



Life After Opioids – Louise’s Story

Life After Opioids – Louise’s Story is a new film from *Live Well with Pain* that will inspire your patients to think again about trying to manage their pain with opioids.

Louise, who has lived with fibromyalgia for most of her adult life, movingly describes in her own words how long-term opioid use not only failed to help her pain – it actually made matters worse, with a range of debilitating side effects that many people with pain will recognise from their own opioid medicine use.

Louise’s experience of finally coming off opioids and her journey to self-management is both inspiring and thought-provoking. She also has some encouraging words for clinicians who want to know how best to support their patients to take the self-management route.

Life After Opioids is a *Live Well with Pain* production. We are grateful to University of Durham’s Wolfson Research Institute for Health & Wellbeing Pain Special Interest Group, for their financial support in making this film.

Watch the film on the *Live Well with Pain* website here: <https://livewellwithpain.co.uk/news/a-new-film-to-inspire-your-patients/>

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Histamine and histamine receptors: **new kids on the block for persistent neuropathic pain relief?**

Despite advances in the understanding of the underlying causes and mechanisms leading to the development and maintenance of persistent neuropathic pain, 40% of Europeans who suffer from chronic pain do not achieve satisfactory pain control, and to date, no medication has shown long-term efficacy and tolerability for neuropathic pain conditions.

A significant contributing factor to these limited therapeutic strategies, is that neuropathic pain has different aetiology and pathophysiology to any other type of chronic pain, making the management of this type of chronic pain particularly challenging. Consequently, there is a pressing need for the identification of new therapeutic strategies to improve management of neuropathic pain that will directly improve the outcome for pain sufferers.

The mechanisms underlying neuropathic pain are complex and multidimensional. Histamine, acting via four distinct receptors, is a key mediator in the processing of nociceptive (pain) information, at all levels of the pathway (top to bottom). In neuropathic pain, histamine released in the periphery by mast cells, has been shown to play an important role in the development of hypersensitivity following nerve injury. This pathological process is associated with recruitment of key immune cells, and as histamine is a powerful chemoattractant of such cells, it regulates this recruitment.

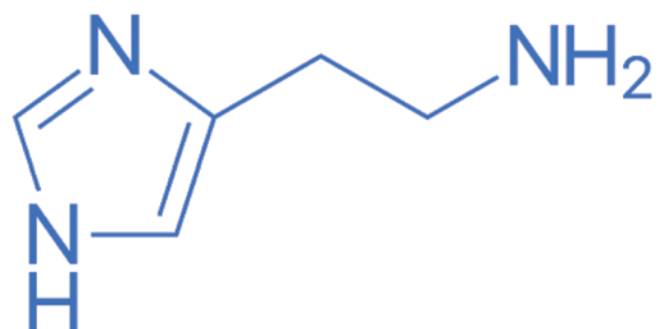
A better understanding of the interaction between histaminergic signalling pathway molecules and specific histamine receptor subtypes may result in identification of further novel pharmacological targets to improve neuropathic pain management (<https://bpspubs.onlinelibrary.wiley.com/doi/full/10.1111/bph.14696>).

Going forward, we have two new clinically-ready histamine receptor-based drugs which are showing significant promise in pre-clinical studies – watch this space.

Drs Ilona Obara (Newcastle University) and Paul L Chazot (Durham University)



Neuropathic pain has different aetiology and pathophysiology to any other type of chronic pain, making the management of this type of chronic pain particularly challenging



In pain management understanding a person's needs, enabling them to prioritise, and providing interventions based on actually available and effective resources is crucial. Here **Frances Cole** discusses the Health Needs Assessment tool and how it can be used in brief face-to-face contact with your patient.

A tool for understanding needs

Using the Health Needs Assessment, in brief face-to-face contact can be helpful in better understanding the needs and issues of someone living with a long-term condition.

Wright and colleagues discussed the importance of taking a systematic approach in examining individual and population health needs, as far back as 1998.

(<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1113037/>)

In health care, need is commonly defined as the capacity to benefit. If health needs are to be identified then an effective intervention should be available to meet these needs and improve health. There will be no benefit from an intervention that is not effective or if there are no resources available.

A Health Needs Assessment tool (HNA) based on functional domains of health, physical, emotional and social roles, was developed to address the impact of pain on health interventions and how locally available resources may provide support.

The Health Needs Assessment tool does several practical things:

- It engages the person to identify their needs from a list of the impact of pain on health, empowering the patient
- It enables the person to identify their three priorities for change in the present time, collaborative action
- It gives a level of severity of the impact of pain such that the more areas of impact identified by the patient the greater the severity of impact.

- It enables identification of people with pain who would benefit from referral to more specialist services, so acts as triage tool.

- It enables the priorities identified to become the focus of further assessment or the baseline for a trial of an intervention. The HNA provides an evidence base and helps to link people to appropriate support such as resources or social prescribing. It is effective and time efficient.

Sleep for example ranks third in the factors identified in an HNA by people living with pain. Further management requires assessment to fully understand the sleep difficulties reported. That, in turn, may require resources such as a sleep diary and then lead to guiding the person to engage in making changes to the way they manage sleep. The HNA helps bring clarity to the problem and specifically to their severity. This can result in more appropriate interventions being suggested, e.g. a cooler room for sleep, limiting TV, or undertaking a CBT-based sleep management programme.

The 13-item HNA shown here is available for download from the website along with guidance for each individual area, including assessment and intervention resources. Experiment in practice and see what you discover.

This is not about creating new services or resources, but knowing what is already available and could be effectively used to address the health needs of people living with pain, on your patch.

Download the HNA and new guidance on how to use it, here:

<https://livewellwithpain.co.uk/resources/supporting-self-management/the-health-needs-assessment-hna/>

Public Health England released their review on dependence and withdrawal associated with some prescribed medicines at the beginning of September. As perhaps could have been predicted, mainstream media quickly jumped into headline mode, with words such as ‘addiction’ and ‘hooked’ used liberally. **Emma Davies** looks behind the headlines to find out what the review can teach us.

Addicted to painkillers?

The reality behind the headlines

Despite the sensational nature of some of the media headlines that followed the publication of their review, Public Health England were very clear in their report that the situation is rather more complex in reality. It is evident the use of benzodiazepines, opioids, gabapentinoids, z-drug and anti-depressants is higher in areas of greater deprivation. It should also be noted that dependence is a physical phenomenon, linked to the mechanism of the drugs. It can be influenced by other factors, particularly where people are living difficult and complicated lives but this still is not the same as ‘addiction’.

Key learning points

So what are the learning points from this review? Firstly, that we are using medicines that can cause significant harm to those that we are here to support. Even if we move away from the issue of dependence, we know that many of these medicines are used in combination, which heightens the risks of side-effects and toxicity.

Perhaps the most important (but less headline grabbing) point, is that the evidence for any of these medicines being helpful in the long term for many people, is actually very poor. So, we are in a situation of prescribing unhelpful and potentially harmful medicines, to large numbers of people.

As a clinician, my main concern is why this happens in the first place. The majority of Primary Care Practitioners that I work with are well versed in the risks of the five groups of medicines examined by PHE. But, they see people presenting week after week with pain and distress and asking for more medication. When there are

The evidence for any of these medicines being helpful in the long term is actually very poor. So how have we got into a situation of prescribing unhelpful and potentially harmful medicines to so many people?

limited services, long waits and people who are not keen to engage in the idea of self-management, it is easy to understand why medicines are leaned on so heavily.

However, this is not a Primary Care issue alone (despite what the papers might say). There is increasing evidence that starting opioids in secondary care settings, perhaps post-operatively without sufficient education (of staff and patients), without advice to Primary Care on reviewing and reducing, plays a role in longer-term use. Providing more than two weeks of opioids at first prescription was demonstrated by the Centre of Disease Control in America, to increase the likelihood of a person remaining on them several months and even years later.

Harry Shaprio, Director of DrugWise (www.drugwise.org.uk) refers to medicines being used to manage ‘Crap Life syndrome’ and whilst some may baulk at the terminology, I suspect we all identify with the sentiment. Pain is a complex phenomenon, influenced by many factors, most of which are not physical symptoms or processes. Persisting pain is even more heavily influenced by psychological and social factors, none of which are solved by medicines. Medicines may assist in taking the individual ‘out’ of a difficult situation for a time and this can, without realising it, be one reason that people find the idea of reducing medicines so difficult.

If we are going to make a change to prescribing of opioids, gabapentinoids and the other medicines reviewed by PHE, it will take significant change to both healthcare and social care systems. Support for reducing medicines can be difficult to access, it takes time and requires flexibility that can be

hard to find in frantically busy Primary Care Practices. We also need to make support available from earlier on when people present with pain, to educate them, reduce fear of pain, improve function and learn to live well with pain.

None of this will happen quickly, we all need to demand better from CCGs, Health Boards and others, in terms of making support more widely accessible. We also need to increase public awareness of persisting pain and how it is possible to live a happy, fulfilled and active life even with pain.



You can read the Public Health England review in full here:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/829777/PHE_PMR_report.pdf

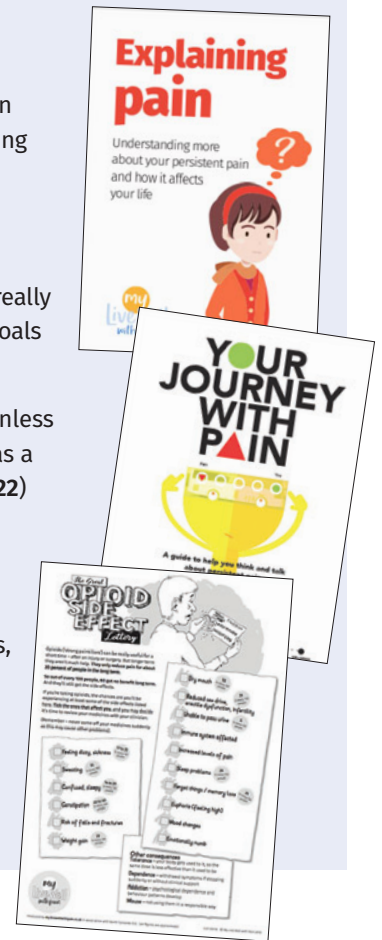
How can *Live Well with Pain* help?

In the meantime, we can change our own approach to supporting people presenting with pain. We can explain pain (try downloading and using the PDF of our **Explain Pain leaflet**)

We can help patients think about what really matters to them and how they can set goals (use **Your journey with Pain leaflet**)

And we can ensure we don't prescribe unless really necessary – and then consider it as a trial (<https://www.rcoa.ac.uk/node/21122>)

For people already taking medicines, making them aware of the side effects that can be caused, which they may not have realised were due to the medicines, can be a first step in making a change. (check out our **Great Opioid Side Effect Lottery and Gabapentinoid leaflets**).



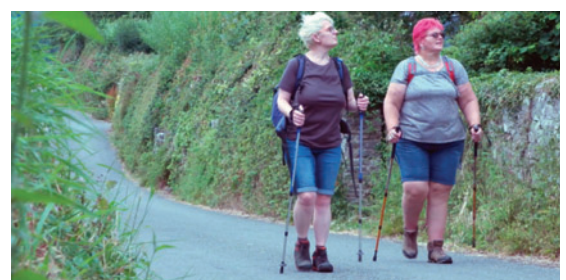
The MSK and Chronic Pain Update Course 

LONDON - Wed 13 Nov

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<https://livewellwithpain.co.uk/news/a-new-film-to-inspire-your-patients>

Managing flare-ups: a practical guide

What is a flare up?

Pain management training enables people with chronic pain to develop the knowledge, skills and confidence to manage their pain on a daily basis. However, most people, even the most skilled 'self-managers', will have times when their pain is much worse than usual such that it severely or totally disrupts their life. This is termed a flare-up or set-back, terms that are often used interchangeably. Flare-ups can last days, weeks or months. During a flare-up people may feel they can do nothing except rest and take powerful medication or they may access Emergency departments, more primary care appointments or occasionally hospital admission. Flare-ups impact on mood, thoughts, physical health and social life and can leave individuals depressed, demoralised, deconditioned and isolated. Flare-ups can also affect people's confidence in their ability to manage their pain.

Why do flare-ups happen?

Flare-ups are part of the chronic pain condition. While they can occur for no reason, frequently there are early indicators and warning signs that sign post towards a flare up occurring. These indicators and triggers vary from person to person and helping an individual recognise their own personal pattern is key to reducing the frequency of flare-ups or preventing them occurring.

Early indicators

These can happen a few days or weeks before the flare up and include such things as: increased stress, unpredictable situations or different environments, taking on too much, stopping pacing, planning and prioritising, reducing or overdoing exercise, activity cycling, becoming overtired, overconfident or socially isolated.

Recognising their personal early indicators enables people to use their self-management skills such as relaxation, pacing activity, goal setting, regular exercise and sleep hygiene to get back on track before the pain becomes more severe and a flare up occurs.

Warning signs and triggers

These can occur from a few days to a few hours before the onset of the flare-up and are often apparent not only to the individual but their close family and friends. Warning signs can include: irritability, low mood, fatigue, changes in appetite, disturbed sleep, difficulty in relaxing, increasing medication use, not wishing to socialise, having negative thoughts or feeling unable to cope.

Even at this stage it is possible to avert a flare-up or reduce its duration or severity. Focusing on relaxation techniques, sleep hygiene, supportive social contact, regular gentle stretching and

exercise, positive thinking and 'being kind to myself' to boost endorphin release, can be helpful in restoring a sense of control.

Managing a flare-up

If a flare-up does occur it is very helpful if the person has a plan, ideally shared with family and friends, to follow. Having a plan increases sense of control, reduces panic and enables the individual to manage the increased pain more confidently, reducing the impact of the flare-up and facilitating a quicker recovery. Managing flare-ups requires a different set of skills than the day to day management of chronic pain: it may be helpful to rest (but not for more than 2-3 days) and for some people a short-term increase in medication is beneficial. Other 'tools' include relaxation techniques, distraction in the form of a favourite film, book or hobby, maintaining social contact, using soothing techniques such as massage, heat, TENS or aromatherapy, favourite foods and maintaining a positive outlook. After 2–3 days the individual should gradually increase activity using a paced approach to resume their normal life. Flare-ups are difficult experiences but should not be seen as a failure of self-management. They can provide valuable learning on how to deal better with pain in the future.

What can you do?

- **Recognise that flare-ups are a normal feature of chronic pain and rarely represent a worsening of the underlying condition.**
- **Help the person to identify their personal early indicators and warning signs and take action to avert a flare-up.**
- **Support developing their own management plan to deal with a flare-up should one arise. This avoids distress and panic which can result in increased and unrequired healthcare use.**
- **Consider short term prescribing of analgesics.**
- **Reinforce the learning that a flare-up provides to manage things better in the future.**
- **Remain positive and encourage a gradual return to normal activity.**

The black hole of pain

Living with pain is like a black hole – everything gets dragged in. So what's the answer? Focus on the doughnut and not the hole, says **Phil Sizer**.

Like most boys I like things about space, so I was excited to see the first ever picture of a black hole. It's a bit blurry but so would you be if you were 53 million light years away.

If you're not sure what a black hole is, it's an area that develops in space where gravity is so strong that it pulls everything in to it. By everything I don't just mean little things like the odd rock, they drag in literally everything including planets and massive stars. As things get closer to a black hole they spin super fast (that's the orange glow) and get sucked in like the water going down the plughole after a bath, but on a very big scale. The gravitational pull is so strong that even light can't escape. That's why they're black.

You might ask: what's that got to do with pain management? Well... years ago it occurred to me that a black hole was a bit like living with pain. It has such a strong pull that everything gets dragged in. Or more accurately, the constant experience of pain drags us down in a way that gets worse over time because it affects more and more of life.

When we feel down with pain then we start to think down too. This always happens in a flare up when the onset of more pain is accompanied by a whirl of thinking the worst, anxiety, stress and low mood... and just like a black hole, the whirl of matter (anxiety, negative thinking, stress, fear, vulnerability) creates more gravity/pain.

Ask yourself: 'what can I do now to feel less vulnerable?' Even if you can't think of something right now, just keep asking: 'what one small thing can I do now?'

Feeling vulnerable is a good way to describe the effect of being worn down by the constant pull of a painful condition. The trouble is that the more we are pulled in the weaker we get and the more vulnerable we feel.

Hopefully you get the link between the pull of the black hole and the way that it is fed by circling matter. In a similar way, pain management is littered with a number of 'vicious cycles' that feed off themselves and drag us down.

There is the over-activity-rest cycle where we push ourselves hard and then are forced to rest only to recover and repeat the process, slowly wearing ourselves out over time. Pacing is the 'answer' to this one.

There is the pain stress cycle where we feel pain and get stressed but the stress then feeds the pain. Stress management and learning relaxation puts the brakes on this one.

There is the racing mind cycle where we try to solve a problem but just create more problems. And there is the can't sleep-rubbish day cycle where not sleeping leads to bad days and bad days lead to poor sleep. There is also a desperate to sleep-can't sleep-stress cycle that keeps us awake. This is often combined with the problem solving and failing cycle. The answer to these lies in understanding yourself better, improving sleep hygiene and learning some relaxation and distraction techniques.

And for this article I've also invented the Vulnerable-do less-Vulnerable cycle, where the more vulnerable we feel, the less we do about our problems and consequently the more vulnerable we feel as our resources diminish and our problems grow or seem to grow. The answer to this one is to work on breaking all of the other cycles, but also to break the habits of vulnerability by doing something to reach out for help. It just takes one small positive act and to realise it was OK, to get the ball rolling.

As you can see there are lots of cycles. Most of them are not about pain per se, but rather about reactions and responses. Most of them are about the knock on effects of living with pain.

Part of feeling vulnerable is being reliant on help that either you don't want to ask for or can't get. With pain this often means being totally reliant on medical help for pain. Obviously it is important to get that help, but that's not the whole story. In fact many people who do get the medical help they crave, are rarely cured as they expect.

The good news is that you can make a difference yourself. The key is to take your focus away from just thinking about pain as the only problem. Just like the black hole, pain is fed by the matter that surrounds it. In the case of chronic pain we need to deal with stress, anxiety, over-doing it, poor sleep, racing minds, low mood, isolation and

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being believed. This is because these all add to suffering, take away our resilience and make us feel vulnerable.

A good way to move forward is to ask yourself a small question with tremendous potential: *What one thing can I do today that will help me to become stronger again?* It might be to start talking, to pick up the phone and ask for help, it might be to read that helpful book you've been meaning to, or to spend more time with the family or friends, to relax more, to play that relaxation, to get fitter, to ask for help, to let yourself accept something, or to simply be kinder to yourself. It might be keep reading this article and see what ideas you come up with. It might be to realise that feeling helpless and doing nothing yourself to improve your situation, means that you are bound to be reliant on others and feel helpless. Another question could be: *What can I do now to feel less vulnerable?* Even if you can't think of something right now, just keep asking yourself: *What one small thing can I do now?*

I hope you will see that you can do something no matter how small and that the answers aren't all medical. In fact they're usually mostly not medical. I also hope you can see that like the black hole we need to focus dealing with what feeds the black hole rather than the hole itself. There's a saying about optimism that fits here: Focus on the doughnut and not the hole.

Live Well with pain

really useful online resources:
by clinicians, for clinicians
www.livewellwithpain.co.uk

About us

Live Well with Pain is a collaborative project led by Dr Frances Cole, Emma Davies and Eve Jenner, with support from other clinicians. It is for clinicians who want to develop their patients' self confidence to live well with pain through better knowledge, skills and resources to guide them. *Live Well with Pain* has an online presence at www.livewellwithpain.co.uk

where clinicians can access a wealth of resources for free, to use with their patients who are experiencing persistent pain.

Live Well with Pain does not receive any support from the pharmaceutical industry or other commercial interests, and is reliant on occasional grant support plus individual donations from clinical colleagues.

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www.livewellwithpain.co.uk/news-sign-up-for-our-newsletter