

Sandra's* Story: Timing is Everything

I had started hearing things about opioids that made me think it was time to come off them, as I'd been taking them (Oxyneo, Percocet) for years. So, I talked with my family doctor, Dr. Christine Luelo, about my options. We started the process about a year ago.

I was on the list for knee surgery, and was told I wasn't a great candidate due to being on opioids. Dr. Luelo says anyone going in for back surgery has to come off opioids before getting the surgery because they just don't do as well.

We'd originally said I should come off them after the surgery, because I was nervous about not having them while I was recovering. When my knee doctor said that waiting until afterwards wouldn't be good for me, Dr. Luelo said there were other drugs I could try, so I was receptive to that. Going into surgery, I wanted the best chance for recovery, coming out the other side.

I got a call before Christmas that my surgery pre-op was set for February, so I knew I had to get going.

On January 9, I took my last Oxyneo. On January 11, I took my first Suboxone. I had a really rough time. I started at home, and self-assessed using the COWS scale, but went way past the time that I should have started the Suboxone¹. I was so scared of starting the Suboxone too early that I ended up going the other way. Over the next three days, I ended up taking 11 2mg pills per day and had horrible symptoms. I was throwing up and had diarrhea. My anxiety level was high.

So I went to see Dr. Luelo, who suggested that perhaps what happened was I'd gotten so far past the point where I should have started the Suboxone that it caused me to need so many pills that it was likely I was now overdosing on the Suboxone². So, we had to come back from that point. From then, I started taking less and less Suboxone.

In the beginning, when my dosage was higher, I was totally doped up – sleeping on and off until three in the afternoon. Right now I'm down to 6mg per day. I don't know if that's the right number; it may be 8mg. I have to find the balance between dopiness and pain. Is it worth the dopiness to cover the pain, or can I handle some pain

to not have dopiness? So far, at 6mg of Suboxone, I seem to be functioning ok. Much closer to the real me than ever before.

In the beginning when Dr. Luelo was explaining the procedure to me, she mentioned that some people stayed at the doctor's office until their first dose of Suboxone was given. I told her that I could not do this and that no way was I sitting around for six hours in a doctor's office.

My husband said that on my first night without taking my Oxyneo, around midnight I started to flail around in bed and even kicked my dog off the bed. I was groaning in pain and a few times cried out that I wanted my Oxyneo back to take away the pain! I guess this is when I should have started the Suboxone. I have a high tolerance for pain, and that's part of the reason I went over my COWS score. I ended up surpassing it and that ended up being the source of a lot of my withdrawal symptoms – that I could have avoided. It was after midnight when I started feeling so poorly, and I was falling asleep then waking up repeatedly, flailing around and in so much pain. I think part of why I didn't really believe I was in withdrawal enough to start the Suboxone was because I kept falling asleep.

It's been a long haul, and you just don't know everything at the start. Perhaps if there was some way I could have had someone checking on me in person, it would have worked out better. I did talk to Dr. Luelo multiple times through text and phone calls those first few days, but this was her first time doing this so we were learning together! I had thought this would be something that would happen in the hospital – with monitoring, and someone to tell me when to start the Suboxone.

That said, I was grateful I was able to do this in the comfort of my own home. Despite the initial days of grueling symptoms I am so proud of myself for sticking it out. Without the loving support and encouragement from my husband and Dr. Luelo, I'm not so sure I would have come through this experience with a positive outlook on this new lease on a narcotics-free life. I owe them everything.

¹ The literature shows that patients are often harder on themselves than clinicians would be with starts in the office!

² Sandra took 22 mg per day; the maximum dose is 24 mg.