

CHit CHat

The Official Newsletter of OUCH (UK)

The Organisation for the Understanding of Cluster Headache

CLUSTER



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HEADACHE

Winter 2025/26

www.ouchuk.org - Advice Line 0800 6696 824



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.



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, and deals with 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 Bahra is a consultant neurologist with a specialist interest in headache. Dr Bahra is part of the general neurology team at Whipps Cross Hospital and headache and facial pain services at the National Hospital Neurology and Neurosurgery and, the John Radcliffe Hospital, Oxford. Dr Bahra's research was in cluster headache at the Institute of Neurology, UCL. She is a Life Member of OUCH. She is part of the BASH Headache Guideline Group which published the updated national headache guidelines in 2019.



Pedro Caires (Deputy Advice Line Manager)

Originally from Portugal, Pedro has called London home since 2011. Living with Episodic Cluster Headaches since 2019 inspired him to get involved with OUCH (UK) after attending the 2024 summer conference. He now volunteers as Deputy Advice Line Manager and supports fellow sufferers. Pedro lends a hand with social media and other areas of the charity too, always keen to help raise awareness and support the community.

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.

Phil Hamblet (OUCH Forum adviser) Phil has suffered from episodic CH for many years. He now volunteers for OUCH(UK) and helps to monitor the website Forum to answer queries and give advice.

Tina Neave (Advice Line) Tina joined OUCH(UK) after her husband was diagnosed with Chronic Cluster Headache in 2008. She feels it is important to raise awareness of the severity of Cluster Headache. She knows how difficult it is to watch a loved one suffer and wants others to understand that supporters too are affected by this condition. OUCH(UK) has supported her in the past and she has now volunteered in order to give something back.

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.

Ben Gibbons (Advice Line) Ben is an Engineer that suffers from Cluster Headaches. In typical Engineer fashion he tried to fix it himself, but then found OUCH(UK) who helped guide him to the tools to help live a fairly normal life. Ben joined the Advice Line in 2025 hoping to help others navigate their pain.

Jeremy Jones (Advice Line) A Retiree who has suffered from Episodic CH since the early 20's was diagnosed in 2001. He became an OUCH(UK) member in 2025 following his attendance at the 2025 Summer Conference. He has now volunteered on the OUCH(UK) Advice Line.

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(UK) he enjoys building and competing with his radio controlled model boats, playing croquet and generally keeping fit.



OUCH(UK) Membership Report 2025

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

A huge **THANK YOU** to everyone who attended our conference on Sunday 8th June at the RVI in Newcastle and helped make it such a success. We'd also like to thank our sponsors, electroCore, for their generous support. Last but not least, to all our speakers on the day - thank you for your continued and valued support, expertise and advice. We really couldn't do it without you.

As promised we have added all the conference presentation slides to our website. Simply select the Meeting Presentations section on the Downloads page and they are all there as follows in PDF format:

Session 1. An overview of the diagnosis and treatment of Cluster Headache and The Trigeminal Autonomic Cephalgias by Dr Nicholas Silver, Consultant Neurologist, The Walton Centre, Liverpool.

Session 2. OUCH - Objectives and Initiatives by Dale Nolan, Trustee, OUCH, and Professor Peter Goadsby, Consultant Neurologist, King's College Hospital, London, Patron and Chair of OUCH (UK).

Session 3. Oxygen Therapy in Cluster Headache by Val Hobbs, Trustee, OUCH.

Session 4. Occipital Nerve Stimulation by Dr Ashish Gulve, Consultant in Pain Medicine, The James Cook University Hospital, Middlesbrough.

Session 5. My Journey through Cluster Headaches by Colin Simpson, Cluster Headache Sufferer. See also video below.

Session 6. Conference Keynote & Current Initiatives with: Professor Peter Goadsby, Consultant Neurologist, King's College Hospital, London, Patron and Chair of OUCH (UK), Dr Diana Wei, Consultant Neurologist, Senior Lecturer, Kings College Hospital, Dr Ravindra Inaththappulige.

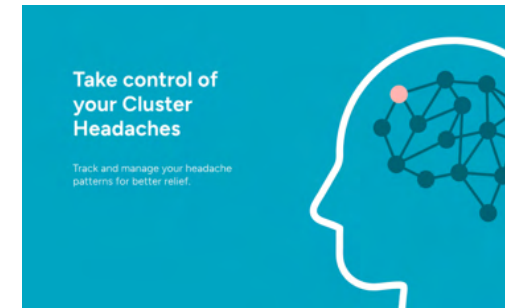
You can also watch the video of Colin Simpson's journey with CH and Occipital Nerve Stimulation.

We hope you find these resources useful, they are very helpful to refer to when there was so much to take in on the day.

Best wishes

The Team at OUCH(UK)

<https://ouchuk.org/news/view-slide-presentations-our-newcastle-event>



The **MyClusters** app recently featured on the OUCH (UK) website has now had over 1000 downloads by users from over 50 countries!

It is a Cluster Headache tracking and analysis app that makes it easy for users to log their CH attacks in under 20 seconds, get personalised insights into their attack triggers and patterns, monitor their medications - and quite a lot more! It was built by a cluster headache sufferer, Darshan Ramanagoudra, after he had a ten-month bout of multiple daily CH attacks.

Darshan is now seeking partnerships across the globe with researchers into cluster headache, its psychological burden for sufferers and its effects on their quality of life. Users of the app can choose to share their data anonymously and contribute to studies into this devastating disorder.

The app continues to develop - the latest new features released include :

- a snapshot profile of the user's CH pattern and lifestyle factors
- cycle tracking: add cycle start and end dates, get cycle specific reports, statistics, and remission period calculations
- export pdf reports, making it easier to share reports with medical professionals
- add preventive medications, treatments, alternate therapies with reminders
- even faster logging of CH attacks

Future releases will include:

- social sharing of reports
- import/export csv files of headaches
- sending weekly emails with reports

The app users themselves are very welcome to come forward with requests and suggestions to add to the development list – just email darshan@myclusters.nl

[Become a user now!](#)



In 2022, OUCH promoted a study undertaken at Staffordshire University entitled "Study into Living with Chronic Pain in Early Adulthood". The study included several Cluster Headache sufferers who volunteered to take part. Here is a summary of the research conclusions to share with our readers.

Experiences of chronic pain in young adults



Dr Paige Karadag, Dr Jennifer Taylor and Dr Amy Burton

The issue

Chronic pain is pain that lasts for more than three months. Up to 30% of young adults may have chronic pain, yet most research focuses on middle-aged or older adults. Being a young adult is an important life stage where lots of changes take place such as going to university, starting work or having relationships.

It can be difficult for young adults to access treatment for their chronic pain as there is sometimes a stereotype linked with their age. It is important to understand what other things may get in the way of young adults being able to manage or cope with the pain.

This study

Fourteen adults (10 females and 4 males) aged between 19 and 30 (average age = 26) took part in online interviews to discuss their experiences of living with chronic pain. The researchers then looked at what the young adults said to find common patterns and themes across their experiences.

Findings

1. The pivotal role of self-advocacy

Participants needed to 'self-advocate' by speaking up to communicate their needs to get a diagnosis of chronic pain and to access treatment. Some young adults felt that healthcare professionals held the stereotype that young adults are healthy, which is why they had to "speak up" to get a diagnosis.

Having a diagnosis gave the young adults the validation that their pain was real, and it made them feel believed. This meant that participants could then focus more on trying to manage their pain, rather than convincing others of their pain.

2. Understanding of chronic pain is essential for self-management

Young adults felt it was important that they understood their chronic pain so they could manage it. However, most were disappointed with the level of information given to them by healthcare professionals. Charities were praised for the information that they provided in a variety of formats.

The young adults explained that there was a lack of understanding from employers about the way that chronic pain could impact their work life. This meant that some young adults felt pressured to prioritise their work demands over managing their pain, and others left jobs they enjoyed due to this.

3. Coping through compassion

The young adults involved in this study did not want to be defined by their pain and their identity played an important role in developing ways to cope. They all adjusted things in their day-to-day life so that they did not miss out. A big part of being able to adapt was through being kind to themselves and having self-compassion and having compassion offered to them by others.

What does this mean?

- Healthcare professionals could signpost young adults experiencing chronic pain to the information already provided by charities, as these are useful resources.
- To do this, healthcare professionals may need better training about how to talk to young adults with chronic pain and what information they need.
- Employers need to understand that young adults can experience chronic pain, and how they can make the adjustments and offer support to help young adults to stay in work.
- To do this, information about invisible conditions should be included in mandatory training for managers, as recommended by [UK parliament in 2023](#).
- Ways to raise awareness of the charity information available for employers and young people with chronic pain also needs to be explored.

The full study can be found here:

<https://journals.sagepub.com/doi/10.1177/13591053251344236>

Thank you to all the young adults who shared their experiences.

How I Explain My Cluster Headaches.

By Pedro Caires OUCH (UK) Trustee, Deputy Advice Line Manager and Cluster Headache Advocate

We have all had that moment. You find the courage to explain what you are going through, hoping someone might finally get it, only to hear: "Oh, I get really bad headaches too you should try drinking more water." And just like that, the invisible wall goes up again. The reality of living with cluster headache, one of the most painful conditions known to medicine, becomes a private experience once more too extreme to be believed, too unfamiliar to be understood.

Trying to describe a cluster attack is like trying to paint fire with a grey crayon. Language just doesn't do it justice. But over time, I have developed a few go to comparisons that sometimes help people get at least a glimpse of what it's like. I'll say, "Imagine the worst toothache of your life but behind your eye. Now multiply it by ten." Or, "It's like someone is stabbing me with a with a hot spike through my eye socket while crushing my skull in a vice. Sometimes, I ask to imagine a lightning bolt exploding from inside your face, like something trying to tear its way out. It sounds dramatic. Because it is.

When those don't land, I reluctantly use the term "suicide headache." Not because I want to shock people, but because the history of that name reflects the severity of the pain we endure. It's not an exaggeration. It's a warning the medical community has known for decades and still, we are often met with disbelief.

During an attack, my body takes over. I rock, I pace, I press my hands into my skull not because I want to, but because I can't help it. These movements are part of my autonomic response. I have had people tell me to "try to lie down" or "just rest," as if I'm choosing this chaos. But the pain of a cluster attack is far beyond the reach of logic or stillness.

The emotional toll is just as real. I can't count how many plans I have cancelled or how often I have let people down. I hate it. Every missed event chips away at relationships, routines, and self worth. It's not just the pain of the attack it's the isolation that follows, the fear that others will never really understand.

I have learned to advocate for myself in different ways, depending on the situation. With friends and family, I try to be honest: "I want to be there, but right now my brain is in full crisis. Can we find a better time when I can really be present?" At work, I keep it clear and clinical: "I have a neurological condition that sometimes requires urgent treatment. During an attack, I may need to leave briefly or use oxygen." And for those who don't believe it's that bad, I refer them to the NHS or OUCH (UK). Cluster headache is ranked as one of the most painful conditions in medicine, even compared to childbirth and kidney stones.

What I want most, what I think we all want, isn't pity. It's belief. The power of someone saying, "That sounds awful how can I support you?" rather than, "Have you tried..." That tiny shift in language can be the bridge between isolation and empathy.

Cluster headache affects around 1 in 1,000 people in the UK, but so many are still undiagnosed, misdiagnosed, or dismissed. Attacks last anywhere from 15 minutes to 3 hours, and often come in cycles multiple times a day, for weeks at a time. First line treatment like oxygen therapy is effective, yet access can still be a postcode lottery. That's why organisations like OUCH (UK) matter so much because we are not just patients. We are people. And we deserve to be heard.

If you are reading this as someone who understands because you live it, know you are not alone. And if you are reading this because you care about someone who does, thank you.

Keep learning. Keep asking. And please, keep believing us.

Join the conversation

Share your experience with cluster headache or how you explain it to others using:

#ThisisClusterHeadache

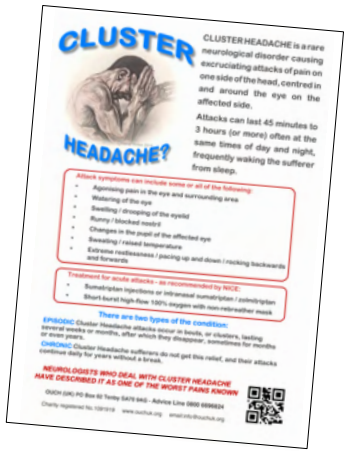
on Instagram or Facebook.

Your voice could be the one that helps someone feel less alone.



Cluster Headache Awareness Campaigns

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. We have an awareness poster outlining the symptoms of CH with the NICE approved treatment guidelines, and various Awareness badges and car stickers. These items are all still obtainable from our online shop. We urge sufferers to take these posters and some OUCH UK leaflets along to their local GP surgeries, pharmacies, dentists and hospitals.



We also issue press releases 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 have also been 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 further, 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



Round Pin Badge Cluster Head Awareness 38mm diameter

Awareness leaflets, three fold, packed with information

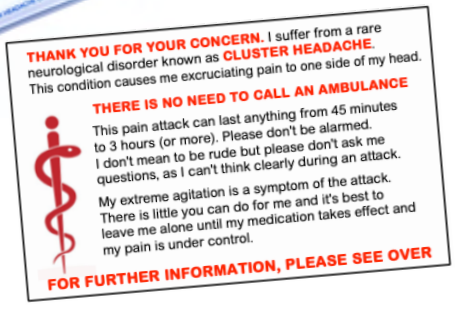
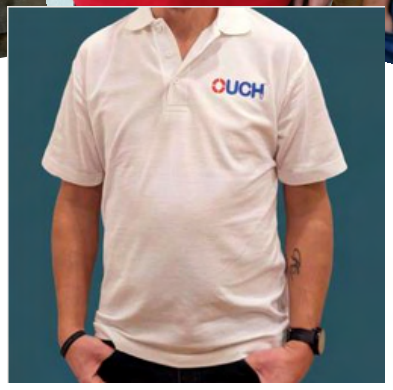


OUCH (UK) ONLINE SHOP

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.



Lapel Pin Badge in Red & Blue



BIKERS RIDE FOR KARL.

CALLING ALL BIKERS!

RIDE TO WEST BAY - Bank Holiday Monday - 26th May 2025

OUCH (UK) is very important to Nicki Baker as her son has been suffering from debilitating chronic cluster headache attacks for 2 years. Karl is a passionate biker and Nicki organised a fundraiser/awareness campaign by getting as many bikers as possible to do a ride to West Bay, Dorset in May raising hundreds of pounds for the cause! Many thanks to Nicki, Karl, all the bikers involved and not forgetting their fabulous supporters who generously donated!



Lindsey Von Backström Plant Sale May 2025

This fabulous fundraiser on 10th May 2025 raised an astounding £6,233! It was a brilliant day and the proceeds are shared between various charities including OUCH (UK). Well done to you all and many thanks for your amazing support and generous contributions!



CLUSTER DIVE by Brian Sutherland. June 2025.

As long as I can remember, doing a skydive has been on the bucket list. Many factors have made it difficult to achieve over the years with excessive weight, family life and of course suffering with the Invisible Beast (Cluster Headaches). In January 2025 I made the decision it was time for a change! Do a skydive and raise money for OUCH UK, so I lost 4 stone, decided CH's will not hold me back and booked the jump.



It was an amazing experience which will live with me for a lifetime, but can I compare the thrill of the jump with what cluster headaches do to me???
Let's try!



If you now turn the page you will be able to read Brian's article entitled:

The Invisible Beast Versus Skydive

For months, the headaches had been a constant shadow. The drilling pain behind the eye, the restlessness that drives you to pace back and forth, the gnawing fear of the next attack of the Invisible Beast was inevitable. So, in a desperate, almost illogical attempt to reclaim some control, to feel a pain "I" chose, the Skydive was going to happen.

I'd woken that morning with the familiar phantom ache, a ghost limb of a headache that hadn't quite fully manifested. It was a warning, a whisper of the impending storm. The drive from Forfar to the airfield in Glenrothes had been a silent battle, jaw clenched, every bump in the road a potential trigger. Yet, I pushed on. I needed this. I needed the sheer, undeniable force of something else, something bigger than the Invisible Beast in my head.

I stood on the edge of the open plane door. Below, the patchwork fields of Fife stretched out like a child's quilt, stitching green to brown, all impossibly far away. Beside me, the instructor gave a final, cheerful thumbs-up. "Ready?" the instructor bellowed over the roar of the engines.

I took a shaky breath, the cold air rushing in. My mind, usually consumed by the internal battle, was now filled with the imminent leap. I wondered, with a strange detachment, if the sudden drop, the G-force, the sheer terror and exhilaration, would somehow cancel out the building pressure behind the eye. Would one immense sensation override another? Or would the headache, in its cruel timing, strike mid-air, a literal freefall into agony? The thought was terrifying, yet morbidly intriguing.

Time to find out.....

The world exploded into a symphony of wind and sky. The initial stomach-lurching plunge was pure, unadulterated sensation. The air tore past my ears, a deafening roar that swallowed every other thought. Eyes, though watering from the wind, were wide open, devouring the vast, impossibly blue expanse. For the first time in what felt like years, the drilling sensation behind the eye receded. It wasn't gone, not entirely, but it was diminished, overwhelmed by the sheer, magnificent terror and joy of falling.

I screamed; a raw, primal sound ripped from the chest by the wind. It wasn't a scream of fear, but of release, of catharsis. I was alive. I was falling. And the headache, for these precious, terrifying moments, was a distant, secondary concern.

As the parachute deployed with a jarring jerk, slowing the descent, a different kind of calm settled in. The world was still immense, but now quieted, allowing a breathtaking glide. As I looked out over the shrinking landscape, a strange peace washing over me. The headache was still there, a dull throb now, but manageable. I hadn't conquered it, not truly. But I had, for a brief, glorious interlude, transcended it. I had chosen a different kind of pain, a different kind of rush, and in doing so, had found a moment of profound, liberating freedom from the Invisible Beast that usually bound me.

I knew it would return, the Invisible Beast, in due time. But forever more, I have the memory of this vast, blue expanse, of the wind in my ears, and the knowledge that even in the face of this personal darkness, "I" could choose what "I" want to do, not Cluster Headaches!!!

So, what's next??? Conquer The Inaccessible Pinnacle on the Isle of Skye!

Life - 1 --- Cluster Headache - 0

Watch Brian's sky dive here:

<https://ouchuk.org/civCRM/pcp/info?reset=1&id=20>



Fantastic Fundraisers

Lee's Whitstable Half Marathon July 2025

Lee Smith is no huge fan of running but he really wanted to support OUCH (UK) with this event after particularly bad recent bouts of CH.

Lee is grateful for your support and says it helped his motivation to run for that long!

Thank you Lee and many thanks to all the great supporters who have donated to Lee's event, raising a fantastic £810!

We're very thankful for our wonderful fundraisers who put themselves through the mill to help with the costs of keeping our charity going.



Some of the reasons given for making donations to OUCH (UK):

I was a past sufferer but have been free of cluster headaches for some years now.

My nephew suffers from cluster headaches so I know how debilitating and restrictive the effects can have on a person's life.

Had (and hopefully stays 'had' for as long as possible) CH for 9 years. Appreciate what OUCH does and wish I had found out about them earlier.

Always There, Thank You.

Birthday collection.

My friend suffers with cluster headaches.

My nephew suffers with cluster headaches. I wouldn't wish them on my worst enemy.

I suffer from cluster headaches and i think you do an excellent job.

Cluster Headaches are a major problem for many people who also suffer with chronic Mental Health issues because of the pain of what they are going through and there is not enough help for any of them.

Love you guys & ladies, I've been to 2 annual conferences now and it's great to see the work you do and I want to support OUCH.

Friend's birthday gift as her son suffers from Cluster Headaches.

Fantastic Fundraisers

James & Gordon's Grand Canal Caper: Llangollen to Middlewich raising money for OUCH(UK) and Fibromyalgia Action UK

Start: Monday 18th August 2025 Llangollen
End : Thursday 21st August 2025 The Big Lock, Middlewich

Once upon a splashy time, two brave adventurers - James the Paddle Master and Gordon the Captain of Snacks - embarked on a legendary voyage from the misty heights of Llangollen, armed only with their kayaks, questionable navigational skills, and an unreasonable amount of pot noodles.

Their quest - To conquer the twisting, winding canal path to Middlewich - powered by arm strength, stubbornness, and the more than occasional pub stop!

The reason for this trip was to raise awareness (and money) for Cluster Headaches and Fibromyalgia. James' wife, Ciera, has suffered with Chronic Cluster Headaches for 7 years and Fibromyalgia for 4 years. Gordon's partner, Jackie, has suffered with Fibromyalgia for 20 years.



Cluster headaches Bottom Line:

Chronic cluster headaches are not just bad headaches - they're a serious medical condition that needs proper diagnosis and treatment. If someone has them, they should see a headache specialist neurologist. Cluster headaches are known as "suicide headaches" because the pain is so bad and intense, it can seem like there is no other option.

Fibromyalgia Bottom Line:

Fibromyalgia is a long-term condition that causes widespread pain all over the body, along with tiredness, sleep problems, and brain fog. It doesn't damage your body, but it can make life really difficult.

It's not in your head as some people think, it is a real medical condition that needs understanding to help manage it. There's no cure, but symptoms can be managed.

This wonderful kayak fundraiser was completed. James and Gordon are splitting the money between OUCH(UK) and FMA UK. The full amount raised was £1360.94!

Well done, James and Gordon! Huge thanks from all at OUCH (UK).



Tracy Wakefield - Great North Run, 7th September 2025

Not a personal best, but a great achievement nonetheless. Well done for completing it, Tracy!

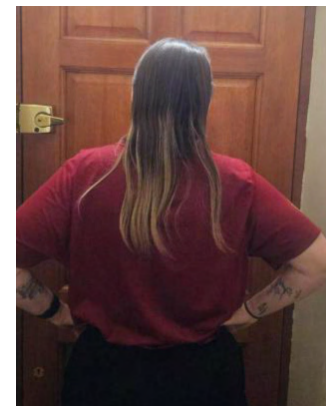
Nine years of running for OUCH (UK) is truly inspiring and Tracy's already registered to take part in the GNR for next 2 years!

Congratulations, Tracy. Many thanks from The Board of Trustees!



Tracy Wakefield Head Shave . . . December 2025?

You may remember Tracy Wakefield shaving her head on New Year's Eve 2024. She planned to grow it afterwards and not cut it until New Year's Eve 2025 then have it shaved again to raise funds for OUCH (UK). Tracy is now bringing the head shave forward by a few days but as you can see, she'll still be donating a pretty long ponytail to The Princess Trust. Nice one, Tracy!



If you'd like to donate to Tracy's fundraiser you can do so via her 3 event challenge link: Any amount is very much appreciated!

<https://ouchuk.org/civicrm/pcp/info?reset=1&id=18>

Thanks, Tracy. You're a gem

Edward's 400k steps in October.

Edward Nesbitt set up this fundraiser for his birthday month of October - let's support his efforts:

"This October for my birthday month I will be aiming to walk 400,000 steps in order to raise some funds for OUCH UK. This charity offers free advice and help for people who have been diagnosed or may need help regarding Cluster Headaches. The main purpose of this is to raise essential funds and also raise awareness for this cause. Any donation big or small will be helpful towards my target. Thank you for reading this and please if you can't donate a share on social media will go a long way."

Here's the link to donate to Edward's fundraiser:

https://ouchuk.org/civicrm/pcp/info?reset=1&id=27&fbclid=IwDGRjcANcYuBjbGNrA1xiqWV4dG4DYWVtAjExAAEersVLZtNDMTL6sXkq4zpcV1bGVFGYI72Yf6zw0JwWjRDhH9dVkuqn7f7jdWY_aem_NQeN6svqZsa9VP8OPLhcg

I have written a short story which I hope you take the time to read as it paints a picture of the torture that is cluster headache. Without OUCH UK, I personally would have struggled to get the support I needed to try and manage life with "The invisible beast"

The rhythmic tick-tock of the grandfather clock in the hall, usually a comforting anchor in their quiet life in Forfar, tonight felt like a mocking countdown. Brian sat rigid in his armchair, his body a tight coil of pain. His hand gripped the worn wood so fiercely his knuckles shone white. Each breath was a shallow, fearful gasp against the searing agony behind his right eye. It was a brutal, internal assault, like a red-hot drill boring through bone.

Laura knelt beside him, the coolness of the damp cloth on his temple a futile gesture against the inferno within. Her own fear mirrored his, a silent dread of these unpredictable attacks that stole her strong husband and left a trembling stranger in his place. "Another one, love?" she whispered, her voice laced with worry.

Brian could only offer a jerky nod, his eyes squeezed shut as if to physically block the torment. "Started... just after the news," he choked out, each word a battle. "...need it to end".

Laura glanced at the clock – 10:18 PM. "It'll stop soon." But the reassurance felt like a lie. This was the fourth attack since morning, each one leaving him weaker, more withdrawn and likely another 3 during the night just to really add to the misery. The normalcy of their quiet life – the comforting routines, the easy banter – felt increasingly fragile, threatened by this unseen enemy.

Outside, the familiar sounds of the Angus countryside – the rustling trees, the distant bleating of sheep – now seemed alien, detached from the brutal reality within the small living room. Brian felt utterly alone in his suffering, trapped in a pain so incomprehensible that words failed. Even Laura, his anchor, couldn't truly enter this agonising space. It bred a silent fear, a growing chasm between them forged by his invisible torment. He worried about being a burden, about the shadow this cast over their future as still no sign of any cure to the invisible beast.

Laura's hand trembled slightly as she smoothed his sweat-dampened hair. "Do you want your oxygen?"

He shook his head, a minute movement that sent a fresh wave of agony crashing through him. Sometimes the pure air offered a brief respite, a tiny crack in the suffocating pain. But tonight, the thought of the mask felt like another suffocating weight. He just wanted the relentless drilling to stop, to be free from the fear that coiled in his stomach between attacks – the constant anticipation of the next brutal episode. He longed for the simple peace of a pain-free evening, a peace that felt increasingly like a distant memory.

The minutes stretched into an eternity, each tick of the clock a reminder of the relentless siege. Laura remained his steadfast guardian, her presence a silent promise that he wasn't entirely alone in this terrifying darkness. But the isolation of the pain, the sheer incomprehensibility of it to anyone who hadn't experienced it, remained a heavy, unspoken burden.



Fantastic Fundraisers

In memory of Aneeka

Aaron Dodwell has been raising funds in memory of his sister, Aneeka, who is remembered always in the cluster headache community. Here's Aaron's story leading up to the run:

"On Sunday October 5th I'll be running my first ever marathon in Chester. It's something I've wanted to do for a long time. I want to raise money for two reasons, I lost my sister 8 years ago she suffered with mental health and depression but she also suffered with cluster headaches. These headaches are called suicide headaches, the pain is absolutely horrific and eventually it gets too much to live with, I just want to raise more awareness.

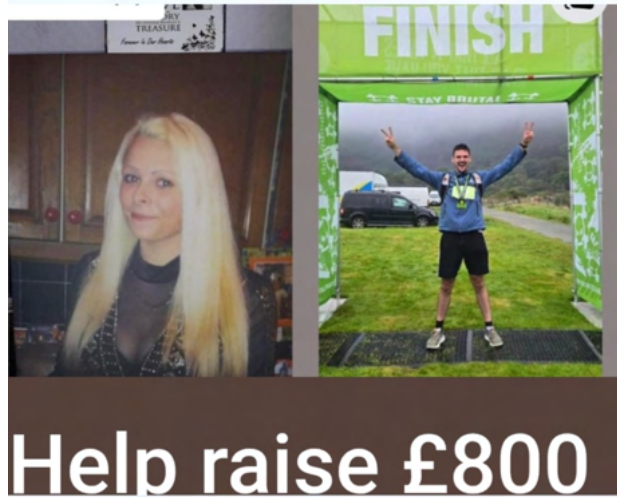
I also want to raise money for the family of Andy McGuinness. Andy passed away on September 4th after a courageous battle in hospital. This was devastating for the family, a lad who had a passion for fitness, walking, hiking, running, swimming and cycling would make this marathon look easy, after all he was Mr Ironman. Andy's dad, Paul, has asked that the money I raise will be donated to charities that are close to their family's heart, in Andy's memory. This will include Hafod (mental health) the ambulance service and the police. I also want them to keep some money to help with funeral arrangements but again this is up to the family.

When I lost my sister Paul and his family were always there for me, I struggled with mental health and gambling at the time and Paul was always there to help me when I needed it, I will never forget that and I just want to give something back now.

Time to get my running trainers on and I'll run my heart out."

Aaron completed the marathon and it went really well. Well done, Aaron, and many thanks for this!

"I finished 247th out of just under 7000, in under 3 hours, and ran with pride. I will be giving this brilliant charity a substantial donation"



Fantastic Fundraisers

Raise awareness with a beautiful OUCH (UK) Christmas card. The cards are sold in packs of eight from the OUCH (UK) shop



'Christmas Wishes'

Drawn and kindly donated by Jamie Charteris.

The greeting inside reads "Merry Christmas"
The title of the image and name of the artist along with this message:
"This Christmas card was purchased from OUCH (UK)
The Organisation for the Understanding of Cluster Headache.
Supporting sufferers of a rare and devastating neurological condition"
with the OUCH (UK) logo on the back.

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Lena Eijvergard, Turtlereality Web Design Ltd, long-term supplier of web and database services to OUCH (UK).
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have the time and commitment, OUCH (UK) is looking for
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skills or background of fundraising would be particularly useful.
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Please contact submissions@ouchuk.org for further information.

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