

Éngage | Éducate | Émpower

Our goal is to change the way people think about, talk about and treat persistent pain.

Flippin' your understanding of pain could change the lives of you and your loved ones.



#### **Issue no. 10**

# Hello again!

We're back from our Community Outreach Tour and can't wait to update you all. On Sunday 12th September, our team of healthcare professionals, educators and people who live with pain set off on a tour around Lincolnshire to engage with local communities and help people improve their understanding of persistent pain.

20 of our Outreach Tour team took part in a cycling peloton riding >250 miles and raising close to £6000 for Pain Concern. The rest travelled from town to town on the Brain Bus, our interactive experience zone that helped challenge our perceptions with the message that what you feel is always real – but that our brains' conclusions can sometimes be inaccurate.

In addition to the peloton and the Brain Bus Experience, each evening we visited a different location. Professor Cormac Ryan was joined by a panel of health professionals and local people with lived experience of pain in delivering free public seminars.

As you can imagine, it was an exhausting week, but equally one with many great moments as we helped people change their understanding of persistent pain. We'd like to say a huge thank you to all of you who visited us during the week, sponsored the peloton riders or supported us any other way from near or far and we're delighted to be able to show you some of the pictures and reflections from the week in this month's newsletter.



Watch our highlight video from the recent outreach tour of Lincolnshire here...





I attended the Brain Bus experience in Mablethorpe, I found the interactive experience really helpful and increased my own self awareness and perception of how I react to and manage pain.

#### Have your say!

The BBC are keen to find out about the experiences of people living with persistent pain. The findings will contribute towards a national news feature planned for early next year. Have your say by clicking here and completing the survey.



## A view from the Brain Bus

We had such a great crew on the Brain Bus, made up of a mix of healthcare professionals including Physiotherapists, a Chiropractor and two students.

Every day we'd get up early, hit the road and unload the bus to set up the range of experiences that helped us demonstrate the complexity of the nervous system Felicity Thow, Physiotherapist & Brain Bus Team Lead

and persistent pain. We had visual illusions, the famous rubber hand illusion, the MIRAGE machine that could seemingly stretch your finger or make your hand disappear and even a Virtual Reality simulation where we asked members of the public to walk the plank at the top of a sky scraper!

All of these demonstrated how your brain receives signals, which it makes sense of through the course of the day. But sometimes, like in persistent pain, our brain doesn't get it right. We feel like we're in real danger (like when you're on a plank on top of a building!) but in reality you're safe to move. This is just like how your pain is always real - but the threat the body perceives isn't necessarily accurate.

We saw some real moments of understanding when talking through the complexities of pain with the public. To watch as someone who has been living with pain moves from a place of fear and uncertainty to hope was a genuine privilege.





## A view from the

Saddle

I was lucky enough to join the Peloton sector of the Flippin' Pain Outreach tour. I'm someone who has lived with persistent pain for much of my life, but changing my understanding of pain has had a fundamental difference in how I manage it. Four years ago, I would have struggled to walk 1 mile let alone cycle 170 of them over 4.5 days! I paced myself and didn't ride two of the afternoons but pacing like this is an important part of pain self-management.

It was an extraordinarily positive experience for me. I'm immensely proud of my own achievements but also so proud of each and every other person on the team in its entirety. And pleased my fab second hand gravel bike Kerowyn not only cruised through the week with no punctures or mechanical issues, but also helped me keep up with the team!

The Peloton ride was wonderfully cohesive, with everyone supporting and encouraging each other, particularly on one very unpleasant day of bad weather! The atmosphere was one of kindness, respect and enabling each other to get the best out of ourselves, which to me is reflective of what good pain management support should look like in practice!

I learnt that I maybe push myself too hard when I cycle on my own; that riding with others is balancing and supportive, and it's lovely to share the joy in the ride, the curiosity and pleasure in the scenery and the gratitude of being there in that moment. That cycling (and life) is easier when you have someone to help you and when you can in turn help others.

The tour was superbly well organised and supported. We cycled around 50 miles each day, with most doing a total distance of 240 miles in 4.5 days. All the way raising awareness for Flippin' Pain with our brightly branded cycling gear! There were many double takes as we filed past people on cycle tracks or as they whizzed past us on the roads... I hope they went home and looked us up!



Niki Jones, Person living with Persistent Pain & peloton rider





## A view from behind the mic



Prof. Cormac Ryan, Pain Scientist and keynote speaker for our Public Seminars



I had the honour of delivering a number of pain science talks to the warm and wonderful people of Lincolnshire. At the end of a day cycling, I'd get changed and head to the venue. As the room filled up, I liked to mingle. I always asked the same question – "Why did you give up your evening to come to a talk about persistent pain?" and I got a variety of answers. For most it was because they themselves had pain, for others it was because they had a loved one with pain. There were some healthcare workers there with a professional interest, as well as the odd individual in attendance because they were interested in science. Regardless of their reasons they all had one thing in common - they wanted to understand pain better.

#### The variety of people and backgrounds stood out to me.

We had men and women of all ages. From babies, to super intelligent 8-year-olds, to super insightful 80-year-olds and everything in between. Each came with their own stories and questions. Some were aired amongst the group, generating lively discussion. Some were quietly communicated with a nod or knowing smile. I even saw some of the same faces at more than one event, so we must have done something right.

Afterwards, as people left, we got some lovely feedback, which warmed my heart and eased my saddle soreness. One comment particularly stuck out for me. That person said, "I really felt you were talking to me". That chuffed me to bits. The immortal Terry Wogan once said, when broadcasting, he was never talking to the nation, he was only ever talking to one person. I really hope that each audience member felt like the campaign was talking directly to them, because we were.



## A view from the Audience and panel

When I arrived at the Brain Bus on Tuesday morning in Boston, it was raining very heavily but this didn't dampen the spirits of all involved. I was invited to take part in a range of sensory experiences which were very thought provoking: one was a Virtual Reality experience that placed me (virtually) in the lift of a high-rise building. I was asked to press the virtual lift button to take me to the top floor of a building and when the doors opened, before me was a plank of wood which I was invited to walk across. Even though I knew it was not real, this is not what my brain thought and there was no way I was chancing it. I was amazed how my brain could be tricked. I watched and listened to other people's reactions as they were taken through the same experiences and already my perception was being challenged.

Later that day I attended the public seminar being held at Skegness where there were members of the local community assembled - it was packed out. Professor Cormac Ryan gave an enlightening talk on pain and everyone in the hall was listening intently. At the end of Cormac's talk a panel of professionals took questions from the audience and I joined them as someone who lives with daily pain. The audience's questions just kept on coming. It was an experience that I shall never forget. I was invited back to the seminar held in Grantham at the end of the week too. Once again there was a full audience who participated with great interest. The whole event was orchestrated to an excellent standard and the enthusiasm of all the members of staff involved was just as high at the end of the week as at the beginning of the week. An amazing event and I look forward to the next one. I must thank all involved. Thank you to each and every one of you.



Tracey Benton, Person living with Persistent Pain and panellist at some of our Public Seminars





## What did YOU think?

If you attended any of the events during our recent Outreach Tour or any other of our past virtual or in-person events and they changed your understanding of pain or your personal journey of living with it then we'd love to hear from you.

You can e-mail us at info@ flippinpain.co.uk or via the Get in touch page on our website.

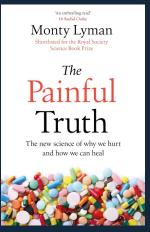
#### Tell us HERE

I finally feel like I have found a community that not only listens but more importantly hears... thank you from the bottom of my heart!!

#### This is Flippin' great!

Here at Flippin' Pain we've been engrossed in a newly released book about persistent pain. **The Painful Truth by Dr Monty Lyman** takes a really thorough, whilst entertaining, look at pain and what causes it. It matches up with our key messages really well and there are plenty of personal anecdotes to keep the pages turning. Great work Dr Lyman!

Click the image to access the page turning book. -



### Pain in the spotlight

Each night on the tour, Prof Cormac Ryan discussed opioid prescription and Lincolnshire has one of the highest rates in the country.

# Seen something in the news about pain science recently?

Let us know about it and we'll ask one of our team to review it and may feature it in a future newsletter. A key objective of Flippin' Pain is to spread the word about the real science of pain. Debunking myths and addressing misunderstanding and misinformation along the way. We're interested in it all; the good, the bad and everything in-between.

While opioids can be useful for acute pain, such as after an operation or dental procedure, we know that they are typically less effective for persistent pain. On tour, Cormac used a fire extinguisher metaphor: all fire may look the same but the cause of it (e.g. electrical, paper, chemical) makes a difference to the extinguisher you choose. For example, if you try to put out an electrical fire with water, this may in fact make the fire worse. We can say the same about opioids when treating persistent pain.



In this new research from the Universities of Leeds and Manchester, they found that educating GPs to 'think twice' led to a reduction in prescribed opioids. View it here...

#### Prof's Corner



In this third instalment of our feature where Prof. Ryan shares short & snappy reviews of interesting pieces of scientific research, Cormac takes a look at a recently published study where 151 people with persistent back pain were randomised to one of three treatment groups. Over to you Prof...

Group 1 received Pain Reprocessing Therapy (PRT). PRT attempts to help people to understand their pain differently. It aims to help people to reconceptualise their pain as a reversible, nervous system-generated, false alarm rather than it being caused by an ongoing tissue injury. PRT is very like pain science education, however it also includes activities like graded exposure, which helps people to build up their ability to do painful movements over time. PRT also used principles from techniques such as Cognitive Behavioural Therapy (CBT) and mindfulness. PRT consisted of two sessions per week for four weeks.

Group 2 received an 'open-label' placebo (sham) injection to the back. This meant the participants knew that the injection was a placebo.

#### Group 3 continued to receive their usual care.

Researchers measured a range of outcomes before treatment, 4 weeks after treatment and one year later. They measured pain, function, and beliefs about pain, as well as using brain scanning techniques to explore brain activity.

The results found beneficial effects for PRT in comparison to the placebo and usual care group. After treatment, 66% of those who received PRT were pain-free or nearly pain-free, compared to 20% of those in the placebo group, and 10% of participants in the usual care group. These results were broadly the same at the final follow up 1 year later. On average, after treatment, pain levels were 1.2/10 in the PRT group, 2.8/10 in the placebo group, and 3.1/10 in the usual care group. These differences are large enough to be considered clinically worthwhile. A similar pattern was seen for other outcome measures like function. The brain scans also showed reduced brain activity in the areas we believe are associated with pain in the PRT group.

Why do we think this change occurred in the PRT group? It would appear that changing your beliefs about whether pain indicates tissue damage can lead to improvements in pain.

These findings provide direct support for two of Flippin' Pain's key messages – that understanding your pain can be key and that recovery is possible. If we can help people to better understand their pain in keeping with modern pain science, we can help them to worry about it less, desensitise their alarm system, which potentially can lead to improved levels of pain and function. When it comes to be pain, the right knowledge can be a powerful recovery tool.



Ashar YK, Gordon A, Schubiner H, Uipi C, Knight K, Anderson Z, Carlisle J, Polisky L, Geuter S, Flood TF, Kragel PA. Effect of Pain Reprocessing Therapy vs Placebo and Usual Care for Patients With Chronic Back Pain: A Randomized Clinical Trial. JAMA psychiatry. 2021 Sep 29.

### Now available

to watch...





Do you get it?

AVRSHIRE

Back in August we joined forces with NHS Avrshire & Arran to host a virtual event for people affected by persistent pain including personal invites to anyone referred to and awaiting an appointment for the local MSK (musculoskeletal) and Pain Management services. The event was well attended and led to some great live discussion between audience members and our panel of local pain experts. If you missed it you can watch the full recording of the event here.



speakers. Thank you so much! JJ

Thank you everyone, it has given me lots to think about. **J** 

Sign up to our mailing list and receive our newsletters straight to your inbox!







Keynote Prof. Cormac Ryan

Panel Dr Nina Cockton

Panel Dr Kieran Clinical Psychologist Dinwoodie | GP



Panel Ruth Barber Person living with persistent pain

Panel Colin Cruickshanks Person living with persistent pain



Did you know that Flippin' Pain are on Social Media?

persistent pain related info via our social

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