

Patient information

Persistent Pain Service: Patient Resources



PERSISTENT PAIN SERVICE: PATIENT RESOURCES	1
Introduction	4
Understanding Pain Medication: Opioids	5
Reducing and stopping opioid medication	6
Faculty of pain medicine’s ‘opioids aware’ website	7
Faye’s Story	7
Brainman stops his opioids	7
Life After Opioids.....	8
Videos – Understanding Persistent Pain	9
Tame the beast	9
What is chronic pain?	9
The Mysterious Science of Pain	9
How does your brain respond to pain?	10
Low back pain myths.....	10
Everything matters when it comes to pain	10
Why do we feel pain differently?	11
Acceptance and Commitment Therapy for Chronic Pain.....	11
Websites	12
EXI.....	12
The Retrain Pain Foundation	12
Tame the beast	13
Live Well with Pain	13
Face Pain	14
Patient Led Websites	15
The Pain Toolkit	15
My Cuppa Jo	15
Living Well Pain.....	16
Unchartered Collective.....	16
Charities	17
Pain Concern	17
Pain UK	17
Mindfulness Practice for Pain Management	18

Bangor University's Centre for Mindfulness Research and Practice	18
Mindfulness Apps (Download to Apple or Android)	19
Aura	19
Breethe	19
Buddhify	19
Headspace	19
Tell us what you think	20
Patient Advice and Liaison Service (PALS) Please contact us if you need general information or advice about Trust services:	
www.bartshealth.nhs.uk/pals	20

Introduction

We understand that living with a long-term pain condition can be challenging, often stirring up difficult emotions and significantly affecting your daily life. The advice you receive can sometimes be conflicting or confusing, leaving many patients uncertain about the best way to proceed.

The purpose of this document is to:

1. Help you in managing your persistent pain condition.
2. Aid you in enhancing your quality of life while living with a long-term pain condition.

The resources below contain a wealth of information. Some parts may be more applicable to your situation than others. You are welcome to explore all the information or, alternatively, discuss with your healthcare team which sections are most relevant to your needs.

Understanding Pain Medication: Opioids

1. Opioids are strong pain medicines. They work well for short-term pain (less than 3 months) and for pain at the end of life. But they might not be helpful for persistent pain.
2. Some people may find long-term pain relief with opioids if they use a small amount and only when needed.
3. Using high doses of opioids can be harmful without giving more pain relief.
4. If you need to lower or stop high-dose opioid medicine, it should be done carefully with the help of your medical team.
5. If your pain is still severe despite taking opioids, it means they're not helping. In this case, you should plan to stop using them (with the support of your medical team) even if there are no other treatments available.
6. Long-lasting pain is complicated. If your pain doesn't get better with treatment and it's affecting your life negatively, a detailed assessment of all the factors causing your pain is important.

Adapted from the Faculty of pain medicine.

Reducing and stopping opioid medication

Link: <https://tinyurl.com/22y98fj9>



The faculty of pain medicine advises that **the dose of drug can be reduced by 10% weekly or two weekly**. It is the experience of the pain team that, for some individuals, a slower reduction may be necessary. Additionally, there might be times when patients need to remain at a specific dose for an extended period.

It is important to reduce or stop your opioids if:

- The medication isn't effectively relieving your pain. Going beyond a dose of 120mg oral morphine equivalent per day can lead to more harm than benefits, and higher doses are unlikely to provide added relief.
- Your underlying painful condition gets better or goes away.
- You undergo a pain-relieving procedure like a joint replacement and no longer require the medication.
- You experience intolerable side effects from the medication.

Faculty of pain medicine's 'opioids aware' website

Link: <https://tinyurl.com/5y6p3ee3>



In this section of their website, **The Faculty of Pain Medicine** provides help for patients who are taking opioid medication.

Faye's Story

Link: <https://tinyurl.com/3s7u5r56>



A special edition of the 'controlled drugs newsletter.' Faye's story. **A moving article highlighting the pitfalls of opioid use in persistent pain.**

Brainman stops his opioids

Link: <https://tinyurl.com/mwv38hwa>



Holds the message that **opioids are no longer recommended for chronic non-cancer pain.** Video Length: 1min 45 secs

Life After Opioids

Link: <https://tinyurl.com/yc2npf5w>



Video Length: 23mins 43 secs



The inspiring story of Louise Trewern. Louise suffered with pain for most of her adult life. Here she talks **through her lived experience of pain and her journey through opioids.**

Videos – Understanding Persistent Pain

Tame the beast

Link: <https://tinyurl.com/58nwuer6>



An animated video narrated by Professor Lorimer Moseley. The video aims to increase the viewers **understanding of persistent pain**

in a visually stimulating way. *Video length: 5 mins.*

What is chronic pain?

Link: <https://tinyurl.com/5facm2au>

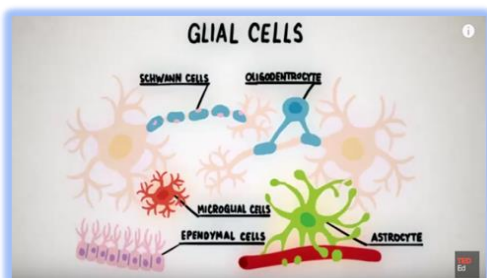


A video explainer from The Guardian explaining the complexities of chronic or nociplastic pain. With specific emphasis on the central nervous system and immune system.

Video length: 3min 8secs.

The Mysterious Science of Pain

Link: <https://tinyurl.com/je6hz6c3>



Joshua W. Pate explores the **biological and psychological factors** that influence how we experience pain. *Video Length: 5mins 2 secs*

How does your brain respond to pain?

Link: <https://tinyurl.com/7ey8nyzd>



Why do some people react to the same painful stimulus in different ways? And what exactly is pain, anyway? Karen D. Davis walks you through your brain on pain, explaining why the “**pain experience**” differs from

person to person. *Video Length: 4 mins 57 Secs*

Low back pain myths

Link: <https://tinyurl.com/yjpcv3jp>



Professor Peter O’Sullivan uses real patient interviews and stories to **debunk common low back pain myths.**

Video Length: 15 mins 21 secs

Everything matters when it comes to pain

Link: <https://tinyurl.com/2e24scsb>



The ‘Flippin’ pain’ group discuss **the many influences on the pain experience.**

Video Length: 2mins 35 secs

Why do we feel pain differently?

Link: <https://tinyurl.com/yc59jsc7>



Dr Janet Bultitude's research explores **the science behind pain**, what pain is and why pain might be experienced differently by different people. *Video Length: 2mins 53 secs*

Acceptance and Commitment Therapy for Chronic Pain

Link: <https://tinyurl.com/ma5572be>

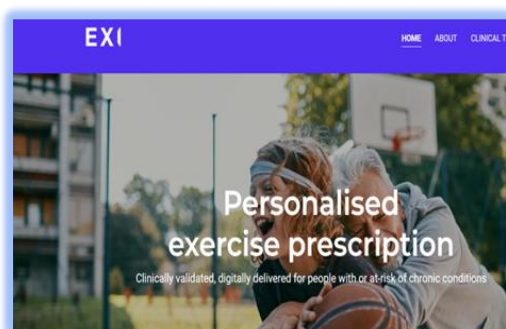


Prof. Tamar Pincus **explains acceptance and commitment therapy for chronic pain**. 'It took me a long time to understand that **acceptance was not the same as giving up or losing hope**, but instead a conscious decision to completely engage with life, including pain'
Video Length: 3min 06 secs

Websites

EXI

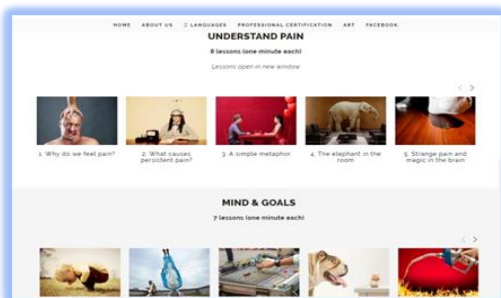
Link: exi.life



EXI is a health platform created by physiotherapists, offering a structured physical activity program. **Using your current health condition as a guide**, the app generates a personalized exercise plan at the appropriate intensity level, which gradually progresses over a 12-week period, **customized for 23 different health conditions**.

The Retrain Pain Foundation

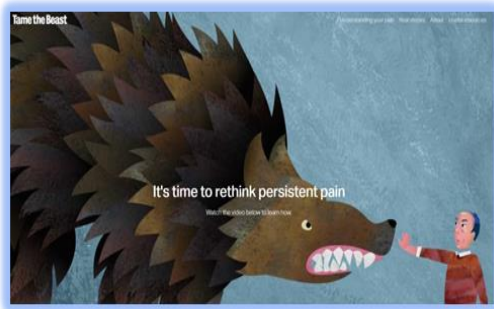
Link: <http://www.retrainpain.org/>



The Retrain Pain Foundation is an excellent resource with a number of **quick, engaging materials** around the topic of persistent pain. **It has translated the material into a number of different languages** so can be accessed by non-English speaking patients.

Tame the beast

Link: <https://www.tamethebeast.org/>



Tame the Beast is a freely available, non-commercial education space that hopes to **inspire research-based action in the treatment of pain**. It includes many useful

resources and real patient stories

Live Well with Pain

Link: <https://livewellwithpain.co.uk/>

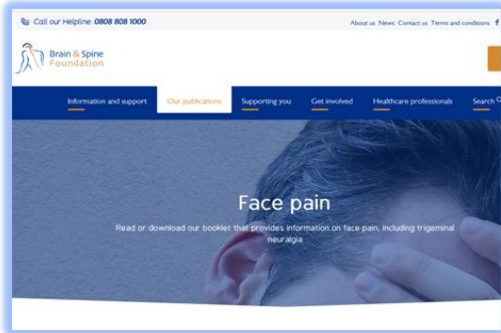


Living well with pain is a website created through the collaboration of Dr Francis Cole (retired GP), Emma Davies (Advanced

Pharmacist Practitioner) and Eve Jenner (Physiotherapist). **It is written for patients and clinicians and has helpful resources on a number of pain management strategies, including opioid management.**

Face Pain

Link: <https://tinyurl.com/22df5w9d>



Download a booklet on **facial pain and trigeminal neuralgia**. This booklet provides information on the different types of face pain, common symptoms, tests, and treatments.

Patient Led Websites

The Pain Toolkit

Link: <https://www.paintoolkit.org/>



Pain toolkit is a site run by Pete Moore. Pete experiences persistent pain himself. On his journey he has amassed **many pain management techniques**. He now uses his expertise to help other pain patients and health care professionals.

My Cuppa Jo

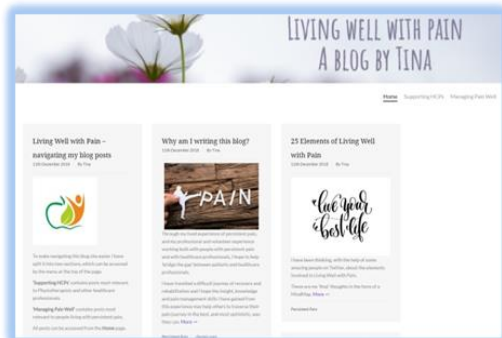
Link: <http://www.mycuppaio.com/>



Joletta Belton writes a blog on **living with chronic pain from a patient's perspective**. The website aims to make sense of pain through science and stories.

Living Well Pain

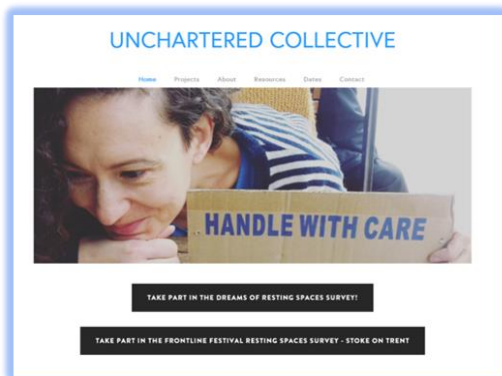
Link: <http://livingwellpain.net/>



“Through my lived experience of persistent pain, and my professional and volunteer experience ... I hope to **‘bridge the gap’ between patients and healthcare professionals**”

Unchartered Collective

Link: <https://uncharteredcollective.com/>



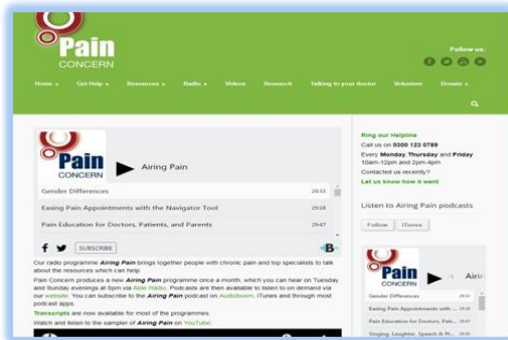
The unchartered collective are a **collaboration of ‘creatives.’** A group of persistent pain sufferers raising awareness and **exploring the pain experience through art and performance.**

“Our name reflects our sense of living in unchartered territory: when an illness becomes chronic and your life counterculture. With few role models and little awareness around invisible impairments, navigating this new world can be a lonely thing”

Charities

Pain Concern

Link: <http://painconcern.org.uk/airing-pain/>



Pain Concern is a **charity working to support and inform people with pain and those who care for them**, whether family, friends, or healthcare professionals.

Pain UK

Link: <https://painuk.org/>



Pain UK is an **alliance of charities** that operates to make a significant difference for people living with pain whether that is through the support of their member charities or

directly.

Mindfulness Practice for Pain Management

Bangor University's Centre for Mindfulness Research and Practice

Link: <https://tinyurl.com/9kse7tmk>

Centre for Mindfulness Research and Practice

< Home

Centre for Mindfulness Research and Practice

CMRP Audio downloads

Workplace Mindfulness Audio Tracks

About

In order to save a track, right click on the track and choose 'save link as'

	MP3	iTunes
Masters in Mindfulness		
Come and Meet Us	Track 1 6:30 Min Breath and the Body (9mb)	Track 1 (24mb)
Train to Teach Mindfulness	Track 2 13:26 Min Body Scan (18mb)	Track 2 (47mb)
	Track 3 12:51 Min Mindful Movement (18mb)	Track 3 (35mb)
Commission a Mindfulness Course	Track 4 8:52 Min Mindful Walking (12mb)	Track 4 (20mb)
	Track 5 10:05 Min Mindfulness of Breath & the Body (14mb)	Track 5 (24mb)
	Track 6 10:01 Min Mindfulness of Sounds and Thoughts (14mb)	Track 6 (27mb)
Compassion Courses	Track 7 8:34 min Three Step Breathing Space (5mb)	Track 7 (13mb)



Bangor University has a number of **guided mindfulness based practices** that could be incorporated into a pain management plan.

Mindfulness Apps (Download to Apple or Android)

Aura



Aura has **mindfulness meditations, life coaching, stories, and music**, created by therapists and coaches.

Breethe



Breethe aims to help you de-stress, sleep better, get happier & be healthier with **guided meditations, soothing music, nature sounds and masterclasses.**

Buddhify



Buddhify focusses on **mobile or on-the-go meditation, which you can do wherever you are and whatever you're doing.** They also have more traditional formal meditations.

Headspace



Headspace has hundreds of themed sessions on everything from stress and sleep to focus and anxiety. **Bite-sized guided meditations for busy schedules** and 'SOS exercises' in case of sudden meltdowns

Large print and other languages

This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request. For more information, speak to your clinical team.

এই তথ্যগুলো সহজে পড়া যায় অথবা বৃহৎ প্রিন্টের মত বিকল্প ফরম্যাটে পাওয়া যাবে, এবং অনুরোধে অন্য ভাষায়ও পাওয়া যেতে পারে। আরো তথ্যের জন্য আপনার ক্লিনিক্যাল টিমের সাথে কথা বলুন।

Na żądanie te informacje mogą zostać udostępnione w innych formatach, takich jak zapis większą czcionką lub łatwą do czytania, a także w innych językach. Aby uzyskać więcej informacji, porozmawiaj ze swoim zespołem specjalistów.

Macluumaadkaan waxaa loo heli karaa qaab kale, sida ugu akhrinta ugu fudud, ama far waa weyn, waxana laga yabaa in lagu heli luuqaado Kale, haddii la codsado. Wixii macluumaad dheeraad ah, kala hadal kooxda xarunta caafimaadka.

Bu bilgi, kolay okunurluk veya büyük baskılar gibi alternatif biçimlerde sunulabilir, ve talep üzerine Alternatif Dillerde sunulabilir. Daha fazla bilgi için klinik ekibinizle irtibata geçin.

یہ معلومات متبادل فارمیٹس میں دستیاب کی جا سکتی ہیں، جیسا کہ پڑھنے میں آسان یا بڑا پرنٹ اور درخواست پر متبادل زبانوں میں بھی دستیاب ہو سکتی ہیں۔ مزید معلومات کے لیے، اپنی کلینکل ٹیم سے بات کریں۔!

Tell us what you think

Tweet us @NHSBartsHealth

Talk to us via [facebook.com/bartshealth](https://www.facebook.com/bartshealth)

Leave feedback on NHS Choices www.nhs.uk

Patient Advice and Liaison Service (PALS)

Please contact us if you need general information or advice about Trust services:

www.bartshealth.nhs.uk/pals

Reference: BH/PIN/1235

Publication date: October 2023

All our patient information leaflets are reviewed every three years.