunteer?

Have you ever thought of offering your services as a volunteer? Have you got skills that could help your charity? If you feel you have the time and commitment, OUCH (UK) is looking for volunteers.

Experience in PR, editorial, IT skills or background of fundraising would be particularly useful. Any Advice Line volunteers will receive necessary training.

Please contact submissions@ouchuk.org for further information.

Play our lottery for a chance to win up to £25,000!

onelottery

RAISING FUNDS ETHICALLY FOR SMALL GROUPS, CLUBS AND CHARITIES

Here's a new way to support your charity - we've joined a lottery!

- Tickets only cost £1 per week
- 50% of all tickets sold from our page go to us
- Support us and you could win prizes of up to £25,000!

Buy tickets through the OUCH (UK) page to help our cause.
www.onelottery.co.uk/support/ouch-uk

Play for a chance to win cash prizes and OUCH(UK) receives 50% of every ticket sold from our page!

Being part of One Lottery means that with your support we can generate regular sustainable funding. Buying a ticket through One Lottery is one way you can help us to continue to grow and provide our services. So whether you buy 1 ticket or 10 tickets, thank you!

Supporters must be 16 years of age or over.

Good luck!

OUCH (UK) and Oxygen Therapy - Valerie Hobbs

Speaking as a lifelong sufferer who became chronic in middle age, discovering from OUCH the benefits of oxygen was one of the best things that happened in my CH life. That was 22 years ago! At that time the only NHS oxygen available was a cylinder with a low flow regulator 2 – 4 litres a minute. When I joined OUCH, I learnt that CH patients needed high flow oxygen [8 to 15 litres a minute] and they had a high flow regulator loan scheme, run by our own 007 [his membership number] Curt Eijvergard . I ordered a loan regulator and I could then abort an attack much more quickly, working for about 80% of the time.

In 2003, OUCH mounted a campaign to get members to write to their MPs and ask them to approach the NHS to adopt high flow oxygen therapy as standard for cluster headache sufferers. We were successful. The masks at that time were okay, but only delivered about 26% oxygen – for successful abortion of an attack CHers need as near 100% oxygen as possible. One of our members discovered that if we used a non-rebreather mask – like those that paramedics use on portable oxygen cylinders – it delivers near 100% oxygen. To me, the non-rebreather mask meant that I could abort an attack within about 20 minutes – half the time it took with the NHS standard mask, if it worked at all. And this turned out to be the case with other oxygen users. With help from the oxygen companies and a change to the home oxygen order forms [HOOF] the non-rebreather masks became the standard mask prescribed for CHers.

Then in 2009, our late chairperson, Mike Pollock, on a trip to the USA discovered that using an ultra-high flow [demand valve] oxygen mouthpiece, the attack time was reduced to 8 to 10 minutes. OUCH did an anecdotal comparison study comparing demand valve oxygen with standard high flow oxygen. The actual demand valve mouthpiece will be familiar to those who have had entinox pain relief, particularly ladies who have had children! The oxygen is only released when the patient inhales and it is then shut off when the patient exhales – it's not blasting out all the time as with high flow oxygen. Because it works in this way it is very safe to use – it's not being absorbed into skin or clothing, or leaking out round the edge of a face mask. The flow rate is governed by the patients inhalation, but you are getting 100% oxygen. And because the oxygen doesn't blast out 100% of the time, it is very economical to use. In 2014 Mike Pollock presented a paper to the All Party Parliamentary Group on Headache Disorders on demand valve and identified a cost saving of £2.5 million to the NHS if all CH patients had demand valve.

Demand valve is available throughout most of England and Wales, if you are unable to get demand valve contact the Advice Line for guidance, or val@ouchuk.org. OUCH is working to ensure this treatment becomes available throughout the UK, but this takes time and the pandemic has not helped.

In December 2019 we began to hear of the first cases of Covid 19 in China and its gradual spread over the world. By late March 2020 we were under lockdown and struggling to buy toilet rolls and PPE, and the spring equinox meant episodic sufferers were likely to be going into cycle. Then for the CH world there came a drastic supply problem – oxygen cylinders. One of our members was contacted by their local respiratory nurse to say that they needed to arrange a time for the sufferers oxygen company to collect their cylinders as they needed them to supply the Covid hospitals springing up in the UK. The member asked could they keep the cylinder they were currently using, and just surrender their spare cylinder/s, but was told by the nurse, "no, the covid patients need it more than you do, after all it's just a headache." The shocked member contacted OUCH and asked did they know about this surrender of oxygen cylinders from CHers. Shortly after this call, another member in the same region contacted OUCH with a similar problem. OUCH contacted the four oxygen supply companies in the UK and they assured us that there was no shortage of oxygen cylinders, but they did ask if it were possible to do so for oxygen users to surrender their spare cylinders and order a replacement for the one they kept when it was getting low, not when it was completely empty, and not to over-order when requesting a replacement. They also gave us a key piece of information that the respiratory nurse had not mentioned – the surrender of oxygen cylinders was voluntary and not compulsory. The concerned member spoke to the respiratory nurse again who said yes, they could keep their existing cylinder and only surrender the spare cylinder if they wished. The member said they would surrender their spare, as long as there was a speedy supply when a replacement for the existing cylinder was ordered. We wrote to all our members and put announcements on our website and on our Friends facebook group to ask that if possible spare cylinders be surrendered, but that it was entirely voluntary to do so; and not to over-order replacement cylinders.

Further discussion with the oxygen companies told us that if the patient was using oxygen in a hospital setting, the cylinder oxygen would be of no use. Hospital oxygen is in the enormous containers you see at the back of hospitals and is supplied through connections at the patient's bedside. The only possible use in Covid for cylinder oxygen might have been if the patient was at home and needed back up oxygen, but high flow oxygen and demand valve oxygen would not have been prescribed for recovering Covid patients, it would have been low flow or via concentrator. We have had contact from two or three members who have had Covid, at least one has had it very badly and was diagnosed with Guillain Barre syndrome – a rare neurological condition. The patient concerned was on a ventilator for some time and at first was unable to walk. They are much better now, but they have long covid as well as the Guillaine Barre syndrome. We wish them well as soon as possible.

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OUCH (UK) and Oxygen Therapy - Valerie Hobbs (cont'd)

On the demand valve front, please let us know if you are having difficulty accessing this type of oxygen therapy. We are working on getting demand valve oxygen therapy as standard for CH sufferers and we need to know what problems you are experiencing. Please, either call the Advice Line, or e-mail val@ouchuk.org. If you want to know more about demand valve oxygen, please read the documents in the downloads section of the OUCH[UK] website.

Demand valve

Non-rebreather mask

The Knight of the Flight by Christopher Evans

Shadows to the left,
Red Bulls to the right,
Is that the beast lurking?
Looking for a fight?

The Knight of the Fight,
Armed to the Teeth,
With triptans and O2,
I'll make this fight brief!

The beast stalks me stealthily,
Thinking I'm unaware,
And pounces when my focus,
Is having fun and elsewhere.

I roar at the beast,
And my visor falls,
As I reach for the triptan,
Struck with bites and mauls.

We tangle and tussle,
We roar and we shout,
Claws, teeth, fists and kicks,
I'm sorting this out!

The Knight of the Fight,
Reaches down for the tank,
The beast ups his game,
He's got more in the bank.

The mask is well fitting,
The gas is unleashed,
O2 floods my body,
The beast's suddenly beached!

His claws are retracted,
His teeth are ungrown,
Baring frightening gums,
He fights on, nowt but bone.

The triptans kick in,
And the beast breathes no more,
I raise my sword high,
"I beat you" I roar!

The Knight of the Fight,
Fades into the mist,
Rocking, sitting and moaning,
The beast can't persist!

The Knight of the Fight,
Will always be there,
To take arms and battle,
Anytime. Anywhere!

Reasons behind donations to OUCH (UK)

Here are some of the reasons our most recent donors have given for making a donation.

- My son has cluster headaches
- Have and continue to suffer from CH for the last 25 years. Whilst a cure remains distant, having somewhere for sufferers to talk and to be understood is vital.
- Good cause
- Need a cure for this painful problem
- Donating as my sister in law suffers from these headaches
- Donating as a Christmas gift for our dear friend, who is a sufferer of cluster headaches.
- My nephew was a sufferer so I would like to help support others in the future.
- Brother in law suffered badly from cluster headaches for many years
- In memory of my friend who suffered terribly with this condition and took took his own life in the Summer
- My father suffers with diagnosed Chronic Cluster headaches, and has done for over 15 years, which have destroyed his previous way of life, and seeing it up close and personal all I can ever hope for is that enough research can be done to either find a cure, or find some kind of medication/physical therapies/anything that might give him and others, respite away from this horrendous, evil, ailment. And in the meantime, I hope people are given the support they need to try and cope with CCH
- A lovely lady was very supportive to me when my son was suffering headaches. Forever grateful x

The most recent comment from a sufferer who is benefitting from a nerve block:

"Ouch uk has been so valuable to me in getting the right support. Without them I really don't believe I would be here."

Winner of the Les Charlton Award 2023

We were delighted to present Dr Anish Bahra with the Les Charlton Award at our Summer Conference on 9th July 2023.

This award is given to honour the memory of our late, great chairman and we're sure that Les would agree with our choice of recipient. Dr Bahra is a great supporter of the cause and she was also presented with an OUCH (UK) Honorary Lifetime Member certificate.

The awards acknowledged Dr Bahra's dedication to cluster headache and other TAC sufferers and it was a pleasure to extend our congratulations and thanks for her continued support of our charity in this way.

Fundraising Highlights

Sarah and Simon Virtual Vitality

London 10k September 2023

When OUCH member Sarah White was emerging from another horrendous cycle of cluster headaches, she celebrated by planning another virtual 10k! She managed to persuade her husband, Simon, to join her. Many thanks to them both.

Fundraising Highlights

Great North Run - 8th September 2023

Tracy Wakefield

A massive thank you to Tracy Wakefield. Yet again she completed the Great North Run for us. This time it was in blistering heat and then she got drenched to the skin in a torrential downpour which flooded the roads. She was stuck in the pub as the roads were gridlocked - well what's a girl to do!

Edinburgh 5K

Sunday, 20th January.

Many thanks to Yasmin Doyle for taking part in this event in aid of OUCH (UK). Yasmin ran it in 34.09 mins - well done!

PLYMOUTH 10K 28th April 2024

Sadie Sharpe completed Plymouth 10k

Sadie raised over and beyond her target for OUCH (UK) - she ran the whole way except for a very brief walk break at 9.75K to catch her breath and then powered through the finish line.

Sadie says that electrolytes do really help with the exertion headaches but thankfully it was pretty cool day.

We are Steffy, Kostis and Fiona, Clinical Nurse Specialists at King's College Hospital and we care for patients diagnosed with primary headache disorders.

We were very lucky to be given the opportunity, through the generous support of OUCH (UK), to attend the International Headache Conference (IHC) in Seoul, South Korea.

During this time we attended many lectures, seminars and poster walks to enhance our knowledge and be able to bring evidenced based- updated practice back to our day to day working.

One of the most impactful sessions, for us, was the nurse session where we saw, in depth, how other services functioned and how we could implement some aspects into our own practice.

Fiona: I really enjoyed seeing the nurse session and especially the emphasis on patient empowerment. I truly believe that all Headache Patients are 'experts' in their own condition, so our role is to ensure that they are listened to and supported to steer their own care. In the presentation, the importance was shown that through dialogue and education patients are able to feel, overall, more in control and less anxious with their condition which is also supported when given better access to resources.

Another interesting point that I have started to keep in consideration when reviewing patients that are suffering with 'refractory' Chronic Cluster Headache would be the evaluation of possible medication overuse (with a migrainous biology background) alongside other possible exacerbating factors.

We also participated in collecting data to be a part of a poster having audited patients who were experiencing vertigo with their headache. We reviewed whether treatment with CGRP monoclonal antibodies was effective in reducing their headache and vertigo symptoms and, we found that a significant number of patients did note a reduction in their vertigo.

It is always an exciting time to come together with other colleagues, who are enthusiastic about headache, learning and seeing existing and upcoming treatment options and the difference we can make by taking steps forward constantly to help support the world of headache.

Kostis: The International Headache Conference proved to be an invaluable platform for advancing knowledge and collaboration in the realm of headache disorders. The event, characterised by its seamless organisation and diverse array of sessions, showcased the latest breakthroughs in headache research and clinical application.

The segment dedicated to cluster headaches was a standout feature, offering a profound exploration of this challenging condition. Renowned experts presented cutting-edge research findings and therapeutic advancements, providing a comprehensive understanding of cluster headache pathophysiology and management strategies. The interactive discussions and case studies facilitated a nuanced exploration of real-world challenges, enhancing the practical relevance of the information presented.

The conference's commitment to fostering networking opportunities was evident, allowing attendees to engage with fellow professionals, researchers, and clinicians. This collaborative atmosphere not only enriched the learning experience but also laid the groundwork for potential future collaborations.

In conclusion, the International Headache Conference, coupled with its insightful focus on cluster headaches, surpassed expectations. It emerged as a pivotal event for the headache community, driving progress in both research and clinical practice while fostering a sense of community among participants.

Steffy: Attending the International Headache Conference (IHC) this year in Seoul, South Korea was an enriching and most valuable experience for me as a Headache Nurse Specialist.

The nurse meeting was particularly helpful and certainly broadened my professional network, whilst engaging in conversations with colleagues from all around the world made it possible to discuss different approaches on how to manage cluster headaches and support those individuals suffering from the condition, all the while fostering a global perspective on headache care.

The lectures on cluster headaches gave us valuable insights into management strategies and the outcomes of clinical trials around the treatment of cluster headaches, while also sparking interesting discussions regarding current practices, research findings and thinking about how to enhance our care and optimise patient outcomes.

This international forum underscored the importance of a multidisciplinary team approach in headache management and emphasised the significance of addressing the complex needs of cluster headache patients, not only at the point of diagnosis but in each stage throughout their patient journey.

The knowledge gained by attending the International Headache Conference has had a positive impact on my day to day practice; and as a headache nurse and a patient advocate, it empowered me to continue to strive to provide high quality, patient-focused care for all our headache patients to help support them in their challenging journey.

Pictured from left to right; Konstantinos Christoforou. Stefania Maniataki. Allison Worth. (Professor Goadsby's secretary). Fiona Greenwood.

I was diagnosed with chronic cluster headaches in 2010; I'd been under general neurology for a few years and had been misdiagnosed with chronic migraine and occipital and trigeminal neuralgias. It took them a while to diagnose me because my clusters have a very strange presentation; I have them for six weeks every night and then get six weeks respite.

When I was diagnosed, I was put on topiramate to manage the headaches. I already had heart issues so I couldn't use a lot of the traditional cluster headache drugs like verapamil. In 2012, I met my now husband, and as we got more serious, we discussed a baby with the neurology team and my cardiologist, and neither could give us any hope of being in remission long enough to have a baby safely.

Just before covid became a thing, my neurologist suggested we try admitting me to hospital for infusions of dihydroergotamine (DHE). You can't have DHE when you're pregnant or planning a baby, but it was a last resort as, at that point, I was taking multiple tablets daily plus draining six tanks of oxygen a week when the clusters were happening.

I was admitted for my first round of DHE when the hospitals were in lockdown. I wasn't allowed visitors and couldn't leave the ward. My neurologist (Dr Selvarajah at the QEUH in Glasgow) was astonished when I had a 3-month respite and prescribed me another three courses, six months apart.

In March 2022, 6 weeks after my last DHE, I felt unwell. I had horrific cramps and nausea that I couldn't shake. My GP sent me to A&E, who did a pregnancy test, and it was positive. Because I'd just had the DHE and was on topiramate, I had a scan that day, which showed the baby plus a huge blood clot about three times his size; they told us it was likely an unviable pregnancy and if we got to 12 weeks, it would be a miracle. They gave me a scan photo, and we went home numb.

I phoned Dr Selvarajah's secretary, and he called me back personally within the hour. He said that from his point of view, we should do everything to make this pregnancy work if that's what I wanted and told me to stop taking the topiramate immediately. He told me to get vitamins from the GP and called my cardiologist to discuss what they could give me for the headaches. We decided that the only safe drug was verapamil, so we should give that a try. It lasted two weeks before my blood pressure bottomed out, and I collapsed at work, so from there on in I was taking on the clusters with just nerve blocks and oxygen (I was allowed sumatriptan injections from 24 weeks).

I needed extra scans to make sure the topiramate didn't affect the baby's spine or brain. Every scan was perfect, and the only problem was the baby didn't want to turn head down. My cluster headaches were getting lighter and lighter, and by week 26, they were gone.

I had a planned C-section at 40 weeks and two days because of the baby's positioning. I remember a nurse holding the baby over me, exclaiming it's a boy. Then I turned to the anaesthetist and told him I didn't feel well before haemorrhaging. It was all very dramatic, but I was in recovery 3 hours after the baby was delivered and managed to get onto the ward before dinner that night. We named the baby Lewis and brought him home several days later.

At six weeks postpartum, I had a call from Dr Selvarajah explaining that he was changing jobs to head up the stroke team in Glasgow. I was devastated. I felt like he was the only person who listened when I was at my lowest, and now he was leaving. I joined the OUCH helpline team around then and enjoyed spending my maternity leave talking to other sufferers about what was affecting them. With this big unknown about my headaches hanging over me, I felt like I was putting out good karma to the world, being the listening ear that I wish I had way back when I was first diagnosed.

It's been a weird journey as a cluster mum; I had a nerve block at around eight weeks postpartum; the baby wouldn't settle, so I held him while the nurse was doing the injection. He visited the DHE nurses on the neuro ward, and he went through a phase of playing with my spare oxygen mask. He was even featured on an OUCH team call when he wouldn't settle for bed one night.

Lewis came with me to my first appointment with Dr Dani. I didn't need to worry about losing Dr Selvarajah because Dr Dani is just as amazing; he got me a prescription for emgality which has been life-changing so far. My migraines are gone, and my clusters are much more tolerable. We decided that after the drama of my delivery, we would be "one and done", but I'll forever be grateful to the headache team at the Queen Elizabeth in Glasgow for giving me the baby we never thought we'd have.

My experience with CH during pregnancy - Jennifer Bunyan.

My CH Experience - Gonçalo Alexandre Batista Freirinha

I'm Gonçalo, 41 years old. I came to the UK in 2014. The UK gave me a second chance in my life. I am really glad to be here. I build my family here, two kids and a lovely Polish wife. I never will forget the first Christmas of my daughter, now 7 years old. I had £10 in my pocket due to unemployment because of cluster headaches. I've suffered from CH since I was 20. During this journey, I have described and written my suffering, a real testimony, reported by me in some of my worst moments. I found OUCH (UK) on social media and decided to share some of my words and was asked to publish them in CHitCHat magazine. I am very happy to be able to see some of my words of pain and suffering published and read by someone other than just me. One of my goals is work to help the people who suffer from this horrible condition. Our lives destroyed over and over again. Raising awareness of cluster headache is needed more and more.

Eyes dilated by astonishment, letting fear invade me, I can't do anything, I can only wait, never sitting, never lying down, never in any way.....I feel the amazement of the dark hours. a lethargy that leaves me permeable, to everything, to everyone. Just like rats abandoning the darkness, I run away to be alone, I feel like rubbish, I feel weak, I look in the motionless mirror, inside me there is no sign of life, and the terrible ideas that assault my brain, as if the blood, which flows stronger and in crescendo of anguish, like torrents of lava. in orgasms of suffocated screams and..........as if it were magic, of sordid juggling like someone playing with my mind, everything goes away, even my body that finally falls and rests.

02:15 in the morning, I get close to the balcony, while the last cigarette for tonight is burning, and I say last to seem sensible, I like to look out the balcony, in front, one of the many windows, but this one stays lit. I look at the stars and there is one that falls, my prayers follow with it, even though it fades, just like the star, so beautiful and so bright but it lasted so little, and the darkness swallowed it.

Today was a day of victory for me, the pain did not torment me, the sharp spear whose tip sparkled in the black of my mind, today it ceased, relief settled, but the damn heat and the excitement of going well prevent me from falling asleep, however I can't stop worrying about the next day, once again I start reviewing the entire route or at least the most complicated parts. I begin to give in to tiredness, my head drops, my eyes close. and in the blink of an eye, between shock and pain, my face looked at me... and today the moon is the woman I'm going to hug.

The terrible edge of the sharp hours... tears my spirit.... with a poisonous anguish and vertigo of dreamy suicides, in the desire to escape the inhospitable void of the time of absence.... So, there I was, who for a moment seemed to be happy, but CH once again closed off all possibilities of following my normal and natural path. Gradually he put pressure on me, "and the right was crooked again." I shouted the creed, I was afraid. A matter of days and the dismissal letter at home, the world collapsed, once again, if you count the times that for one reason or another, I began from nothing....

Here I am by George Ryley

You've always come at night, in the dark, uninvited. While I sleep, in fear, unaware of when you will arrive.

I plead for you to stay away, pray for you to leave alone what's left of me. Hiding is out of the question. If you want me, you will find me.

Terrified of sleep, I always eventually cave, and thoroughly exhausted, I let go. I fall asleep quietly, hoping you won't know that I slumber. I try to fool you. If you think I'm awake, you may stay away?

But you know, and you come for me. Silently, suddenly, stealthily.

The ferocity of your attack stuns me. You have your violent way with me, the way only you can. You take my breath away. I am vaguely aware of time slipping by, and wonder how long you will last this time. If I will survive, again. And honestly it matters not any more. The here and now obliterates all else.

I fight the tears, knowing that if I cry, my submission to you is total. My crying triggers a level of violence I don't even want to survive. Weakened, the tears always come though. Through my terror, I submit to you and you have your way with me. I rock and wail, weep and flail. Endlessly.

I suffer in silence, aware that no one can stop you. I am solitary and I am doubtful. Ashamed of how this looks. Like a wounded animal, I fight alone; a tired and ill-equipped warrior.

I pray again, this time that you will win. Just take me completely, so it will be no more, so there will be nothing left for you to keep coming back for.

Victorious, you slam away at my shocked body. I am in awe of your relentless viciousness. Your intensity is blinding, albeit familiar. You are the Master and I am yours for the taking. I know this.

I am hurt. Broken, hoarse, breathless and shuddering uncontrollably. I feel myself fading to black, somehow aware that you are finally leaving, just as stealthily as you arrived.

I am shivering, and unable to move at all now. I am grateful for the approaching darkness sweeping over me. I am aware that I will wake up additionally sore from whatever distorted position my body is in now. There is also gratitude for the approaching daylight. There is some safety there.

Yet somewhere in the recesses of my fading mind, just before I lose consciousness, I warily, falsely, claim my own strange, familiar victory. I won.

You're just a Cluster Headache.

F.U.C.H.

You're The Beast, but I am The Warrior. I know this every single time you leave. It's always my last coherent thought before I pass out.

Until you come again, I am The Warrior.

I am here.

Another wonderful tale from Darren Hamilton's "clustery world"

Darren prefers spellings to remain for awareness of dyslexia. In Darren's own words: " id prefur the spelling mistakes as it brings dislexikea to light, most will have less problems decifering my riting than i did riting it, so meny wonderful words i nowe but cant begin to spell them on paper, bedeviled by silent bloody letters as well"

hi all, have you ever wondered how long man kind has had cluster?? well i heard megolithik man could have had ch, if thay werent sacrificed thay were sead to be possesed by demons,(not far wrong there) well this morning i trecked south to a not so distant land, where i hear tails of miniliths, bit like a monolith but smaller, secret shrines and sercals, by a bend in the river by a narly old ash tree, protected by a beast of a guardien, i parked the cluster bus, prepared for an adventur one that men have never come back from, i rolled a fag, poured a coffee an put me hat on, mysterious eddies in the wind in the sound of a fart told me i wasent alone, in the gloom came a thump thump thump, slowly drawing near, i heald my breath not dareing to make a sound, thump thump thump, closer an closer, a shape mooved out the darkness, i could hear my heart beating faster as the shape came toward me , i could see a narly tree and a river, could this be the spot? suddnley i realised it was silent , i froze not dareing to turn, a presance was right behind me, breath plumed at the back of my neck, this must be the beast, i wasent dissappointed, turning i was faced nose to nose with it, slowly it sniffed my hands and face i didnt moove, the beasts verry lips mumbled my beard and rested its mighty head on my shoulder, i was speared this time, so offered a polo in tribute it was excepted , and i was nudged in the direction of the river, the still ness of this place where time its self cesses to exist, a forgotted monument to the great god suma was there in the early gloom of this shortest day, the minilith was south aligned, as i approched the suma circle my shadows ran from me to darker places in my mind fearing the power of this place, the central slab seem to be for some kind of offerings, may be early neandthal dwp minions, we will never know, but im willing to sacrifice a few modern ones to see if it will cure us all? worth a try thay wont be missed, the still ness of this place calmed the spirit eased the mind, i was lost in thort when a snort from the beast told me my time here had to end else id dissapear in time is self and be lost to memories, i thanked the beast with a big cuddle an fuss, we stood for a while an unspoken under standing i give polo and live, i live, i gave polo, slowly the beast wandered away treding fammilar paths only known to it, my path was home ward bound, pickure graphik evedence in hand, i board the cluster bus, and head from home,,, till i get fidggity again

" some times kind words count more than a mountain climbed,, and theres meny kind words given from all the chers to each other,, im sure mike* would agree , just 2words to save a life,, " I care" smiles are free"

*Mike Pollock, our much missed chairman. Always remembered by CHers who knew and were helped by him.

The new cluster rota for the shortest night of the year,

More of Darren's musings . . .

ok cluster heads, righty its the solstis(midsummers night longest day ect,, so calling the 1.30 club 3am club, and the 4-6am club, (episodicks fit in where you can please and bare with mee) as its the shortest night we got a lot of attacks to fit in befor morning, so can the 1.30s start at 12.15 till 2am the 3am start at 2.45-4, and the 4-6 start at 3-5am that way we will fit in all the suffering in one night, now if a 1.30 is late thay can move to the new 2.45-4 but not the 3-5am as that will be busy with the all nighters making the most of things, now if your a 4-6er and want to move up no you cant because thats prime time and you should be grate full, but a 1.30er wanting to move to the all night club is probly a socal climer and run out of o2, so lee way may be alowed, tea breaks will be at 2am till 2.45am, unless some one in need ripps the arse out of it, any questions, please email someone else,

Patients Face ‘Unacceptable’ Barriers To Treatment

New survey to mark Cluster Headache Awareness Day (Thursday 21 March) highlights the obstacles faced by patients seeking effective care.

A new survey by leading headache organisations has highlighted the obstacles many patients affected by cluster headache must overcome to access effective treatment options.

Cluster headache, which affects around one person in a thousand, is considered to be one of the most excruciatingly painful conditions known and is often referred to as the ‘suicide headache’. Yet despite its devastating impact, the new survey shows many patients remain unable to access the care they need, with around a quarter not receiving access to recommended oxygen treatment.

Cluster headache is characterised by pain on one side of the head and is rapid in onset, reaching a peak in several minutes. Sufferers often become very agitated and pace around or writhe in pain, hitting or banging their heads on the wall to try to distract from the horrific pain. This sign of agitation helps to distinguish the condition from migraine attacks which are often worsened by movement. A cluster headache attack may also be accompanied by a red, watering eye, drooping eyelid or stuffy nose.

The relative rarity of the condition and a lack of awareness may lead to long delays in accessing effective treatment, since many people with cluster headache may be misdiagnosed with migraine.

The goal of the survey was to understand the challenges patients with cluster headache face when seeking treatment with oxygen and sumatriptan injections - the gold standard treatments for cluster headache.

Feedback from patients highlighted the variability of care across the UK, the battles many people with cluster headache face and the continuing need for education and awareness among the medical professional and the wider public.

Oxygen cylinders, when prescribed, can resolve the pain in under 30 minutes - and sometimes as few as five minutes. Yet the survey found that in many areas of the UK nearly 25 per cent of people with a diagnosis of cluster headache have not been prescribed oxygen at all, despite it being one of the first line acute treatments recommended by the National Institute for Health and Clinical Excellence (NICE).

Dr Katy Munro, senior headache specialist at the National Migraine Centre said, “Cluster headache is one of the most agonising conditions we know of and all those affected must have easy access to effective, proven treatments. It is simply unacceptable that patients still need to fight to overcome barriers to care. We need a step-change in awareness and understanding and we hope that this year’s Cluster Headache Awareness Day will act as a springboard for change.”

The new survey was conducted by a coalition of leading UK headache organisations:

- Organisation for the Understanding of Cluster Headache (OUCH UK),
- the British Association for the Study of Headache (BASH), and
- the National Migraine Centre

Survey Results:

145 responded to the survey, 79 were affected by episodic cluster headache and 57 by chronic cluster headache.

The diagnosis of cluster headache was made by a neurologist in 70 per cent of cases, a GP in 19 per cent of cases and by the patient themselves in about three per cent of cases.

Why were patients not receiving oxygen treatment?

Of 142 patients, only 33 were being prescribed oxygen by their GP and 58 by neurologist.

There are different protocols and different oxygen suppliers throughout the UK, leading to frustration and long waits for patients who need this therapy.

Patients responses when asked why oxygen was not made available:

- Smoker. Offered to quit said no point still can’t have it
- Partner smokes. Although he doesn’t smoke in the house
- They (GP) said they are not allowed
- Sumatriptan works
- Needs to be prescribed by neurologist
- Smoking
- Availability / Effectiveness / Insurances at home

cont'd . . . .

- (Doctor) Unsure of procedure for referrals

- He said for now because imigran, sumatriptan are working in relieving the pain we should stick to it. Also the oxygen is too expensive for the NHS

- Needed to be done by NHS neurologist.

- Smoker. Although outdoors

- I smoke

- To use nasal spray, then injection and go to hospital for oxygen if it didn't work

- I'm a smoker, but I smoke outside and not that much

Smoking by the patient or their relative was cited as a reason for non-prescription. Yet many people who smoke have had a risk assessment for home oxygen and have obtained a prescription in other areas.

The need for professional education.

Other comments highlight the need for better education of clinicians and increased awareness of cluster headache. Access to treatment feels like a constant battle to some patients:

- GPs have absolutely no idea how to treat CH. My faith has gone. I now use my GP and advise them on how to treat my disability. It's crazy. We need reform immediately in how CH is treated in the UK by the GP

- Sumatriptan works very well generally, in 10-15 minutes, and has only failed twice. Because I saw Dr XXX privately and she prescribed the first Sumatriptan, I had to buy first prescription. After that my GP prescribed and I have a repeat.

- Don't think my GP has ever wanted to discuss the condition. I have never found a treatment that 'works' for my condition - I also have chronic migraine. Topiramate has reduced its effects slightly. But nothing stops it and stress and any upset always bring it on.

- The GP was scared to prescribe oxygen and the neurologist prescribed verapamil which has stopped the clusters for the time being which means that I haven't pursued this further.

- My oxygen company will not prescribe a demand valve.

- (Doctor) Unsure of procedure for referrals

- He said for now because imigran, sumatriptan are working in relieving the pain we should stick to it. Also the oxygen is too expensive for the NHS

- Needed to be done by NHS neurologist.

- Smoker. Although outdoors

Now the other view:

- My GP is amazing. I had changed practice since my last bout (I had been in remission for 12 years) and was worried about seeing a new GP when this latest bout started. She went above and beyond for me and I had oxygen delivered by noon the next day. I can't fault the care I've had over the years and am extremely grateful for the NHS and its staff.

- I feel very lucky with my Drs surgery and neurologist

- My GP gave me a prescription over the phone after I'd filled out an online form after being in hospital twice and diagnosed

- My neurologist writes to my Drs regarding my medication that's required and then my Drs prescribe what's needed from his letters. They are very good

- My GP is an exception and takes my advice and that of my neuro and OUCH on my treatment.

- I knew to request Oxygen from my GP because OUCH told me! I shall be eternally grateful to Val for her help at least 10 years ago!!!

- Without help from OUCH I mean I don't think I would be here today!

Thanks all involved with OUCH over the years you have helped me in so

many ways and I will be forever grateful.

www.ouchuk.org - Advice Line 0800 6696 824

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