

# Opioid banning and pain acceptance

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I have written before about the buzzword of ‘Self-Management’ either empowering sufferers or tidily hiding their suffering away from surveys or ever-increasing waiting list figures.

What worries me even more than this term is the theory of pain acceptance as promoted by the opioid-denying disciples. ‘Accepting your pain’ is something I often say myself to be honest. I tell people that you only begin to live with chronic pain when you accept it. I don’t mean this to be used as an excuse to disregard chronic pain sufferers but rather that the sufferer begins to realise there is rarely a cure for chronic pain. While some people were wrongly prescribed over-strong medication and should be prescribed more suitable analgesia, those who need opiates must never be denied them through a blanket evangelical movement that says opiates are bad, bad, bad.

Any chronic pain sufferer has heard, or more likely been made aware by their clinicians, of the backlash against using opioids to treat chronic pain. This came about because of the ‘opioid crisis’ in America which put the blame on people in pain instead of the illegal drugs and pushers on the street.

Some patients are now forcibly being taken off their opiate medication because this theory has become accepted throughout the world and not just in America where the prescribing conditions are different. I find this particularly galling in Scotland because it’s the Scottish Government’s stated aim that clinical care must be ‘person-centric’. ‘Aye right!’ as the sarcastic Scottish saying goes. The lack of control the Scottish Government has on the Scottish Health Boards is a matter for another debate.

Sadly, one way the forced withdrawal of opiates by clinicians has been sold to sufferers is through their erroneous understanding of ‘pain acceptance’. Accepting your pain doesn’t mean the pain disappears. It is still there with all its devastating side effects. This flawed understanding of pain acceptance means that patients are told to live with pain and the length of time a person is devastated by the pain is not considered relevant. Such is the concern of some to analgesia addiction that this perceived threat becomes paramount and the alleviation of pain given far less importance. It is clear that these people have never experienced chronic pain for anything more than the prescriptive 3 months. Chronic pain may be part of their job, but they do not live it. Living with it makes a

massive difference to one’s perception. They should really consider the following.

## Chronic pain sufferers don’t get a ‘high’ from taking opioids

Experienced clinicians, such as those in palliative care, know that taking painkillers because your body is in pain does not get you high. The only thing you experience is a dulling of the pain. The pain doesn’t go away but becomes bearable. Only people who endure constant pain understand the difference. You are not addicted – you are relieved.

Thanks to my own free-thinking GP, I not only have slow-release opioids in my arsenal but also instant 20mg oxycodone capsules. In all the years I’ve had these I haven’t constantly increased the dosage as I would if I were addicted. I only take them for breakthrough pain. Yes, there are times I take more than usual, but that is because I am in a pain flare not because I want to get stoned. These breakthrough opioids get my pain down from ridiculously high levels to bearable levels. I now make a point of staying away from Pain Clinics as I know from listening to many Affa Sair members that I would be ‘encouraged’ to stop the opioids and use paracetamol and non-analgesia techniques to control the pain. This means obeying the derisory National Institute for Health and Care Excellence (NICE) guidelines which actually don’t have any bearing in Scotland as we use the more acceptable SIGN guidelines.

I should also add at this point that I have tried to stop my own opioid medication under medical supervision. I gave it a damn good try over many months, but it was a disaster for me. The pain became so uncontrollable that I had no choice but to restart my oxycodone dosage. I didn’t suffer any withdrawal effects at all – unlike when I stopped taking pregabalin. That’s another story. For me, and many, many others, pregabalin is far more dangerous than opioids with disastrous consequences for users’ mental health.

The work of Dame Cicely Saunders, who drove so much of modern thinking behind palliative care, should also be considered. Palliative care specialists are far more aware of how to control pain than other specialties. Her work in using opiates to ‘kill the pain and not the patient’ recognises opiates

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have their use. 'But wait', I hear you cry, 'these people are dying – not living with chronic pain'. Well take it from me, decades of chronic pain makes death seem a pleasant alternative for many sufferers at some point in their lives. Why on earth should we be denied analgesia of any type which, when properly managed, can let us live again.

I am heartened to learn of a recent study of almost 200,000 opioid prescribed chronic pain sufferers who had no signs of being addicted to and abusing opioids. Three dosing strategies were studied: abrupt withdrawal, gradual tapering and continuation of the current stable dosage.

Those who were gradually tapered showed a higher incidence of opioid overdose or suicide events compared with those who continued taking a stable dosage. Mark LaRochelle, MD, Assistant Professor of Medicine, Boston University School of Medicine, Massachusetts, and colleagues wrote, 'This study identified a small absolute increase in risk of harms associated with opioid tapering compared with a stable opioid dosage. These results do not suggest that policies of mandatory dosage tapering for individuals receiving a stable long-term opioid dosage without evidence of opioid misuse will reduce short-term harm via suicide and overdose', they add.

The findings were published online on August 12 in *JAMA Network Open*. Referring to the now discredited Centers for Disease Control and Prevention (CDC) 2016 guideline, which recommended tapering opioid dosages if benefits no longer outweighed harms, the researchers went on to say that 'some health systems and US states enacted stringent dose limits that were applied with few exceptions, regardless of individual patients' risk of harms. But in reality, there have been increasing reports of patients experiencing adverse effects from forced opioid tapering'.

### Pregabalin is the real danger

While undoubtedly helping reduce neuropathic pain, for me and for many thousands of others, gabapentinoids can do incredible damage to a person's ability to live a meaningful life. Yet these drugs are doled out with scarcely a murmur of a question on their long-term safety. There is hardly a whisper of this type of medication causing more cases of addiction than the maligned opioid. Where are the enraged politicians, focus groups and bandwagon-jumping evangelists on this one?

Back around 2019, I was placed in a 3-week programme at Scotland's National Residential Centre for Chronic Pain in Glasgow. One of the tenets of the programme was reducing medication, of course. In my case, I was more interested in

reducing or stopping altogether my high dosage of pregabalin. I had been on this favoured medication for many years after my first visit to a Pain Clinic way back in the early 2000s. I started off on gabapentin, but the headaches were too difficult and so switched to pregabalin. I was really very happy with it as it did significantly reduce my neuropathic pain levels. And so it continued for many years, or so I thought.

You really need to ask my wife and family about the changes in me that robbed me of so many years of life and gave my wife, in particular, many years of a lonely unhappy life with a man slipping away into a dementia-like existence. My own recollections of those years are very sparse as I was unaware of what was going on around me. It was like living in a sea of mud.

I found it incredibly hard and tiring to even think straight. What hurt the most, when I was told about it later, was how I had changed from a hero-like uncle to someone who was no longer any fun or had no answers to the endless questions of a highly intelligent nephew. He told me once that it was like I had stopped being interested in anything around me. My wife, who knew I was ill before she married me, had the worst of it. There were no rows, or violence, just soul-destroying disinterest. She has often said since that those years were very lonely for her. I do have recollections of sitting in my chair, with perceived darkness enclosing me, struggling to even put words together for a simple sentence. My sharp intellect (I do have a high IQ level thanks to Asperger's Syndrome) just disappeared.

These days, my mother is in a care home with all the problems of dementia, and I recognise much of what she is going through now as the same as my time on a gabapentinoid. I was a miserable shell of a man compared to what I am now. There is no way I could have led Affa Sair to what it is now. I could never have written our website, articles and presentations I can now deliver reasonably easily, though never to my complete satisfaction – but that is another battle.

The withdrawal effects of pregabalin were terrible. In hindsight, winter was a bad time of year to do that anyway. My ever-attentive GP took me slowly through the tapering phase but even then there were times I was pleading with the receptionists on the end of the phone line for help that had me classed as an addict in withdrawal. I had a memorable frightening encounter with a man in a car park who so enraged me that I came within an inch of doing him physical harm. Such was my ferocious anger at him that I was bellowing incoherently at him and would have attacked him if he had been within reach. That was so out of character for me. I am a very placid, faint-hearted person in reality. When I calmed down

at home, I was terrified at my outburst but realised it was the withdrawal from pregabalin at fault. The thought of what might have happened scares me to this day. I remember my GP saying that they are told that these drugs are so helpful for chronic pain sufferers and have no reason to disbelieve what they are being told by pharmaceutical reps and fellow clinicians. He was really dismayed at what the pregabalin had done to me.

The way the effects had crept up on me led everyone to think it was just a progression of my many conditions and problems including an aorta-femoral bypass at 36, vascular disease, sleep apnoea, diabetes, hypertension, cholecystectomy, bowel resection, 3 TIAs, low testosterone levels, migraines and atrial fibrillation.

It took a good couple of years to be totally free of the effects of pregabalin, but I'm delighted to be able to do what I can do now. Such a huge change.

### Chronic pain has severe side effects beyond agony

Accepting your pain doesn't mean the consequences of being in constant agony disappear. Chronic pain has many devastating side effects, way beyond the physical experience of pain, and to brush them aside with a blanket approach is negligent and dangerous for the sufferer.

Though not often spoken about, and completely denied by the DWP, one of the biggest side effects of trying to cope with chronic pain over many years is suicide. The suicide rate of chronic pain sufferers is roughly twice what it is for people without chronic pain. Once their medication is taken away and they can no longer live with the pain, ending it all is the only escape for some souls.

How can any opioid-denying clinician say that these sufferers were not helped by their opiates and just needed to accept their pain.

### Pain acceptance is already part of chronic pain sufferers' lives

When you live with chronic pain year after year, you do eventually have to accept it is not going to go away. Searching

vainly for a cure will do more damage to your mental well-being when your hopes of relief are constantly shattered. Once you learn to accept that living with pain is now your new life, you learn coping strategies to stop focusing on it. The very thing that the opioid banning brigade vigorously promotes is already a normal part of sufferers' lives. It is only made possible because strong pain-killing medication allows the user to reduce their pain to a liveable level.

I've written many times about strategies and techniques which help me cope with pain and distracts me from it. Methods such as reiki, meditation, massages, chiropractic treatment, acupuncture, TENS machines and my latest distraction technique – Painting by Numbers – allow me to live an acceptable life. Using and unavoidably spending a lot of money on these techniques are not the actions of people who don't accept their pain.

In conclusion, accepting your pain doesn't mean turning your back on medication nor should it be acceptable to make people suffer unnecessarily for a fashionable policy. The constant refrain of 'there is little evidence of opioids helping chronic pain' only means the research and opinion is all based on the harm they do rather than the good. 'Lack of evidence' frequently means a lack of study rather than a lack of efficacy. Clinicians and supporters of the 'opioids are bad' movement should remember that by taking an appropriate dose of opioids, users are relieved not addicted.

