# Live Well with Pain news for people with pain and those who support them

ISSUE 14 | JANUARY 2024 | For resources to help you live well with pain, visit: livewellwithpain.co.uk

# **Happy New Year!**

We hope you've all had a lovely Christmas and are now raring to go for 2024. We've certainly got plenty of exciting things in store, as well as lots of news to share. This is the first newsletter of our new, quarterly cycle, so look out for further bulletins in April, July and October and do keep checking in on our website. It's had a complete overhaul, has a great new look and is easier to use than ever!

#### Inside this issue

- Training the trainers: new courses from *Live Well with Pain*
- How to set up a pain café: a social prescriber explains all
- Meet the practitioners our new Q&A feature
- And much more!

### Did you know?

Admiral Lord Nelson lost his right arm when he was injured by musket fire during an attack on Tenerife.

The arm had to be amputated by the ship's surgeon. But in spite of a complete recovery, the Admiral continued to feel pain in his missing arm. Now we know that phantom limb pain is common (up to 80% of amputees report feeling pain or other sensations in absent limbs) but Nelson believed his pain proved the existence of a immortal soul, complete with a full complement of limbs! Just another example of how weird and wonderful pain science can be.



#### New printed resource: The Ten Footsteps Handbook

Developed by clinical psychologist Patrick Hill working closely with *Live Well with Pain*, the Ten Footsteps Handbook is designed to be used in conjunction with the Ten Footsteps programme on our website.

It provides a range of complementary activities for a person to do while exploring the Ten Footsteps programme.

*The Ten Footsteps Handbook* is produced in black and white with lots of space to make notes or even do the odd bit of mindful colouring!

Copies can be purchased by completing the order form on our website. There is a minimum order of 50 copies.

#### Find out more here

"Group members in our pain cafés find the Live Well With Pain Handkbook very useful as they like to have a hard copy of the resources as well as the website. They also like the plain cover, saying they can read it on the bus or the train without anyone knowing what they are doing." Sean Jennings, Pain Café Co-ordinator

### News round-up

# **Training the trainers**

January and February see the start of courses 14 and 15 of *Live Well with Pain's* new cycle of training for practitioners.

This time we're concentrating on 'training the trainers' – in other words, helping those who have already completed practitioner training to develop the skills and confidence required to train others on the *Ten Footsteps* Programme.

More than 500 practitioners have been trained in the 10 Footsteps approach to supported selfmanagement, and founder Dr Frances Cole calls this 'an explosion of activity' that is extending the reach of the training nationwide. She adds, "it's incredible that such a small group of people can make such a positive impact on pain for so many. I am sure that it is also partly because we are sharing skills, tools and resources that are trusted, accessible and practical for everyday living and working."

If you or your team are interested in *Ten Footsteps* training for practitioners, or the new Training the Trainers courses, visit livewellwithpain.co.uk/training-for-practitioners

### British Pain Society survey

Results of the first British Pain Society Patient Survey (which was conducted in late 2022) are currently being analysed with a view to bringing out a report and summary in early 2024.



Almost 900 people took part, some of whom may well be readers of this newsletter. Interim quantitative results are now complete (pending some crosstabulations) and together with the textual analysis of the free-text responses (adding up to a total of 25 pages) the survey promises to be important data source which will help both patients and practitioners.

To find out more about the British Pain Society's Patient Voice Committee, visit: www.britishpainsociety.org/people-withpain/patient-voice-committee

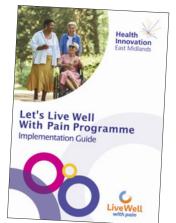
### **Digital resources**

Finally, exciting news about the digital resources developed jointly by *Live Well with Pain* and Derby and Derbyshire Integrated Care Board.

The resources – which form part of a six week programme – have now been beta-tested and are soon to be made more widely available.

The three tools cover Health and Welbeing, Medications and a Pain Management Action Plan.

These user-friendly resources will enable a personalised approach to the management of chronic pain to be structured in a way that integrates seamlessly with the clinical support available from a range of healthcare practitioners.



# How to set up a pain café

Pain cafés are rapidly becoming the new big thing in patient pain self-management. Informal, social and convivial, they provide a valuable platform for peer support as well as a unique opportunity for patients to share the successes (and setbacks) of their own pain journey. **Sue Crisfield** is Social Prescribing Coordinator for the Rural Practice Network based at Castle Cary in Somerset. She has been running groups for some time now and in this article she explains, from her own perspective, what has helped the project to work well.

#### First find your venue

Identify a suitable venue – preferably free. It should be comfortable, warm, have level access, a disabled access loo, kitchen facilities and parking nearby.

Make sure that the venue you choose is not in a GP surgery or medical building. Pain cafés are a completely non-clinical, skills-not-pills approach so they're best carried out in a community setting.

In our part of Somerset, the local housing association was happy to let us use their communal lounges at no cost if their residents or tenants were invited. Housing association staff (Independent Living Partners) manage schemes at the local level, so we found out who they are and developed relationships with them!

#### Inviting people to the café

A health coach or other member of the practice can identify patients who live with pain conditions (surgery can do a records search for osteoarthritis, osteoporosis, rheumatoid arthritis, fibromyalgia, etc) and invite them to come along. The practice can also search for potential attendees via the specific pain medicines they may be prescribed. Invitations can be sent by SMS text or letter.

We also did a search for which patients were on the Somerset Community Pain Management Service waiting list and emailed or wrote to them, giving information about the support available via the cafes.

Try sending SMS text or letter invitations.

# Reaching out beyond the practice

Use a range of ways to get the message out and reach people living with pain in the community. Try:

- Putting posters up locally, in GP surgery, shops, libraries, etc.
- Putting regular articles in local parish and town magazines.
- Promote on local Facebook pages (GP surgeries, health and community pages etc).
- PowerPoint slides for GP waiting rooms
- Create event on Facebook or Instagram.
- Create a page on surgery websites for living well with pain.

Whoever is delivering work on the ground, ensure your contact details are available for people to call or email for more information.

Ensure the practice knows you are happy to call people who are interested in the pain café and be available to talk to them, listen to their story and their struggles and encourage them to get involved or signpost them elsewhere if they are not ready for this approach.

#### How often are they?

In the Rural Practice Network, we hold the LWWP cafés once a month, during the day, for an hour. This will be reviewed and, if needed, we can increase to 1.5 or 2 hours. We also run a monthly evening online LWWP café (via Teams) for patients registered with any of the five practices.

#### What happens at the café?

At the café meetings ensure everyone is comfortable, warm and has a cuppa.

Meetings are likely to start with just a few people initially, so ensure they have plenty of opportunity to get to know each other and chat informally. Pain can be very isolating and it's important to give people time to chat and realise they are not alone with living with pain.

The power of the Live Well with Pain programme is peer support and hearing from others with lived experience. These cafés are a perfect opportunity to let that happen organically.

As conversations develop, there will be plenty of opportunities to introduce the Live Well with Pain Ten Footsteps and to show how everything is linked with everything else:

- Understanding Pain and The Brain
- Acceptance
- Pacing
- Setting Goals and Getting Active
- Relaxation and Mindfulness
- Sleep
- Communication
- Managing Moods
- Medicines and Nutrition
- Managing Setbacks

You can introduce the Ten Footsteps by talking about the Pain Cycle and how everyone is affected to one degree or another by everything on the cycle – although everyone's pain is different and unique to them, everyone will be impacted the same.

You may find that the café attendees are happy to chat informally with you throwing in the odd Footsteps conversation, or if you/they are stuck, you can have some pre-prepared questions to put on the tables for people to discuss, such as:

- Is there anything you are struggling with at the moment that others might be able to help with?
- Have you recently found something that helps you manage your pain?
- What methods do you use to relax and de-stress?
- If you struggle with sleep and have found ways of coping, do you have any helpful tips for others?

- Have you found any ways to incorporate more movement into your day?
- How have you managed to pace your daily activities and reduce your pain?
- Do you have any ways of managing and improving your mood?
- Are there things that you would like to achieve but are not sure how to start?
- What do you do to help yourself when your pain flares up?

The questions here are focussing on the positives, not the negatives!

#### What else can we offer?

Use the pain café to introduce people to what's going on in their community that would enable them to become more active and involved and less isolated.

Local knowledge of community groups, clubs, volunteering opportunities and exercise classes is important here, especially activities suitable for people with limited mobility (short health walks, Tai Chi, Qi Gong, Flexercise, etc).

If there are enough people interested in learning the Ten Footsteps in more depth, we can offer a 12-week group programme – 2 hours per week. I would suggest between 6-12 people is ideal. For those who don't want to take up this offer, they can continue to attend the monthly pain café.

#### You can read Sue's online promotion for their local pain café here: Bruton Road Surgery's website Milborne Port Surgery's website

Sue Crisfield lives in Somerset and since 2019 has been Social Prescribing Coordinator with a Primary Care Network of five GP surgeries in South Somerset.



Sue works closely with the voluntary, community, faith and social enterprise sector and works in partnership with many organisations to set up a range of local community groups and activities to help support local people's health and wellbeing.

# Meet the practitioners: Betsan Corkhill

Introducing our new, regular feature *Meet the Practitioners*, a chance to find out what makes pain practitioners tick. In this issue, Live Well with Pain's **Tim Atkinson** meets Betsan Corkhill...

Betsan Corkhill is a former physio, now wellness coach, production editor, Tai-Chi practitioner and all-round super-star famous for pioneering 'knitting therapy.' But what did she want to be when she grew up? Why is she such a big fan of Tai-Chi? And why is she keen that we move on from the biopsychosocial model of pain?

#### Tim: As a wellness coach you're known for pioneering 'knitting therapy.' Can you explain how you came to regard knitting as such a valuable wellbeing tool?

Betsan: I had a complete change of career when I left physiotherapy in 2002. I did a year long PA course followed by an on-the-job training scheme to become a Production Editor. I became a freelance Production Editor working on a wide range of leisure-based magazines. A request to fill a vacancy on a large craft portfolio put me in charge of the 'letters' pages... sacks full every day! This entailed reading all the letters. Most of these were about the therapeutic benefits of craft but particularly knitting. They were profound, life changing stories.

The most striking thing was the large numbers of people from different backgrounds, cultures and educational backgrounds from around the world saying very similar things

As a physio who specialised in neurology and the treatment of strokes, I was immediately intrigued as to whether the two handed, rhythmic, repetitive, automatic nature of the movements were important. It wasn't long before knitters from around the world started sending me their stories and it has grown from there.

#### That links nicely to the next question, because I know you've written about the importance, in healing, of the 'stories behind symptoms'. Why is that background so important?

Symptoms never exist in isolation. They are always linked to what is going on in the whole person in the context of their environment (past, present and predicted future). A person's story influences how their biology/bodily systems evolve and change. Their story makes them who they are today. Their environment is the context of their health and wellbeing. If we don't know the person's story we can end up simply treating symptoms (unsuccessfully) and medicalising social issues.

#### That reference to medicalising social issues reminds me that the opposite can be true – the use of nonmedical solutions, like Tai-Chi, to help treat medical problems. How do you think Tai-Chi can benefit those of us with long-term health conditions?

I teach an adapted form of Tai-Chi called Tai-Chi Movements for Wellbeing which teaches that the mind and body are intricately entwined. That the body reflects the mind and that bodily gestures can change the atmosphere of the mind. The rhythm of the movements induces a sense of calm. The brain likes rhythm because it's predictable. Rhythmic movement



makes the brain feel safe (there are similarities with knitting here).

Most people live in their heads most of the time, and this can be particularly so if you are experiencing unpleasant or painful bodily symptoms. Bringing our mind and body into the same place at the same time enables us to be present, to live in the current moment. It brings with it a natural relaxation. It teaches us how to live in our body.

#### Most of us in this field are desperately trying to promote the biopsychosocial model of pain, health and wellbeing. But I see you've written about the need to 'go beyond' that. Why?

The idea of 'Bio Psycho Social' was introduced to remind us that we are complex beings, that we are a lot more than the biomechanical. However, even the bio-psychosocial model doesn't grasp the full complexity. In fact, it has introduced artificial boundaries that has resulted in patients being 'chopped into three' resulting in patients often being sent down multiple pathways of care, seeing many 'experts' in their field and ending up with a range of labels. This often ends up in fragmented care especially when communication between different specialties is poor. It is always important to remember that there is no boundary, that we are a complex mix of bio, psycho and social or environmental issues that are constantly interacting in a dynamic way that cannot be separated out.

'Bio Psycho Social' encourages people to view these as separate entities and over time can lead people to forget that a person is a dynamic whole embedded in their environment.

## Finally, some fun questions: What was your burning ambition as a child?

To be a vet or a farmer's wife! (it was in the 60s!) I was at my happiest outdoors in the mud and around animals.

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

Life Time: The New Science of the Body Clock, and How it can Revolutionise Your Sleep and Health – by Professor Russel Foster, Professor of Circadian Neuroscience, University of Oxford.

I'm currently reading about baking bread.

#### And finally... Android or iPhone?

iPhone.

#### Tim Atkinson's top ten books to help beat pain

The list of books dealing with the subject of chronic pain keeps growing. There may soon come a time when browsing the healthcare shelves of your local bookshop or library might be more time-consuming than is desirable. But help is at hand. In what we hope will become a regular feature of these newsletters, here's a round-up of Tim Atkinson's top ten books to help beat pain, ranging from the academic (but accessible) to self-help guides and even taking in the concept of "pain-as-pleasure" along the way!

You can read Tim's top ten (as published first on the Yorkshire Bylines website) on LWWP's blog *Inspire*.

Another great curated resource with book recommendations you can trust is **readingwell.org** which is delivered by The Reading Agency in partnership with Libraries Connected as part of the Libraries Connected Universal Health Offer and funded by Arts Council England, The Department for Digital, Culture, Media & Sport and the Welsh Government.

Their recommendations (all made by health professionals) cover a wide variety of health topics (including pain) and should all be available free to borrow from your local library. **Find out more here.** 



**livewellwithpain.co.uk** resources for people with pain and those who support them