

In Feb 2007 I was 34 years old.

I was healthy, I was fit(ish), and I was getting married in 2008.

Then May happened!

I developed a pilonidal abscess next to my anus.

Although the surgery to clear the abscess went well, I developed a fistula during the healing process which required a few surgeries to correct, and it was on awaking from one of these surgeries that I felt intense pain in my left leg. I was given Tramadol and sent home with instructions to call my local GP if the pain was an issue.

My GP prescribed 2 Tramadol tablets 4 times daily. These were 50 mg tablets.

Things went okay for a while, until the itching began!

I had to stop the Tramadol. My GP put me on 30/500 Co-Codomol, again, 2 tablets 4 times daily. My pain eased but never went away fully. However, it was tolerable, so I kept up with them. I never noticed my toilet habits changing as it happened so slowly.

Eventually my body began to need more / stronger medication and I was waking up during the night in pain. I went back to my GP and he suggested I try a patch called "Butrans". After wearing the patch for 3 days the world turned black and I began to think dark, dark thoughts. I ceased the patch immediately and called my GP.

He referred me back to the pain clinic to get Tapentadol (MR) prescribed.

I was given a 100mg modified release tablet (MR, roughly 40mg Morphine) to be taken once a day and by process of elimination I discovered the best time to take this was around 9pm.

Things were great again. My pain was under control. I was getting full nights sleep and my mood improved.

But Geoffrey Chaucer once said "All good things must come to an end" or words to that effect and I began noticing that I had to start taking my tablet at 8pm.

8pm became 7pm. 7pm became 6pm and 6pm became 5pm. I also began waking up during the night in pain.

I spoke to my GP, and he suggested I take a 30/500 Co-Codomol as a "breakthrough" tablet whenever it was required. By this point I think I was now approaching my 40th birthday.

Days turned to weeks and then months and I began having to take the "breakthrough" tablet more frequently. Until I noticed "I couldn't "go" anymore".

Enter Laxido.

I persevered with the 1 tablet at 5pm but after a number of years and a few Dr's later I went to my GP and explained how I was "chasing the pain" around the clock and having to take more and more of the breakthrough tablets.

Her answer was to double the Tapentadol dosage. Take one in the morning and one in the evening. I was now on 200mg (MR) or the equivalent of 80mg of Morphine a day and I wasn't happy. I knew enough about morphine to know I was now treading a slippery path. Before long I was saying "Hello itches, my old friend" and I called my GP once again and explained the situation. My Doctor referred me back to the pain clinic to allow me to discuss alternative medications.

Incidentally, by this time I'm now 49 years old.

Annnnnnnnnnd the world fell apart thanks to Covid-19. My appointment took a while, but it arrived in Jan 2022 in the form of a video conference with a pain clinic pharmacist.

I explained my history and my journey with Morphine to the pharmacist. I told her why I'd asked for the appointment and what my goal was.

The pharmacist explained how things in pain management had changed and it was now known that the very drug itself could cause the brain to demand more. What blew my mind here was the fact that the pain meds themselves could cause the brain to INCREASE the pain in order to make you feed it more and more pain meds.

The plan was simple. Slowly wean myself down from Tapentadol 100mg twice daily to 50mg twice daily by making consistent reductions of 25mg every couple of weeks.

Now I need to tell you here that patience isn't one of my strong points and I thought "I don't need 2 months for this" and I simply stopped taking the 100mg twice daily dose and went straight to 50mg twice daily.

I caught a sickness and diarrhoea bug and the next 2 or 3 days were HORRENDOUS. On day 4 I suddenly realised I didn't have any bug and my illness was my body's reaction to stopping the dosage too quickly.

Things stabilised and I was back to Tapentadol 50mg twice a day. On my next meeting with the pharmacist, we discussed my experience and we both had a laugh at my foolishness. It was then agreed that I try to take my Tapentadol dosage down further, but more slowly this time. I tried a few times to drop one of my doses by 25mg (MR) but found it extremely difficult and each time had to revert back to the 50mg twice a day dose. I wanted off regular meds but began to think this might not be possible since I couldn't get my doses down any lower.

At the next video conference with the pharmacist, we discussed that further reduction might still be possible if we converted to a different opioid, as that would allow smaller decrements to be made each time. We agreed to try coming off Tapentadol all together and switch to simple Morphine on an MR tablet. And it worked great, and there was no illness, thankfully. The only problem was me!

My goal was to eventually be off regular meds altogether. As I had reduced down, my pain had not increased, in fact it became better controlled! The itch had now gone completely, other side effects had improved and I felt much better within myself, so I wanted to continue reducing to see how far I could get. And with that the simple Morphine came and went and I was on Dihydrocodeine. 1\*90mg (MR) tablet per day, or the equivalent to 9mg of Morphine per day, along with a non-modified release tablet of 30mg to use as a break through tablet should I need it.

It's been 3 months since that call with the pharmacist and things are great. I've only had to take 1\*30mg break through tablet but that was my fault as I forgot to take my 90mg tablet.

I had another call with the pharmacist today (04/01/2024) and we agreed to take the Dihydrocodeine down further to 60mg MR (equivalent to 6mg of Morphine) with the view to staying on that for 3 to 4 weeks then ditching the MR tablet and taking just the 30mg break through tablet whenever I need it.

I was 34 when I began this journey. I'm now a few weeks away from my 51st birthday and for the first time in 17 years I can see light at the end of tunnel.

As journeys go it's certainly not the most pleasant one I've embarked upon. There have been many lows. Too many to count and I have skipped over my time trying the anti-depressants for nerve pain.

Needless to say, I got no benefit from any of them, in fact 1 of them gave me "night terrors".

I guess what I'm trying to put across is this "You know your body and your tolerances better than anyone".

Don't be dissuaded!

Set yourself a goal and stick to it!

Not every day is going to be like a walk in the park.

You'll get complacent, you'll stumble, you'll fall, but as long as you pick yourself back up and keep heading towards your goals then you'll get there.

It might take you 17 years, like me. It might take you 5 years. But no matter how long it takes keep going until you get there.