## Working together to live well with pain

## The possible and impossible....

### WRIHW Pain Challenge Academy Public Lecture October 2021

### DR FRANCES COLE GP, LIVE WELL WITH PAIN DR CHRIS PENLINGTON CLINICAL PSYCHOLOGIST UNIVERSITY OF NEWCASTLE DR PAUL CHAZOT NEUROPHARMACOLOGIST, WRIHW UNIVERSITY OF DURHAM

## **Definition & prevalence of chronic pain**

### Definition

Pain that persists or recurs for more than 3 months

(International Association for Study of Pain IASP)

### Prevalence

□ Affects one third + one half of UK population = 28 million adults

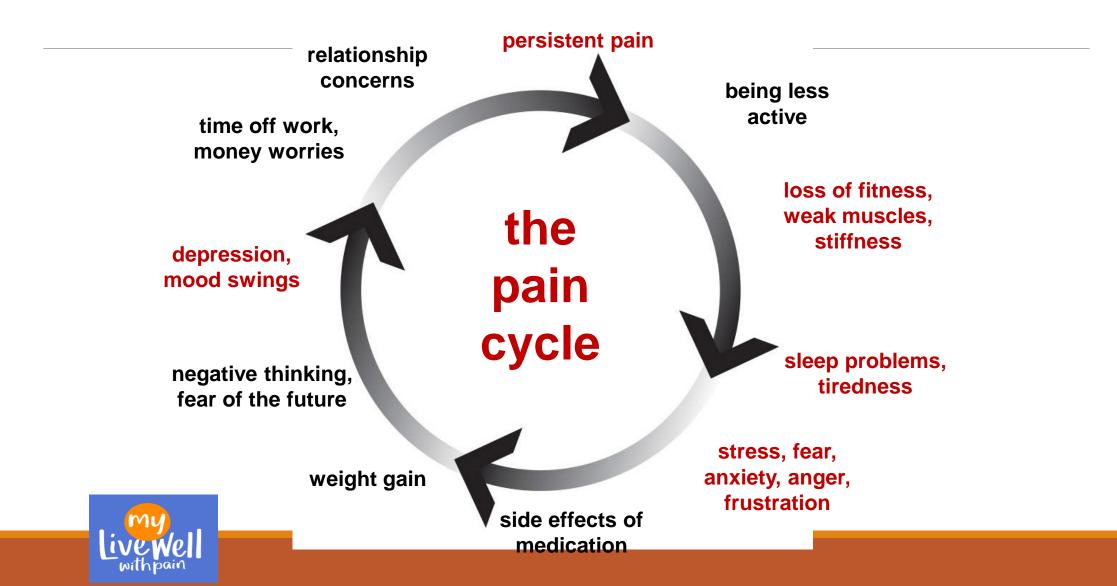
- □ Severely disabling chronic pain 10.4% -14.3%
- □ Increasing prevalence with age up to 62% > 75 yrs
- Prevalence likely to increase with aging population

(http://bmjopen.bmj.com/content/6/6/e010364)

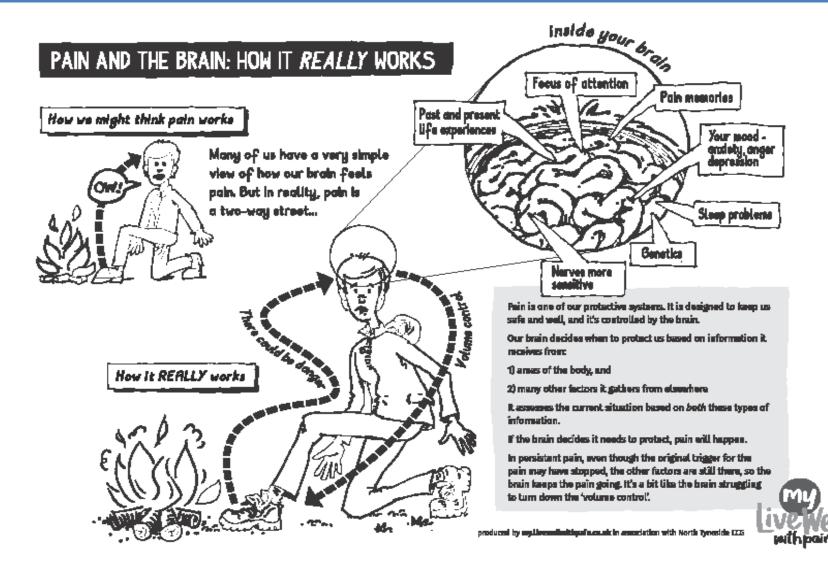
# The pain cycle



### Understanding the 'what' before the 'how'



# Understanding pain and the brain



### **Pain: revised definition 2020**

The revised IASP definition of pain: concepts, challenges and compromises. Raja et al (2020) Pain DOI:10.1097/j.pain.00000000001939

#### 2020 Revised Definition of Pain

'An unpleasant sensory and emotional experience associated with, or resembling that associated with actual or potential tissue damage'

#### 2020 Revised Definition of Pain Notes

•	Pain is always a personal experience that is influenced to varying degrees by biological, psychological and social factors	•	A person's report of an experience as pain should be respected
•	Pain and nociception are different phenomena. Pain cannot be inferred solely from activity in sensory neurons	•	Although pain usually serves an adaptive role, it may have adverse effects on function and social and psychological well-being
•	Through their life experiences individuals learn the concept of pain	•	Verbal description is only one of several behaviours to express pain: inability to communicate does not negate the possibility that a human or non-human animal experiences pain.

## Changing the impact of pain Self care cycle

Now the 'how' – knowledge, skills, tools and resources



https://livewellwithpain.co.uk/ten-footsteps/

## Lived experience share on supporting self management

### "It is just about caring so we can move ourselves from enduring to enjoying life"

Self-management enabled me to resume my previous activities, makes me feel like a real person again.

To have a better life, with much reduced pain, the pain reduction is a secondary gain.

Self management is moving away from an endless and unsuccessful quest to find the 'solution' to the problem. Instead it is embarking on a wild, exciting daily journey to find joy in my (current) life.

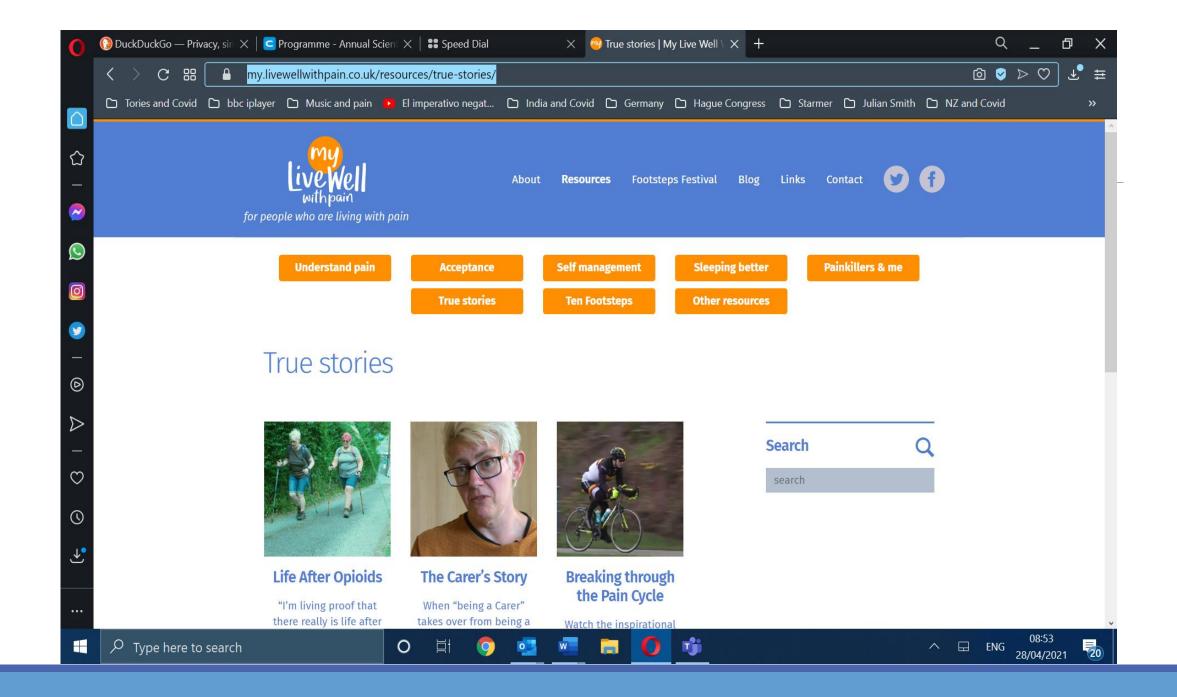
#### Key message

#### "Listen and walk with me"

Clinicians need to devote time and effort to listening to people with lived experience if they want to have an effective focus on self-management

Listen to find what empowers each person living with pain to take control of their own experience with support

Walking beside them and being their coach and friend.



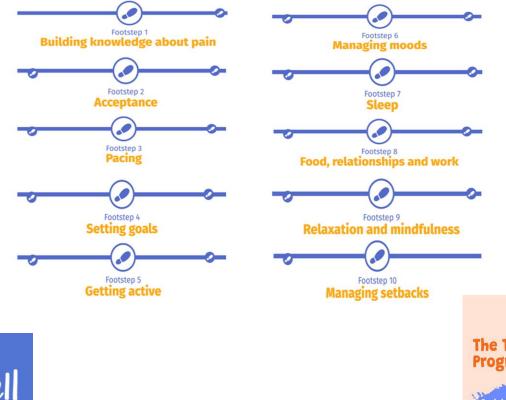


#### **Objectives to increase**

- 1- Clinician and social prescriber confidence
- 2- Patient confidence
- **3 Safer Prescribing**









## Lived experience share on supporting self management

"It is just about caring so we can move ourselves from enduring to enjoying life"

- Compassion changes everything.
- Compassion heals.
- Compassion mends the broken and restores what has been lost.
- Compassion draws together those who have been estranged or never even dreamed they were connected.
- Compassion pulls us out of ourselves and into the heart of another, placing us on sacred ground and journeys where we instinctively take off our shoes and walk in reverence.
- Compassion springs out of vulnerability and triumphs in unity.

# The Gabapentinoid and Opioid Tapering Toolbox: Early Findings







ive Well with pain



**Clifton Court Medical Practice** 

**Dr Paul Chazot FBPhS** 

**GOTT Team**: Dr Frances Cole, Dr Rebecca Kinchin, Lucy Johnson, Konrad Winiarek, Andrea Frances, Dr Camila Caiado, Michael Keane, Thalia Seale, Prof Kate Hampshire National Institute for Health and Care Excellence

• There is "little or no evidence" that treating the condition with commonly used painkillers actually makes a difference to people's quality of life, pain or psychological distress, NICE said. Watch Live Full Series Shows Categories News

Painkillers should not be prescribed for pain with no known underlying cause

🕓 Wednesday 7 April 2021, 12:01am



The National Institute for Health and Care Excellence (Nice) said that people with chronic primary pain should instead be offered a range of therapies including exercise programmes, psychological therapies, acupuncture .....

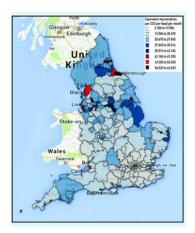
.....basically an effective biopsychosocial GOTT programme



# Why develop GOTT?

**Clifton Court Medical Practice** *Darlington, Country Durham* 

- Practice population 12,000
- Training Practice
  6 GP Partners, 1 Salaried GP, 3 Registrars,
  2 Clinical Practitioners, 1 Pharmacist, 1
  Pharmacy Technician, 5 Nurses and 3 HCA's
- Darlington has a high deprivation score
- The highest opioid prescribers within the CCG
- Patients with unsafe polypharmacy and still in pain



# What is GOTT?



**Toolbox of 10 Footsteps** = framework for self management of pain for both clinicians and patients

- **1- Clinician confidence**
- **2- Patient confidence**





# **Building Clinician Confidence**

- Clinical team's knowledge, skills and confidence to support self management
- Baseline assessment of clinician confidence
- Training programme created:
  - Health coaching for the whole practice team including our administration (care navigation staff)
  - Face to face / online sessions: reviewing chronic pain management resources and case discussions
  - Email supported learning on different Footsteps. Ideas to engage patients in self management.
- Shift from biomedical to biopsychosocial approach

GOTT implementation within practice

Live Well with Pain Health Check

- Systematic person-centred pain management review.
- Build patients confidence in self management
- Dedicated appointment for pain health check:
  - Invitation letter, health check and opioid lottery forms.
  - Heath check includes screening of health needs, wellbeing measure, self confidence to manage pain score, pain intensity and distress scores
  - Health checked use to guide self management goals
  - Linked into Social Prescribing
  - Medication review, use of "Opioid Lottery Decision Aid" and dose reductions

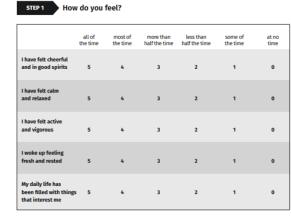




Live Well with Pain Health Check Exploring how pain affects your health and life

Please help us understand about your health and the main obstacles to improving your quality of life and self managing with confidence.

There are four steps to completing this Health Check. Please complete all four steps - tick or circle all the answers that apply to you.



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#### Do you have any problems or difficulties with: Nalking or moving about, lack of fitness and stamina Balance or recurrent falls Π Side effects or problems with current pain medication e.g. tablets etc. Π Pain relief Understanding why persistent pain occurs An unhelpful cycle of activity of less pain, so do too much, so more pain, so rest more often or for longe Eating the right sort of foods, weight changes Π Disturbed sleep, tiredness or lack of energy Π Managing mood changes of depression, anger, anxiety or worry Relationship difficulties: with partner, family etc, or sex life concerns Remaining in work or returning to work and/or training Π inancial or money difficulties Other difficulties (for example, concerns about housing, leisure or social events, drinking, gambling or drug use). Please describe here:



If you ticked more than three boxes above. please circle the three most important ones to change.

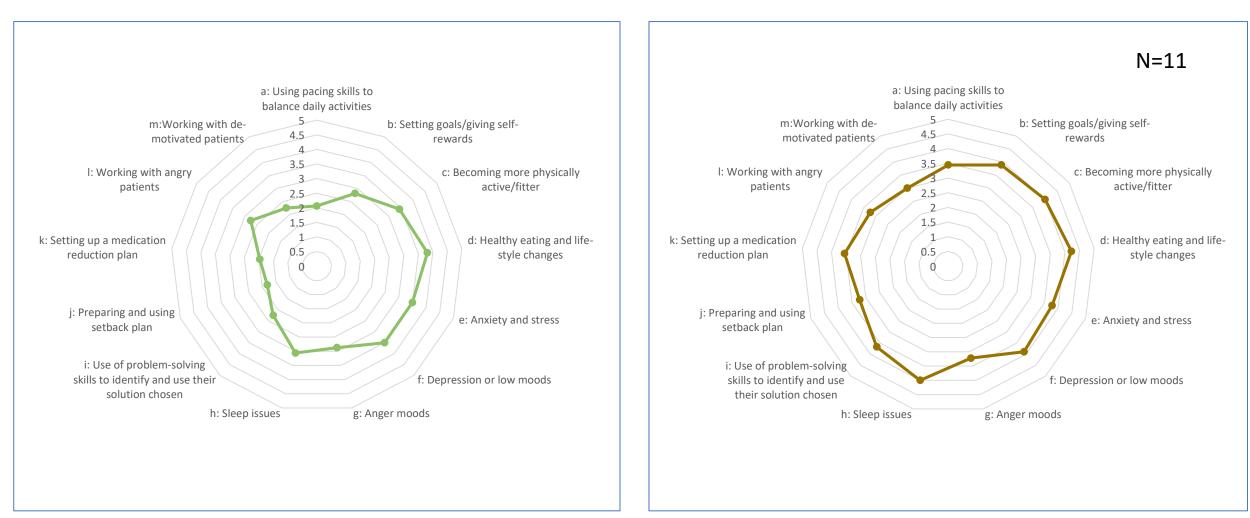
you completed all four steps? have the completed form with you at your pain management and medicines review. Il look at it together to help explore your concerns, issues and problems linked to your Thank you for helping us understand how your pain is affecting your health and life.

me Your date of birth led in

# Live Well with Pain Health Check Tool

## **Evaluation findings - change in confidence at baseline and mid trial**

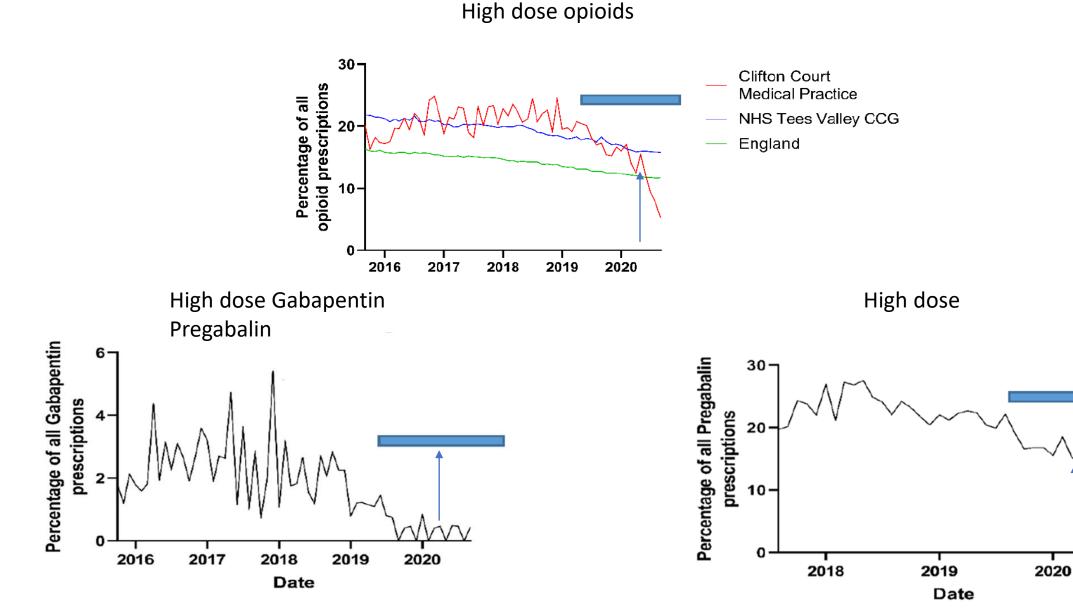
How confident do you feel in supporting patients in the following ways? (Scale 5 = most confident - 1 = least confident)



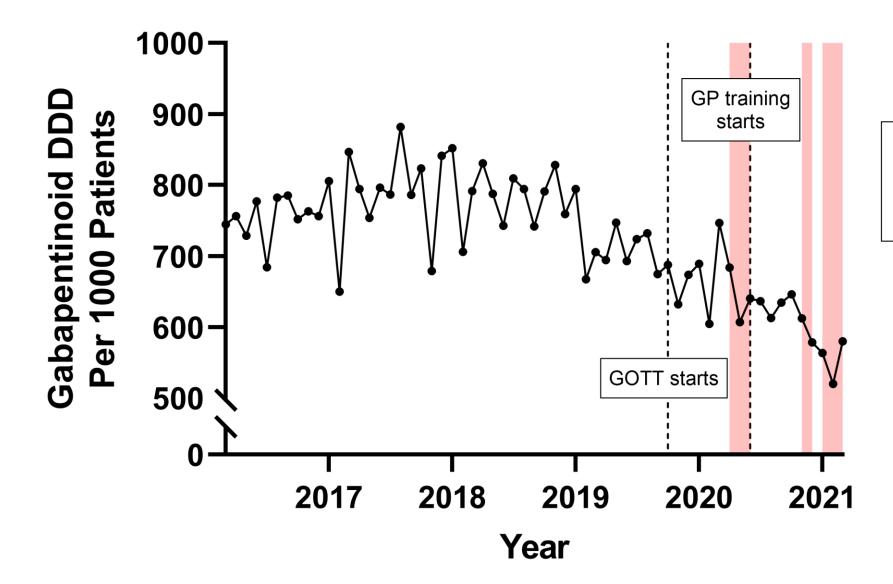
Average respondent confidence score June 2020

Average respondent confidence score December 2020

## Safer prescribing evaluation findings

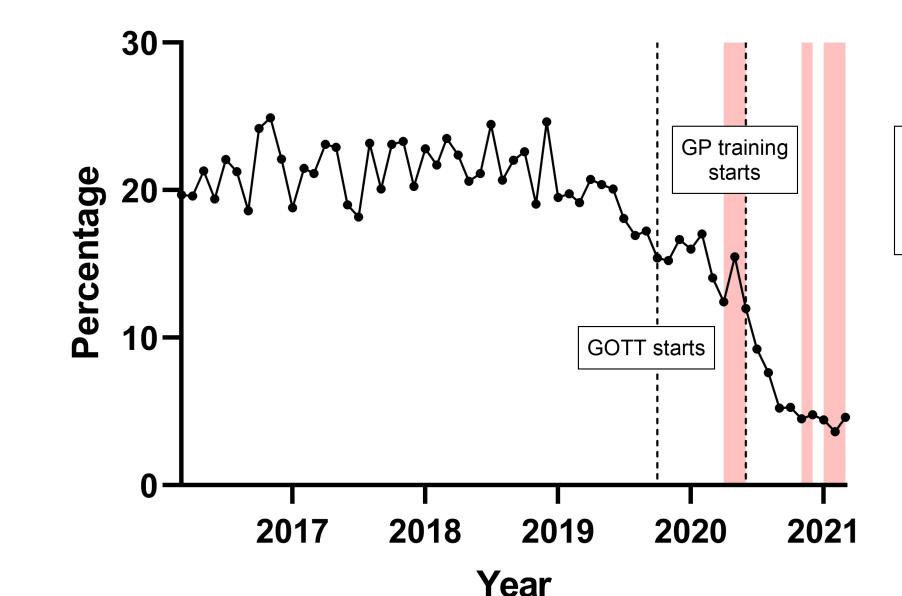


## **Gabapentinoid Defined Daily Dose**



Shaded areas indicate periods of national lockdown

## HDOs as a Percentage of All Opioids



Shaded areas indicate periods of national lockdown

# Summary of discoveries so far from GOTT project

- Increased confidence of clinician knowledge, skills and use of tools and resources.
- Reduction in high-dose pain medication & total GABApentinoids
- Systematic approach to pain management and medication use



Project funded by ESRC (SPF), ESRC, IAA and ESRC NINE DTP, Arts Council & www.livwellwithpain.co.uk

# The Footsteps Festival Collective









# Footsteps Festival 2021

## A year-long celebration of living well with pain

















#### Pain is more complex than I thought 08/04/2021

An advocate of living well, with extensive experience of living with pain chats to a clinical psychologist about what she has learned about the complex nature of pain and why, in her experience, everything matters when it comes to pain.



#### Mindfulness Based Stress Reduction Programme (MBSR) 23/02/2021

Please note, the current course is now full. If you are p interested in finding out about possible future courses please get in touch...

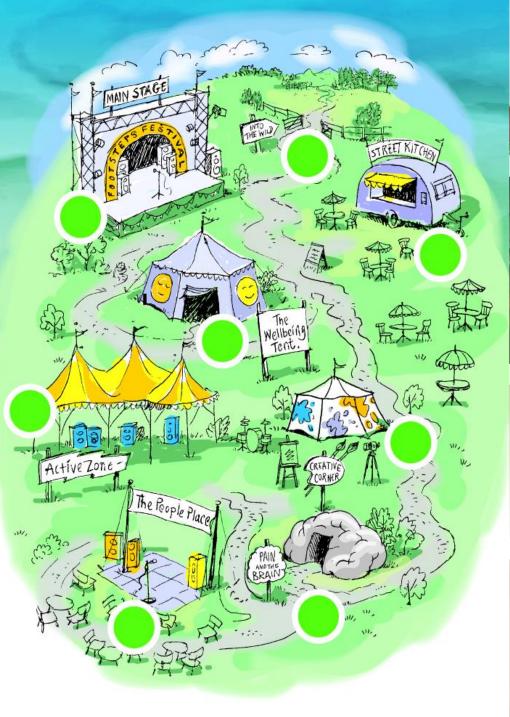


#### Chronic Pain the Dr Seuss Way

Learn what the wisdom of Dr Seuss has to do with chronic pain!

Your Story Matters 30/03/2021

Have some fun and connect with others in this live creative writing workshop by Clair, Debra, Jenny and Sanja.



## Cookfulness

with Ian Taverner







#### Cookfulness 23/04/2021

In this series of six sessions specially created for people with pain, you'll learn amazing and very simple ways to adapt cooking, adapt ingredients and adapt dishes, so you can cook them and celebrate them no matter how bad...

#### Step into Singing – session 7 20/04/2021

Footsteps Festival 2021, in partnership with Opera North, is proud to bring you Step Into Singing – a series of online singing workshops designed especially for people living with persistent pain. Led by opera singer, Marie Claire Breen, Step Into...

#### Origami for Wellbeing; Focusing the Mind 17/04/2021

11.00 am on Saturday 17th April Make something beautiful in your hands through paper folding. No experience needed just bring any piece of paper! Try something new and wonderful with Dr Lizzie Burns who helps people of all ages...

#### Pet Show and Tell – social gathering 11/04/2021

A friendly informal social occasion where we can show each other our pets (the more portable ones!) and have a lively discussion about the many and varied ways they help us live better with pain.



# Key Features

- All events co-produced.
- Live and recorded content.
- Trusted presenters and resources.
- Voluntary basis.



• Fun!



## Courses

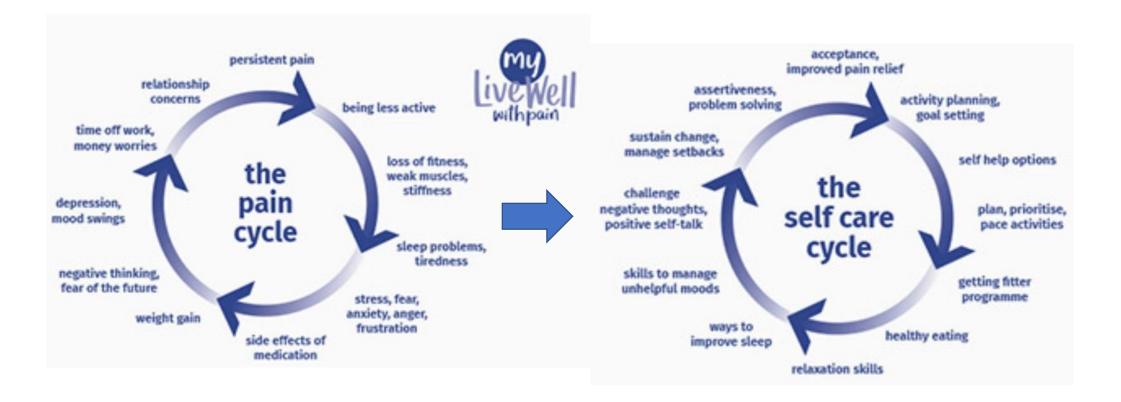
### Courses

- MBSR
- Ten Footsteps
- Step Into Singing





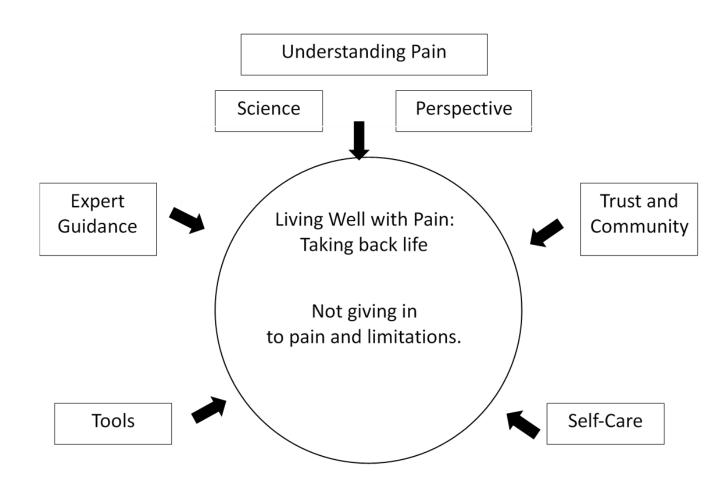
# Turning down the volume



From Newcastle. For the world.



# Feedback: How do people benefit?



From Newcastle. For the world.







A year-long celebration of living well with pain

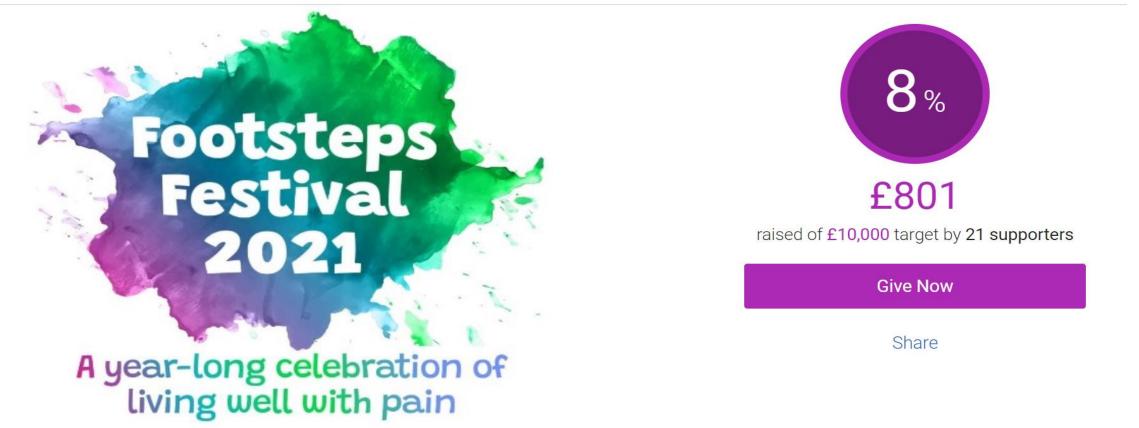
Footsteps

Festival

2021

p.p.a Physiotherapy Pain <u>Association</u>

From Newcastle. For the wc





Footsteps

Festival

We're raising £10,000 to Support Footsteps Festival so it remains free to access for everyone!! No amount too small



Thank you to

- Clifton Court Practice, Darlington
- Footsteps Festival T2021 Team
- Chris Penlington University of Newcastle
- Paul Chazot and Lucy Johnson, University of Durham Wolfson Research Unit for Health and Well-Being
- Live Well with Pain Team
- GP Red Whale
- And the many, many people with pain who have guided our journeys