CHit CHat

The Official Newsletter of OUCH (UK)
The Organisation for the Understanding of Cluster Headache

See inside for details of upcoming 2025 Summer Conference

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.

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

SAVE THE DATE!
SUMMER CONFERENCE
8th June 2025

The Trustees of OUCH (UK) are delighted to announce that we are arranging to hold our Summer Conference 2025 in Newcastle.

The conference will take place on Sunday, 8th June, 2025 in
The Education Centre, ROYAL VICTORIA INFIRMARY, Newcastle.
This is your chance to mix with the experts,
meet the OUCH trustees and chat with fellow sufferers.

Watch out for more details on the OUCH (UK) website:
www.ouchuk.org and our Facebook page.
"Registration not yet open"

OUCH UK

Organisation for the Understanding of Cluster Headache

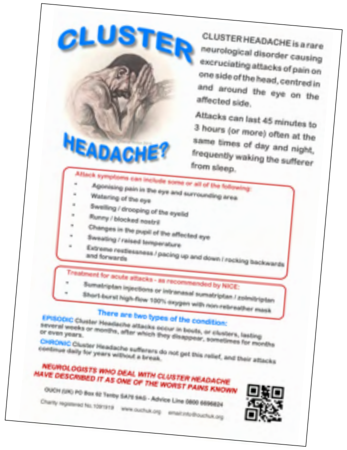
OUCH(UK)
CLUSTER
HEADACHE
SUMMER
CONFERENCE
SUNDAY
8th JUNE 2025

ROYAL VICTORIA INFIRMARY
EDUCATION CENTRE
Queen Victoria Road
Newcastle upon Tyne
NE1 4LP

Registrations not yet open

www.ouchuk.org

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

OUCH (UK) PO Box 62 Tenby SA70 9AG - Advice Line 0800 6696824

Charity registered No. 1091919 www.ouchuk.org email:info@ouchuk.org

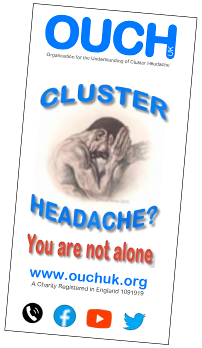
A key aim of OUCH (UK) is to raise awareness of Cluster Headache within the medical profession and the general public. We are also keen for CH sufferers to be aware that OUCH UK may be able to give advice and support when they need it most.

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 a new poster 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 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 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



OUCH UK

Organisation for the Understanding of Cluster Headache

CLUSTER HEADACHE?

You are not alone

www.ouchuk.org

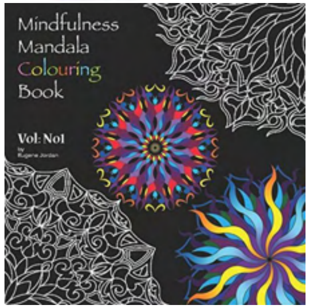
A Charity Registered in England 1091919

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

As we all know, cluster headaches don't shut down for Christmas or any other special occasion we might have planned - but we can be prepared!

Make sure you stock up on injections and oxygen supplies in plenty of time. If you use oxygen and are going away to somewhere in the UK, contact your supplier (giving them plenty of notice) and they can arrange delivery to your holiday address.

Sometimes they can arrange oxygen for you overseas, particularly in Europe. For the rest of the world, google medical oxygen supply – we have members who have successfully arranged their oxygen in Australia and the United States! It can be done. Also, if you are holidaying in Europe apply for an EHIC Health Card, from: http://www.nhs.uk/NHSEngland/Healthcareabroad/EHIC/Pages/about-the-ehic.aspxIf you are in cycle already before you go on holiday, try asking for a short course of high dose steroids on a tapering dose, that may be enough to get you through the holiday. You could try a triptan tablet called frovatriptan [brand name Migard], these have a half life of up to 26 hours in the body and will get you through a long haul flight. The drawback is the more you use frova, the shorter the pain free period gets, but for occasional use they are brill!

Some airlines will allow you to take oxygen on board an aircraft, but before you book your flight, check with the airline concerned. It is also worth noting that all aircraft carry an onboard medical kit which includes a portable oxygen cylinder. Check with ferry companies before taking oxygen away with you, some will allow you to carry it provided you notify them when you book, and they can priority park

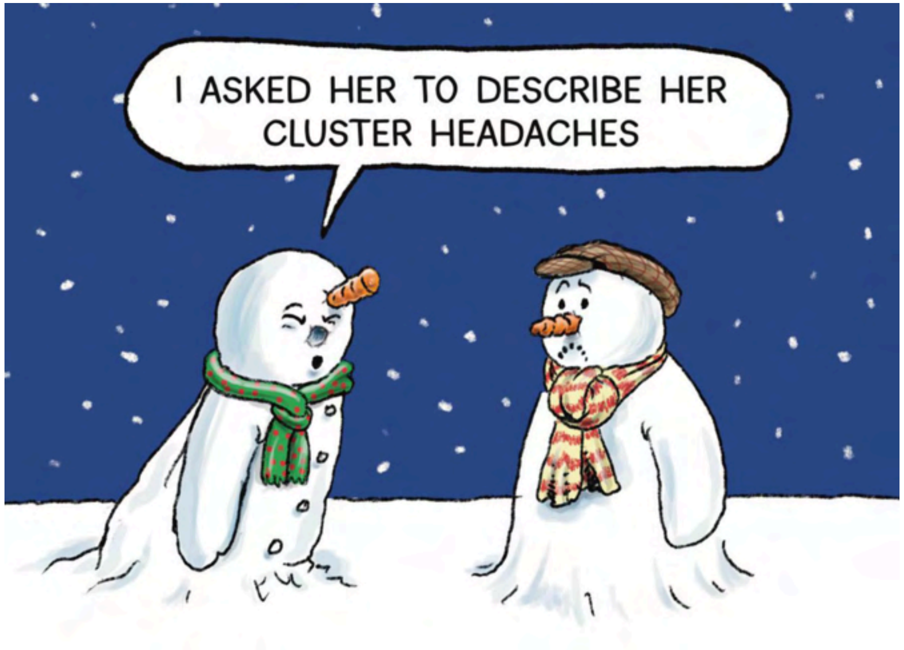
you in a well ventilated space. London Underground does not allow portable oxygen. Rail companies will allow you to take oxygen provided you inform them when you book. We'd suggest reserving a seat near the luggage racks, toilets etc, no extra charge for that.

Remember to wear a hat, keep your bodily and environmental temperature as even as possible and don't forget to drink plenty of water, and stay in the shade; extreme changes of temperature can kick off an attack/cycle.

When taking injections with you on a flight, put them all in your hand luggage so if your checked luggage gets lost, at least you will have your meds with you! Get a letter from your GP/neuro explaining why you have injections with you and carry your repeat prescription with you too. If you use oxygen, take your own mask with you just in case.

Advice Line: The Advice Line will remain open to leave messages over the Christmas period. Please remember that Christmas Day, Boxing Day and New Years Day are monitored for emergencies only.

The Trustees and Officers of OUCH (UK) wish you a joyful and hopefully pain free holiday!



cartoon kindly provided by Jamie Charteris

My Journey with Cluster Headaches:

A Story of Resilience and Awareness By Pedro Caires

In 2011, as Portugal faced a economic recession and my future felt increasingly uncertain, I made a life-altering decision. I reached out to a family friend in London, hoping for new work opportunities. By August 15, I had moved to the city, and by the end of September, I was employed. I never imagined that, years later, I would face one of the most grueling health challenges of my life: Cluster Headaches.

A Shocking Onset

Fast forward to 2019, amidst a hectic period of travel between London and Portugal, I experienced something terrifying. After recovering from a severe cold, I boarded a flight back to London. Mid-flight, just after my meal, I was hit with a sharp, piercing pain on one side of my head, radiating behind my eyes. My eyes teared up, and my nose began to run uncontrollably. It was the most excruciating headache I had ever felt, leaving me in a state of panic and confusion.

The flight crew, unsure of how to help, assumed I was having a mental breakdown. By the time we landed at Gatwick Airport, emergency medical staff were waiting for me. They suspected I had experienced a Cluster Headache attack—a term I had never heard before—and advised me to consult my GP for further evaluation.

A Battle Begins

Weeks passed, and I hoped that the attack was a one-time event. Unfortunately, the pain returned, often striking multiple times a day. After enduring these debilitating headaches for about four weeks, I finally saw my GP, who suspected Cluster Headaches and referred me to a neurologist at Guy’s and St. Thomas’ Hospital.

While awaiting my neurology appointment, I was prescribed Sumatriptan nasal spray, limited to two doses per day. Though it provided some relief, it was far from sufficient. At my neurology appointment, after presenting my headache logs and undergoing tests, I was diagnosed with Episodic Cluster Headaches. I was prescribed Sumatriptan injections and introduced to OUCH (Organisation for the Understanding of Cluster Headache), a charity dedicated to raising awareness and supporting those affected by this condition.

Navigating a Misunderstood Condition

I began researching Cluster Headaches and quickly realised how little I knew about this debilitating condition. The OUCH website became a vital resource, but it was disheartening to see how often Cluster Headaches were misunderstood as migraines, underscoring the need for broader awareness.

In May of this year, another health scare added to my growing list of challenges. During a meeting at work, I experienced a Cluster Headache and administered my injection. Minutes later, I felt a crushing pressure in my chest and numbness on my left side. An ambulance rushed me to the hospital, where I was informed that I had suffered a minor heart attack—likely due to a conflict between my headache medication and my treatment for high blood pressure.

Following this scare, I was instructed to stop using the injections until cleared by a cardiologist. I was put on oxygen therapy instead, but I quickly realised how few healthcare professionals were familiar with Cluster Headaches, making it difficult to receive the care I desperately needed.

Finding Community and Strength

Attending the OUCH summer conference in Liverpool was a turning point. Meeting fellow sufferers and speaking with the charity's trustees, many of whom also live with Cluster Headaches, provided me with a sense of community I had been missing. It was comforting, yet troubling, to hear stories of others struggling for proper care and recognition of their condition from healthcare providers. I felt fortunate to have supportive doctors, but I was deeply aware of the systemic gaps in awareness and treatment.

A Call for Awareness and Change

My journey with Cluster Headaches has been a relentless battle filled with pain, frustration, and a desperate search for effective treatment. However, I remain determined to use my experience to raise awareness of this poorly understood condition. Cluster Headaches are not just severe headaches; they are a crippling neurological disorder that profoundly affects those who endure them.

By sharing our stories, we can push for greater awareness, better treatment options, and a more informed healthcare system.

To all those suffering, I want you to know: "You Are Not Alone."
Together, we can make a difference.

National Migraine Centre:

Back in 1980, a group of headache specialists discussed their concerns about quite how variable standards of headache care were in the NHS. Headache care varied from region to region, but accessing care too often depended on having a supportive GP who had some awareness of the treatment options available. These consultants got together to found the National Migraine Centre, a unique charity dedicated to helping all those with migraine, cluster headache and other primary headache conditions. We were set up to make sure help is available to all, irrespective of ability to pay – and that remains the case today.

In the 44 years since, much has changed and the range of treatments has expanded. Yet, for many, the barriers to accessing NHS care can be stubbornly entrenched.

Each year, our headache specialists see thousands of patients with cluster headache and migraine. We recently invited them to participate in a survey to understand these barriers to access – what we found was shocking. Most people (60.7%) will wait over five years to receive effective treatment – while a shocking 39.5% wait ten years or more.

A combination of long waiting times at hospital headache clinics, obstacles to accessing effective new medications, misdiagnosis and a lack of awareness of the new treatment options are all believed to be factors in the long delays.

At the National Migraine Centre, we're committed to improving access to NHS headache treatment. But our focus is on making sure that we get urgent and effective care to all those affected, which is the primary purpose of our charity.

We are open to all those affected by primary headache and allow people to self-refer via our website – there's no need for a GP referral. During the registration process, we identify those affected by cluster headache and ensure they are given our highest priority and seen soonest. This is made possible thanks to the generous, ongoing support we receive from OUCH(UK).

All our clinicians are headache specialists, with months of additional training in headache medicine and we work hard to match every patient with the most appropriate clinician for their needs. Our patient feedback has been extraordinary with 99% finding the advice they received helpful.

Initial appointments are extended, given doctors a chance to really understand each patient and develop a tailored treatment plan. The plan can involve prescribing and is supported by a letter to the patient's GP, making recommendations for continuing care, ensuring continuity with NHS treatment.

Finally, we can provide access to our own injection clinics, with treatments such as greater occipital nerve (GON) blocks available at heavily subsidised rates, thanks to the support of OUCH(UK).

Alongside our clinic, our team of headache specialists also produce a range of self-help information, including factsheets and the award-winning Heads Up podcast.

To find out more about the National Migraine Centre, to access our information or to book your consultation, just visit out website today at www.nationalmigrainecentre.org.uk. We look forward to helping you.

Thanks and kind regards,

Charlotte

National Migraine Centre

Get back to living

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!

Lily's Poem

I am a 14 year old chronic cluster sufferer since I was about 11, called Lily and I've been reading the cluster headache magazines because they make me feel less isolated. My mum also suffers with them.

I saw a poem the other day and got inspired to write my own and was wondering if it could be published in the magazine because i think other sufferers would benefit from reading it like i have from writing it.

Stabbing
Not lethal, nor physical
but merciless
Deep in my eye, burning up my cheek
An inescapable doom
What ever have I done? To deserve
This twisted fate.

A hurricane in my brain.
But where's the eye of my storm?
The calm. It lasts for a while.
But not long enough.

Tossing and turning, struggling to sleep,
With this guaranteed horror tomorrow.
And forever more.

In my dreams: a typical teenager
Who can leave her home -
Without constant fear of being stranded unwell.

It's always 'get well soon',
never 'what can I do'
It's unforgiving, nobody understands
They try.

It's not their fault.
But it's not mine either.
So whose is it?
Some all mighty God
Is this his plan?

Thank you so much for sharing your very special poem. My name is John and I am the Editor for CHit CHat, also a fellow CH sufferer.

OUCH (UK) Christmas Cards

Raise awareness this year with a beautiful OUCH (UK) Christmas card.
The cards are sold in packs of ten with five of each design:
'Christmas Morning' and 'Robin Redbreast'.
Drawn and artwork kindly donated by Jamie Charteris.

The greeting inside the card reads:
'Merry Christmas'

The inside also gives the title of the image and name of the artist and the following message.

**'This Christmas card was purchased from OUCH (UK)
The Organisation for the Understanding of Cluster Headache.
Supporting sufferers of a rare and devastating condition.'**

The **OUCH (UK)** logo is on the back.

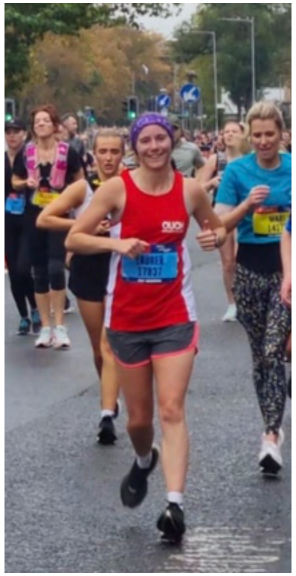
Just £4 per pack of 10 (5 of each design)

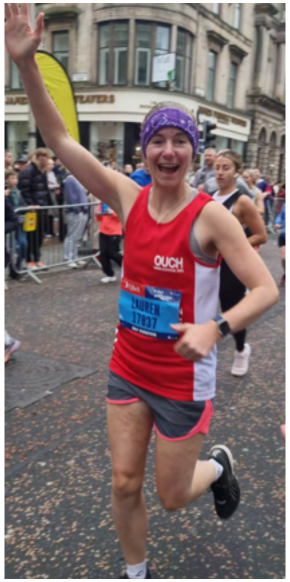
Order from our shop website at www.ouchuk.org/shop

Fantastic Fundraisers

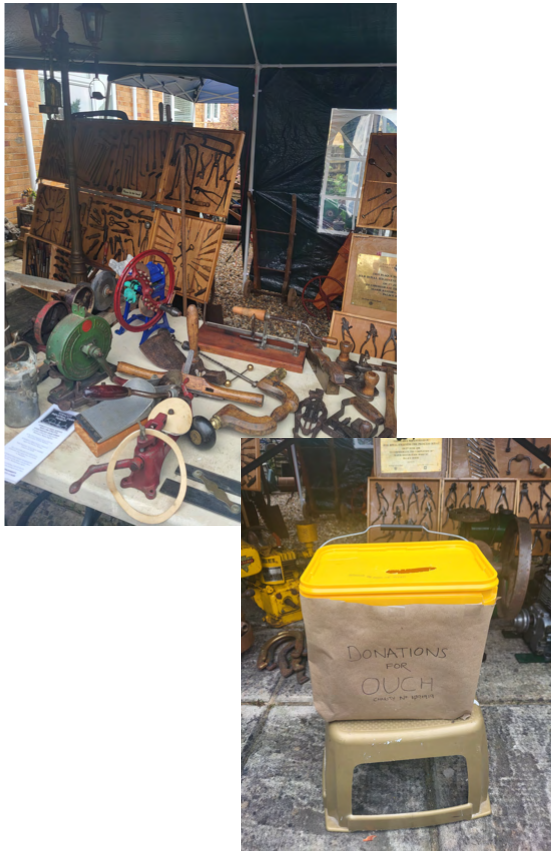
Since our Summer CHit CHat, dedicated OUCH (UK) supporter, Tracy Wakefield, completed the Great North Run 2024 for us and has already set up another three event challenge to include the London Marathon, the Great North Run and the Great South Run in 2025. Many thanks to Tracy who has been raising funds and awareness for us every year since 2016, wearing out a huge amount of running shoes and collecting scuffs, scrapes, blisters and The Mike Pollock Award along the way!

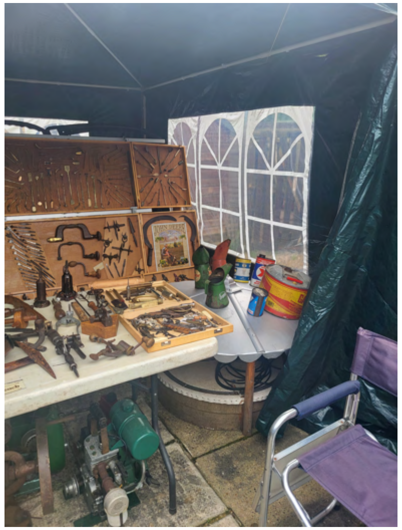
Huge thanks also go to Lauren Scott for her summer of fundraising with a multi-event challenge. She completed the women's 10k in Glasgow in July, as well as multi-functional fitness competitions in July and October, the Paisley 10k in August, capping it all off with the Great Scottish Run (Half Marathon) on 6th October.





My Father in Law Eric Neave held an open day at his House showing his collection of tools and bikes. He was turning 80 and asked for donations to OUCH as my husband/his son is a sufferer. He collected £90. I have attached a few photos to indicate the range of tools that he had.
Thank you, Tina Neave.





We have more fundraisers planning events for 2025, details will be published in our next CHit CHat.

Thank you to all fundraisers, past and present and to your supporters who continue to generously donate to our cause. Their donations help us with the upkeep of our Advice Line, the updates to our website, printing of awareness materials and arranging our conferences so that sufferers can meet the experts and their fellow sufferers. We are very grateful for every penny raised towards the running costs of our charity.

OUCH support for a Health Innovation Yorkshire & Humber project

OUCH (UK) has recently been thanked for contributing to a project of Health Innovation Yorkshire & Humber. This project aimed to produce a new patient insight framework to encourage stronger and more effective collaboration between all the stakeholders involved in developing local plans to support the adoption of medical innovations.

OUCH helped to recruit cluster headache patients for interview to share their experiences relating to the innovative gammaCore non-invasive vagus nerve stimulator. This work, along with other areas of investigation, helped guide the project team's approach to developing the patient insight framework.

The National Institute for Health and Care Excellence (NICE) views innovation in healthcare as critically important, but the pace at which innovation is adopted often does not match expectations. Patients themselves are uniquely placed to shine a light on some of the reasons why.

During the project, the team engaged with patients, carers, clinicians, SMEs, and colleagues from all 15 health innovation networks across England, aiming to learn from past innovation rollouts and to better understand the challenges and barriers faced by patients.

The resulting framework has been designed to align what matters to patients with the actions that can be taken by stakeholders at various points along the care journey.
It encourages stakeholders to collaborate on identifying and resolving inequality in service access and provision, so as to minimise inequity in patient care. In particular, it is intended to help stakeholders to:

- understand any patient insight and information already available about an innovation
- consider what else to ask patients in order to better meet their needs and expectations
- describe how these insights can guide the responsibilities of each stakeholder
- identify the actions that each stakeholder can take to better support patients through their care journey
- create an evidence-based and collaborative action plan

Framework and report now available on the Health Innovation Yorkshire & Humber website:
https://www.healthinnovationyh.org.uk/wp-content/uploads/2024/08/A-Framework-for-Driving-Innovation-Adoption-Through-Patient-Insight.pdf

With thanks to Graham Prestwich and Adele Bunch, Health Innovation Yorkshire & Humber Project commissioned by the NHS Accelerated Access Collaborative.

Thoughts, by Gonçalo Alexandre Batista Freirinha

It is the words that I write without ceasing that guide me, that relieve my mind deteriorated by CH.

On the thin sheet of paper I find the perfect place where I drag my corpse and die on the altar of myself, a pain almost as horrible as a man's heart.

CH steals my soul, in a cold and hindering way and where I let myself be possessed by the frenzy of intense pain that tears me apart, until I fall, empty of myself, prevented from defeating the enemy, because I don't see him, I can't touch him.

An atrocious carousel that turns frantically, and that I face with the bravery of the North Sea, captain of myself in pain and suffering, because the end will arrive, majestically, in the depths, while those on board overwhelming with that despair you know so well.

Relentless the pain that destroys us, I would give anything for my words to be reminiscent of a dream, but the nightmare is real like me.

Impatiently I wait for the day when justice is done, in a society that is governed by feeling and not by reason, reason can be framed and modelled. I want to find a way out, but there is no way out, there are paths.

With CH the relief between crises is just waiting to descend into darkness again.

My name is Gonçalo and I promise not to give in.

If you find that you have a spare moment why not try this Suduku?

All of the groups of 9 squares, rows and columns contain numbers 1 to 9.

Give it a try, it can be quite addictive!

				9		3	4	
5					2		6	1
	8	9						
	9				1	8	2	
7	6						1	5
	1	8	5				9	
						6	3	
6	4		3					7
	3	7		8				

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