

Live Well with Pain news

for people with pain and those who support them

ISSUE 15 | APRIL 2024 | For resources to help you live well with pain, visit: livewellwithpain.co.uk

Welcome to the Spring newsletter

Diarmuid Denny has now taken over as clinical lead for Live Well with Pain's Ten Footsteps training programme and – appropriately enough – he's this issue's Q&A interrogatee!

Also in this newsletter, we have the first of a couple of pieces by Dr Patrick Hill on the history of pain self-management. Dr Hill has been involved with LWWP since the outset and continues to have an input which includes routinely checking in on the LETs trainees. It was during one of these sessions that a conversation became a question about pain self-management which Patrick answered with his usual erudition... at which point the potential for sharing the story more widely became inevitable! You can read the first of Patrick's fascinating pieces inside this issue.

It's just over a year since the launch of *Live Well with Pain's* new website. The site is attracting increasing numbers of visitors: we averaged around 8,500 page views a week last year. We're really proud of these results so we've put together some graphics showcasing the site's headline statistics. You can find them inside this issue.

Finally, in our regular 'books on prescription' slot, author (and editor of this newsletter) Tim Atkinson reviews three more books on pain – one classic and two very new – that should become worthy additions to your pain self-management bookshelf.

Live Well with Pain on Channel 5

Our very own Lead Lived Experience Trainer Louise Trewern did what she does best and appeared on National TV explaining her pain management journey. Channel 5 news recently ran a special investigation into opioids and persistent pain and Louise was part of the feature, giving her own inspirational first-person perspective on how she came off opioids and learned to live well despite her persistent pain.

You can watch the Channel 5 investigation in full on our home page



Louise Trewern (left) being interviewed by Channel 5's health correspondent Catherine Jones

Background reading

A brief history of pain self-management

Pain has been around a long time. So has pain management, in one form or another. 8,000 years ago a Neolithic man was buried with an opium capsule embedded in a rotten tooth. It was no accident, either: analysis of the man's bones showed evidence of long-term opium use. So much for modern ideas about tooth decay being a function of the amount of sugar in modern diets! But how long has pain *self-management* been a thing? Longer than you might think, as we discovered in conversation with LWWP's clinical psychologist **Dr Patrick Hill** recently. Patrick writes...

Self-management is not a new idea, but one that has evolved over about 400 years. As we have gained a better understanding of pain and particularly the complexity of long term or persistent pain, self-management has become the approach seen as most likely to offer a positive way forward.

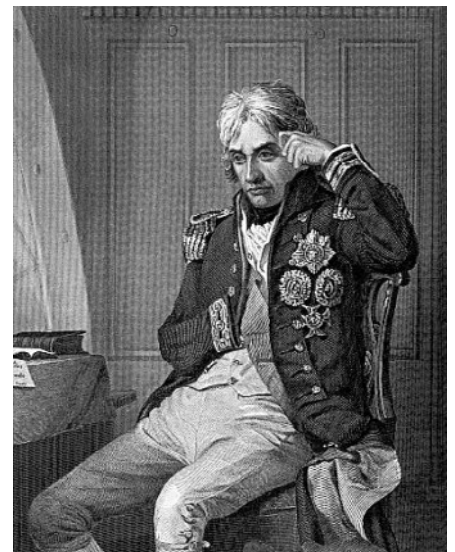
René Descartes was probably the first to suggest that the brain was important for pain. The famous woodcut, showing the boy with his foot near a fire, suggested that a signal was being transmitted directly along a pathway, where it rang an alarm bell in the brain, activating pain to tell him to remove his foot from the danger. This idea of a 'hard-wired' pain system held up for about the next 300 years.

There were many other important discoveries, for example Charles Scott Sherrington (1857–1952) discovered specialised nerves, that he called nociceptors, just under the surface of the skin, which were activated by things that had the potential to cause harm or damage. They send messages along the nerve pathways, to the spinal cord, which relayed them up to the brain, where pain eventually emerged.

However clinical observations constantly challenged this idea of simple pain circuitry. Doctors dealing with battle injuries recorded phantom limb pain, as it was named by an American Civil War surgeon, Silas Weir Mitchell. Notable sufferers include Lord Admiral Nelson, who lost his arm in a 1797 naval battle. Lord Nelson reported feeling his missing fingers pressing into his missing palm. These experiences were thought to be anomalies, but we now know that almost everyone who loses a limb experiences this, in some shape or form.

Other problems emerged, as there appeared to be no pain centre in the brain to co-ordinate these messages and the idea of thresholds of neural activity being needed before pain appeared didn't hold up, as in some cases it was known that pain could be produced just from light touch.

We now know that a highly complex, biopsychosocial system is involved in the production of pain and in the last 15 years, researchers such as Irene Tracey, using specialist functional MRI scanners, have shown how large numbers of seemingly unconnected areas of the



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Background reading

central nervous system (brain and spinal cord) get involved in the process.

Some notable researchers have helped us understand this complexity, including Charles Beecher, who published his work in 1956, comparing the requests for pain relief between soldiers in the second world war and civilians with similar injuries. Beecher's work suggested that the 'meaning' of the pain was key. For soldiers, being injured meant leaving the battlefield and the end of their stress, for civilians, being injured was the beginning of theirs. This clearly suggested that psychological and emotional factors had a part to play. Anxiety or stress seemed to make pain worse, whereas relaxation seemed to have the opposite effect. Other research suggested that using placebos and distraction, seemed to turn the volume of the pain down, whereas paying a wound lots of attention seemed to amplify it.

In 1965, Ronald Melzack and Patrick Wall (a physician and a psychologist working together) suggested that rather than the spinal cord acting as a sort of neural junction box, just passing nociceptive signals to the brain, that there was a gating mechanism in the spinal cord that could change the flow of signals. A simple example is that, if you knock, say, your elbow, the first thing you will do is rub it – this activates touch sensitive nerve fibres and their idea was that this closes a 'gate', blocking the nociceptor (damage) messages. The breakthrough here was a coherent theory that suggested it wasn't a fixed system, messages could be changed or modulated (turned up or down) by other things.



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Next time Patrick will explore the psychological aspects of pain and the implications for self-management

Interview

Q&A with Diarmuid Denneny

Diarmuid Denneny is a clinical physiotherapist with a long history of working with people who live with pain. He is a former chair of the Physiotherapy Pain Association and was on the committee responsible for the NICE guideline for chronic pain. Most importantly (of course) he is an integral part of the *Live Well with Pain* team and has just stepped up to take on a lead role in the training. But what did he want to be when he grew up? And what's top of his 'to read' pile at the moment. Read on, and all will be revealed...

You've just taken over as Clinical Lead on the Ten Footsteps Training Programme – congratulations! How did you become involved in Live Well with Pain in the first place, and what do you think is its USP among the ever-growing number of pain self-management courses and resources?

As someone who works in the pain space (I'm a physiotherapist and decided to specialise in pain about 20 years ago now... eeks!) I was aware of LWWP and the great work Dr Frances Cole and Emma Davies had been doing since it started. I was asked by them to become part of the team about two years ago and I was delighted as I think it's been a great and much needed support for practitioners and people who live with pain. About one year ago I made a big decision to stop my NHS work, and so you could say it was serendipitous in terms of timing, as I had more time available to be more involved in the delivery of Ten Footsteps courses. The rest, as they say, is history...

As for its USP, I think what LWWP and the Ten Footsteps programme do brilliantly is to break down often quite ambiguous terms and ideas into bite-sized practical activities that practitioners can apply immediately, and in ways that people who live with pain can apply. The resources are extensive, visually attractive, and free! Brilliant to help people make sense of the strategies and where to start.

How's the PhD coming along? How long before we have to start calling you Dr Denneny?

Ha! Thanks, it's moving slowly forwards. I'm lucky enough to have been involved in the Footsteps Festival and to work closely with great people like Louise (Trewern, also a member of the LWWP team) and Niki

(Jones) who are the co-chairs of Footsteps Festival. Footsteps Festival has really informed my research questions which relate to what people are doing outside healthcare services that they find valuable to support them living with pain. It was prompted by all the great offerings from the Footsteps Festival, things I'd notice aren't often offered by the NHS – or indeed that have much research about them. It felt to me like these approaches (the events offered by Footsteps Festival for example) have been under-appreciated in healthcare and research so I wanted to explore this further and see what else happens in that space. I wanted to do it with the Footsteps team if possible using participatory approaches in research.

I'm currently interested in liminality as a possible lens to explore this (I won't go into what that is, something for you to look up!) I am lucky enough to have a fellowship with the Economic and Social Research Council (ESRC) to do this PhD part time, so it could take a few years (I'm in my second year and can take up to seven!), so I think 'Doctor' won't be happening anytime soon!

Talking of the PhD, you recently travelled to New Zealand to talk about some of your research. How did that go?

It was wonderful! I was grateful to the CSP (Chartered Society of Physiotherapy) who kindly supported me to go through the Charitable Trust Education Awards grant scheme. I was able to present preliminary findings in a workshop at the conference. The conference was called 'In Sickness and In Health' and was a sociology-of-health conference. This was something new for me as I tend to have gone mostly to clinical pain conferences before. It has already helped to stretch my thinking and introduce me to some great

Interview



“I’m still interested in spiritual aspects of life, but not in any organised religious kind of way. I think this aspect of our being is largely neglected in a secular health care delivery system, and I understand why this is so, but I wonder if there might be avenues to revisit, relating to a sense of community and how we can cultivate that again.”

Diarmuid Denny

new researchers and social scientists to draw upon for my research. Of course it helped that it was summer there and the weather and beaches were beautiful and the sea was clear and warm!

Clearly, pain self-management is now a worldwide phenomenon but is there a difference between the way it’s done here in the UK compared to, say, New Zealand?

I think we are in an interesting time as there is a growing critical lens being applied to self management. What exactly is it and how is it applied is of course still open to interpretation. The *Live Well with Pain* Ten Footsteps provide a great grounding in strategies and approaches that come under the umbrella term of self-management but there are also other things that can influence how self-management is enacted in different parts of the globe. There is some really interesting research for example in New Zealand where they use co-production approaches with the indigenous Māori population to support people in developing self-management strategies – Hem Devan’s work, for example.

Let’s finish with some fun questions: What was your burning ambition as a child?

Interesting! It’s boring to say it but I’m not sure I had any ‘burning’ ambitions... as a child of the 70s in Ireland, in the rural north west, the influence of the Catholic church on society was strong. I’m still interested in spiritual aspects of life, but not in any organised religious kind of way. I think this aspect of our being is largely neglected in a secular health care delivery system, and I understand why this is so, but I wonder if there might be avenues to revisit, relating

to a sense of community and how we can cultivate that again. Sadly it feels like the opposite has been happening of late... leading to divisiveness and ‘othering.’ The land perhaps has had more of an influence on me and I find myself returning to it and to my interests in nature, and how that can care for us, if we can learn again to care for it. I’ve recently finished training in forest bathing and therapy as well as doing sea swimming groups and it’s wonderful to see people responding and (re)connecting with nature.

What is top of your to-be-read pile at the moment?

All things sociology! This generally means revisiting classics. I have the wounded storyteller (Arthur Frank) in front of me right now... I am also interested in complexity theory (having recently read a fascinating book by Neil Theise called *Notes on Complexity*) and think I’d like to explore that rabbit hole further!

And finally... Ireland for the Six Nations?

Bit of a sore point this week! [England beat Ireland the weekend before the interview]. I mean I think they should but that’s the fun of the six nations... anything can (and often does) happen!

Further reading...

Diarmuid is particularly interested in Hem Devan’s research into the use of co-production approaches with the indigenous Māori population of New Zealand.

[Read more about it here](#)

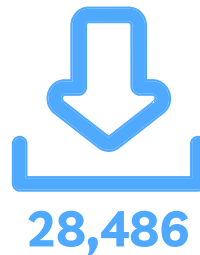
Website analytics

Our website goes from strength to strength

We recently reviewed the performance of *Live Well with Pain's* website over the course of 2023. Here are just a few of the key findings...

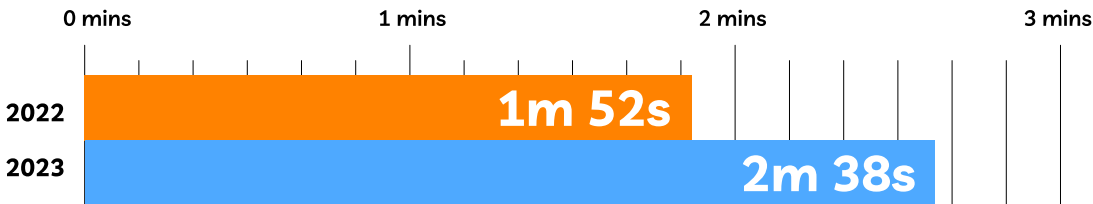
Number of downloads

PDF resources are a core part of what the site offers. Users downloaded PDFs almost 30,000 times during 2023. These resources were downloaded by 6,341 users meaning that, on average, 4.5 resources were accessed per 'downloading user.'



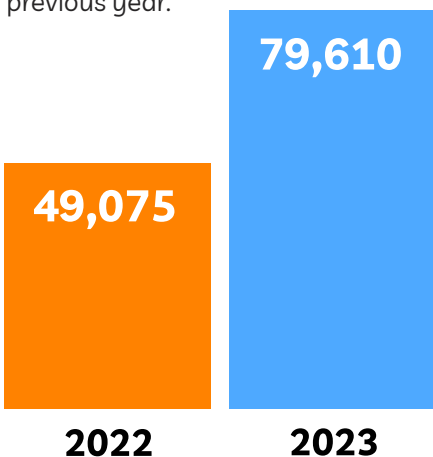
Average session duration

The average duration of each session increased: users spent on average about 41% longer on the site at a single session than during the previous year.



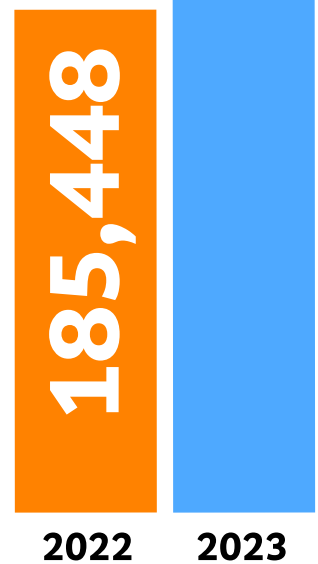
Number of site users

During 2023, the total number of site users increased by 62% compared with the previous year.



Number of page views

The number of pages viewed more than doubled compared with 2022. By December 2023 the site had achieved almost half a million page views.



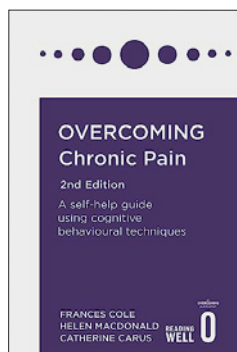
Book review

Books on prescription

Books about pain reviewed by **Tim Atkinson**, author of *Where does it hurt?: a memoir of life with chronic pain*. Three excellent books in this newsletter's round-up, one old and two very new...

Overcoming Chronic Pain

by Dr Frances Cole, Helen MacDonald and Catherine Carus (Robinson, London, 2020)



First, *Overcoming Chronic Pain* by (among others) Live Well with Pain's founder, Dr Frances Cole is a fabulous work book which combines the science of pain management with a variety of case-studies and practical examples designed to build into a fully-informed action-plan.

The layout is crystal-clear with handy chapter intros, check-lists and summaries. And with theory applied to real-life case studies, this book provides the perfect template for using knowledge to develop invaluable life skills.

Understand and Overcome Your Chronic Pain

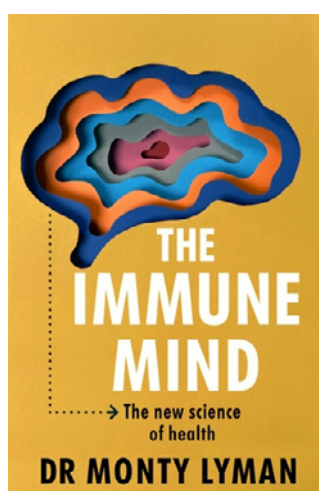
by Richmond Stace (Sequoia, London 2023)



Understand and Overcome Your Chronic Pain would appear at first glance to do much the same thing as the previous book, a fact that may, indeed be true. But it does it in a rather different way. Stace, a physiotherapist by training, has over 30 years' experience working in healthcare, much of which has been devoted to chronic health issues and chronic pain. His book is readable, and reassuring, as well as being very thorough. As Louise Trewern says on the cover "It... feels like you've got a reassuring arm around your shoulder" and the genuine voice of the sympathetic therapist is indeed what carries the day here.

The Immune Mind

by Monty Lyman (Torva, London 2024)



Finally, something a little different. Monty Lyman will be known to many thanks to his excellent 2022 book *The Painful Truth: The New Science of Why We Hurt and How We Can Heal*. His latest book broadens the scope to uncover the fascinating links between the mind, the immune system and the microbiome. Lyman is a doctor, researcher and author working in the NHS and an academic with affiliation to Lincoln College, Oxford. As anyone who has read *The Painful Truth* knows, he is also a chronic pain sufferer and if his approach isn't exactly 'physician, heal thyself' then it is infused with the sympathy and understanding of someone who knows what it's like on both sides of the consulting room. *The Immune Mind* is

subtitled 'The New Science of Health' and much of it is cutting-edge thinking while at the same time tapping into the most ancient of holistic thinking. The main thrust is that, whatever we are, it's not a collection of different body parts controlled by a brain, but a complex, integrated and above all, unified whole. And until we start treating the whole patient, rather than just an isolated illness, we're unlikely to make much progress. Stating that "body affects mind and mind affects body" or that mental health conditions are also physical seems like stating the obvious. But the fragmented, silo-mind of much current healthcare practice gives lie to that. *The Immune Mind* will be published by Torva on 4th April 2024.