

# Live Well with Pain news

*for people with pain and those who support them*

ISSUE 12 | SEPTEMBER 2022 | For resources to help you live well with pain, visit: [livewellwithpain.co.uk](http://livewellwithpain.co.uk)

## Live Well with Pain at this year's Best Practice Show in October

The UK's number one event for the primary care and general practice community, established over a decade ago, returns to Birmingham on 12–13 October 2022. And this year *Live Well with Pain* is proud to be involved, both as an exhibitor and by providing speakers for some of the sessions.

If you are working within a practice or group of practices, don't miss out on the opportunity to join us!

To book a place at Best Practice 2022, please click here:

**Book your place**

or visit [bestpracticeshow.co.uk](http://bestpracticeshow.co.uk)

*Live Well with Pain* team members will be leading sessions at the show, on:

- NICE guidelines: safer prescribing of analgesics – patient and prescriber perspectives
- A bright idea? The Gabapentin and Opioid Toolbox and 10 footsteps for improving primary care pain management
- Using the *Live Well with Pain* website to develop pain management in practice



# Live Well With Pain

will be exhibiting at the  
Best Practice Show

**12 & 13 October 2022**

**[BESTPRACTICESHOW.CO.UK](http://BESTPRACTICESHOW.CO.UK)**

## Arts news

Here at *Live Well with Pain*, we are delighted to be involved and working in a valuable, new experimental endeavour. Balbir Singh, choreographer and artistic director of Leeds-based Balbir Singh Dance Company, tells us more about the project to *unmask pain*.

# Unmasking Pain



Photo: Malcolm Johnson

**Changing the world of pain management through the lens of art and culture is the steep mission of a new collaborative project.**

*Unmasking Pain* is the brainchild of Balbir Singh, the artistic director of Balbir Singh Dance Company, more usually found in an arts centre than a medical centre.

However, working in a multi-disciplinary team alongside artists, academics, health professionals and people who

experience living with pain, is proving to be unexpectedly exciting. *Unmasking Pain* is achieving much more than the team imagined as early evaluation results demonstrate improvements in sleep, happiness and general wellbeing from the participants.

The projects' twin bases are Durham and Kirklees in Yorkshire, based at a university hospital and a theatre. Over the last year participants and artists have been coming together in 'co-labs' to explore, through artistic activity and creation,



shared understandings about what it means to live with pain. There's a wide variance of approaches to pain management and *Unmasking Pain* is an approach that requires participants to take a risk and to be brave.

Dancers, like sportspeople, accept injury as part of the experience of being a dancer. The co-lab gatherings have created space for three dancers who experience chronic pain themselves: Villmore James, Mansi Dabral and Kali Chandrasegaram. This has deepened the connections within the group.

Working under Balbir's direction, the artists have gently encouraged participants to open up and reveal the person behind the pain, through the joy and fun of creative encounters. Cultural interventions have included puppetry, comedy, movement, mask-making, music and storytelling.

'It's great to know that a dance company or a visual artist can contribute to the field of pain management, that we can be in the conversation with physiotherapists and general practitioners,' explains Balbir Singh, project director. 'It's fantastic how many of the participants are rediscovering their



*Clockwise from top:* BSDC dancer Kali expresses pain in an artistic dance; Learning that putting trust in someone is not always easy but can be a nice experience; Participants explaining what their 'faces' are saying about their pain. *Photos: Malcolm Johnson*

creative side. Our dance company has been using its repertoire at the metaphorical level to reveal themes and inspiring starting points for discussion and creative workshops.'

*Unmasking Pain* is at the pilot stage and has been initially supported using public funding by the National Lottery through Arts Council England. Over the next couple of months, the team will be creating resources to share more widely with the public.

We are hoping to expand the project into a community for people willing to look at new ways of pain management.

'It is growing organically' explains Balbir. 'The team hopes that as more people either experiencing pain or working to alleviate it will look at how the unmasking of the person beneath the pain can unlock a better future for them.'

Find out more about the work of Balbir and his dance company at [balbirsinghdance.co.uk](http://balbirsinghdance.co.uk)



*Clockwise from top:*  
 Recollections of childhood games – when did pain begin?;  
 The quantitative aspects of measuring the project – Professor Paul Chazot of Durham University measures physical signs of pain in heat maps of participants' faces during the sessions; Talking about the implications of their pain – participants finding a safe space to share experiences during the creative sessions. *Photos: Malcolm Johnson*



## Pain and sleep

Poor and unrefreshing sleep is a problem experienced by many people living with painful conditions. **Ann Livingstone**, who is one of our Footsteps Festival volunteers and lives with chronic pain and fatigue, was keen to share her experience of Sleepstation. Here, she describes how with patient and persistent steps, she has changed her nights for the better ...

# Sleeping well with Sleepstation

I cannot remember the last time I had a 'a good night's sleep.' My normal on a 'good' night was: *Can't get to sleep – sleep – wake up – can't get back to sleep – fall into exhausted sleep – wake up – get up exhausted, tired, unmotivated, fed up, etc.*

All feelings of negativity. When I went to sleep and woke up say after 20 minutes, my brain and body would often conspire together to insist I'd had enough, and I'd find it impossible to return to sleep mode.

A typical pattern was bed at 8pm because of pain and weariness. I would sleep for 60 – 90 minutes before midnight, then wake for about 4 to 6 hours. I would stay in bed fretting about not sleeping. I might then doze for just over an hour before waking and lying-in bed until about 11am. I would reluctantly get up, feeling exhausted, unrefreshed and dreading the day ahead. I wondered how I'd get through it with so little energy. I'd often doze for about 20 to 30 minutes during the afternoon but then beat myself up, knowing a doze would stop me sleeping when I went to bed. This was me and my sleep life for so many years.

I didn't feel I was living my life. I felt fed up, depressed and worn out. I was going through the motions with great despondency and utter frustration. I had little or no interest in my home or my hobbies. I was barely able to function. Being my partner's carer was the only thing that kept me going. He has a serious mental health illness and without constant support would be regularly admitted to a secure unit. Being constantly vigilant however, was exhausting and I was sinking into a place of darkness.

So what changed? Thanks to two very important people, Dr Jon Dolman and my GP, Dr Lucy Pendered, I was supported to self-refer to the Sleepstation six week Sleep Programme and was accepted. Completing the course has made a massive difference to my sleeping pattern. I have been surprised, how in such a short time, just over six weeks, things have changed.

Ann: "Evidence of my feeling positively different is visible in my craft and art works, as these photos show." *Below: 'good sleep', Bottom: 'bad sleep'*



It hasn't been easy, but as I began the online course, I'd told myself that I had to look on this as a great opportunity to access a treatment that I might have had to wait years for. I was told by an acquaintance that they have been on a waiting list 'for years' to access some help to 'battle' their insomnia.

The big change was to have my own personal sleep plan and routine, supported by an allocated sleep coach. For the first week, that support was via daily messages, which gradually

lessened over the weeks. You are able to message anytime you have a query or want advice. I had the option of keeping a daily diary and so I did. It helped me focus my aim of sleeping better and sending my insomnia packing. It also gave me insight into what was working for me and what needed a tweak.

My starting point was going to bed at 2am and getting up at 7am. Five hours may not seem much, but was double what my previous average nightly sleep. I now like getting up at 7am instead of late morning. In fact, I have tried to sleep in or have a lazy morning but by 7.30am, I am downstairs with my morning cup of tea. As importantly, I now feel good about the coming day.

It wasn't always plain sailing of course. If I couldn't get to sleep I became anxious, the enemy of relaxing and sleeping well. During the programme we had time away from home and spent 4 nights in a hotel room. Following my plan to gradually increase my time in bed, I needed to stay awake until 1am. This was tricky once my partner was asleep and I was in the same room with little distraction. On two nights, I gave in and settled down before my planned sleep time. That disrupted my wake-up time, which became 3am rather than 7am. So, with nowhere to go I sat up in bed alternately reading and berating myself for not staying awake until 1.00am. I noticed my energy levels during the day were adversely affected and every activity, even going for breakfast, was an effort.

However, this reminded me of how I had felt most days prior to starting the sleep programme. The memory gave me the determination to get back on track. It also helped me to understand the difference between the fatigue I experience from ME/CFS and pain and the weariness and tiredness from lack of sleep.

Since getting more and better sleep, I have noticed changes in myself, as have those around me. I am less frustrated as I no longer lie awake worrying about not sleeping. I've noticed I am managing my pain better; my tinnitus is less intrusive and I generally have more energy. As a result, I've started some new hobbies including Zentangling and watercolour painting. I've hung washing out and prepared and cooked more meals, things I haven't felt able to do for years. My average daily step count has doubled. Life is already more enjoyable; I smile and laugh more and am making plans including booking a holiday for next year. I am also finding myself able to run an online session for other people living with pain without dipping in enthusiasm. It is a joy!

My partner has also noticed changes in me, such as having more energy and being able to take on some tasks around the house. I am eating better, making healthier choices and

**Things I have learned which can improve sleep, in addition to my routine:**

- **Turn devices off at least 90 minutes before sleep time and do not look at them if you wake up in the night**
- **No eating or drinking two hours before settling to sleep (except sips of water)**
- **Worrying about what the next day may or may not bring, including worrying about being awake and then feeling tired in the morning only makes you less likely to sleep**
- **Planning unachievable to-do lists for the next day, or feeling guilty about not doing things today is unhelpful and keeps you awake**
- **Breathing and relaxation techniques can be really helpful**
- **This is not a quick fix and a work in progress. Similar to pain management, the key is retraining the brain and resetting it's alarm for 7am**
- **There is a difference between normal tiredness and weariness and fatigue experienced from conditions like ME/CFS and pain**

with a more normal eating pattern. Generally, he says I am calmer and 'easier to live with' and taking more of an interest in my appearance.

All these changes have occurred due to my sleep hours doubling and sleep efficiency increasing from 34% to 74%. I have moved from having moderate to severe insomnia to having mild insomnia in 6 weeks. I wish I'd been made aware years ago of the importance of sleep and the adverse effect the lack of it can have on my wellbeing and my ability to self-manage but as they say, 'better late than never'.

To sum up, this has been and will be a life changing experience for me! It is worth the struggle to keep to the programme and continue the sleep plan. Life can only improve and help me live my life to the fullest possible in with chronic pain and fatigue. Over time, I aim to increase my sleep time from 12.30am to 7.00am, three times the duration of sleep time a night I had existed on before. This now feels realistic and possible. I'm enjoying life more than I have for years and together with Live Well with Pain I feel full of hope and optimism that I will be living the best life I can.

*Ann Livingstone*

## Online developments

The websites you know and (we hope!) love are changing. A makeover for *Live Well with Pain* is underway that will bring everything we offer bang up-to-date – and all under one virtual ‘roof.’

# Living well, looking great

*Live Well with Pain* has been developing and providing online access to a wealth of trusted self management resources for a number of years. Initially known only to a relatively small group of clinicians, the project has gathered support as its profile has increased. Last year over 40,000 people accessed the clinicians' site, with another 40,000 visiting our sister site which provides resources directly for people living with pain.

Now, thanks to a successful bid for funding which was supported by Durham University's Wolfson Institute for Health and Wellbeing, we are giving *Live Well with Pain* a makeover.

We've had really useful feedback from a number of people from different stakeholder positions within the persistent pain 'world' and we've used their insights to reshape the way we deliver our content, making it easier to find, more user-friendly and more 'joined-up'.

**Both sites – the original one for clinicians and the site for people living with pain – are being brought 'under one roof' into a single place: [livewellwithpain.co.uk](https://livewellwithpain.co.uk)**

This will not only simplify things for users, it also gives us the opportunity to direct people more accurately to the kinds of resources most relevant to them.

For clinicians there will be simplified access to downloads so they can print out resources quickly and easily for patients in consultations.

For people living with persistent pain, it will now be possible save resources as 'favourites' so you can return to them whenever you want to brush up on your self management skills or need reassurance that you're on the right track.

Up until now *Ten Footsteps to Living Well with Pain* – our self management approach set out in a step-by-step format – was accessed by yet another route. This too will be brought into the main site. All the *Ten Footsteps* content, which has proved so useful both for clinicians and people living with pain alike, will be there, easier to navigate as a self-directed 'programme' supporting people on their self-care journey.

Guidance for clinicians in using *Ten Footsteps* to support patients to become effective self managers of their pain will also be on the site, again easy to navigate and refer to when needed. As you'll see elsewhere in this newsletter, we're now

supporting this invaluable online resource with training in how to use it, with courses specifically aimed at clinicians and social prescribers, including pharmacists (see back page for details).

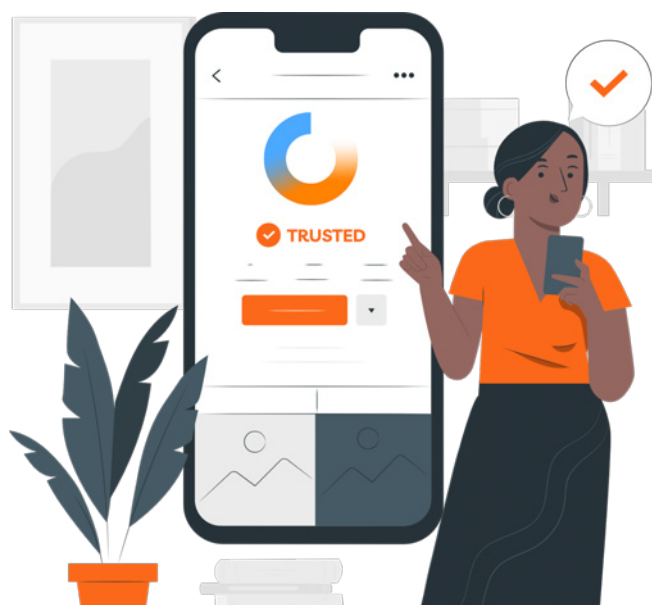
We're also taking the opportunity to revise and update some of the *Footsteps* themselves, to reflect the evolving landscape around opioid prescribing and, more generally, as a result of the growing input at *Live Well with Pain* from people with lived experience who have joined the team in recent years.

One thing that won't change is our commitment to providing trusted resources to anyone who needs them – free of charge. *Everything on our website will remain completely free to use.*

### Beta phase

For now the site is in its 'beta' development phase, and visiting [livewellwithpain.co.uk](https://livewellwithpain.co.uk) (or [my.livewellwithpain.co.uk](https://my.livewellwithpain.co.uk) for people with pain) will take you to the same sites you already know well. As soon as the beta phase is complete we'll go live, and you'll automatically be redirected to the new website. This will be later this year. We'll be letting our regular newsletter audience know in advance, so you'll be able to familiarise yourself with the new interface.

In the meantime, if you'd like to see how the new site looks, why not join us at the Best Practice Show in Birmingham this October? We'll be presenting a preview of the site and explaining to delegates how it can support them in their work with patients (see cover story).



## Clinician news

Are you interested in improving the confidence of your practice to support people to live well with pain?

# The Ten Footsteps Training Programme: training for social prescribers and clinicians in supporting pain self management

Led by the *Live Well with Pain* team including clinical psychologists, pain management physiotherapists and people with lived experience of persistent pain, the *Ten Footsteps Training Programme* is designed to develop participants' confidence in guiding patients to self manage their pain.

The training is for clinicians or social prescribers, including pharmacists, working with people with chronic pain. All training is online, delivered over two half day sessions of four hours each and one follow-up session, also four hours.

We recommend spreading the sessions over a period of several weeks so that participants can practice implementing and reviewing their skills in everyday work situations between sessions. Activities will be set for participants to complete between each session.

Time is allocated within sessions for problem solving and case history support, to increase confidence in supporting pain self management.

Pre-course preparation will consist of brief reading and video-related tasks.

Self assessment of knowledge and skills, both before and after the course, will be undertaken to enable participants to identify their learning objectives and outcomes.

### A co-production

The trainers are joined by members of the *Live Well with Pain* team whose lived experience of pain brings unique insights and perspectives to the course.

### Find out more

To find out more about what Ten Footsteps Training Programme can offer you and your team, please get in touch for an informal chat about your needs.

Contact course co-ordinator Dr Laura Hissey via email:

[laura@livewellwithpain.co.uk](mailto:laura@livewellwithpain.co.uk)

### Did you know?

*Live Well with Pain* has been delivering self management training for over 15 years around the NHS throughout the UK including Northern Ireland. Recent training has included pharmacists and pharmacy technicians in North Tyneside and Wolverhampton; GPs and practice staff in Yorkshire and County Durham; and social prescribers in York.

*Live Well with Pain's* training programme has recently been accredited by the Personalised Care Institute. This means it has been assessed against the PCI's rigorous quality assurance so that participants can be assured it meets the very highest standards of training.



Find out more at:

[www.personalisedcareinstitute.org.uk/accredited-training](http://www.personalisedcareinstitute.org.uk/accredited-training)



[livewellwithpain.co.uk](http://livewellwithpain.co.uk)  
resources for people with pain and those who support them