

# A Journey Through Tapering

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## Abstract

Living with rheumatoid arthritis (RA) for almost 40 years has not been an easy journey. My disease has been severe and difficult to manage; from the beginning there were challenges getting a diagnosis and in finding medications that were effective long term. Thirty years ago, unable to cope with the extreme pain and with 3 children aged 8, 11, and 13 who needed a functioning mother, my doctor prescribed an opioid. This medication gave me back some quality of life but taking opioids is not without significant risks. No one discussed the challenges I would face if and when the time came to stop taking them. With the opioid crisis there has been more pressure from government and medical licensing bodies to implement policies to restrict access for patients prescribed opioids and to encourage tapering. With the change in policy additional funding and resources are needed to help patients through the process but those supports do not exist across Canada.

## Keywords

opioids, tapering, health planning and policy

## Key Findings

1. The importance of appropriate prescribing for opioids.
2. Patients need compassionate and evidence-based care.
3. Thoughtful and evidence informed health policy decisions with input from those who will be affected by the change in policies is critical.

## Introduction to the Issue

Inappropriate and over prescribing of opioids over decades has resulted in a crisis in Canada with people dying every day.<sup>1</sup> At the age of 23 I received a diagnosis of rheumatoid arthritis (RA). For the next 2 decades I cycled on and off numerous medications, with limited success in controlling the disease. This article details my experiences with tapering after 30 years of taking opioids. In 1993, no longer able to cope with the pain, I was prescribed an opioid with the explanation that because I was taking them for pain I would not become addicted. The medication gave me back some quality of life and helped me to be present in my children's lives. The arrival of biologics was transformational for me, stopping the destruction of RA in its tracks and leaving me with 2 joints unaffected by RA. From 1998 to 2005 I underwent 12 surgeries to replace or repair some of the joint damage caused by RA.

In 2022, with my RA stable for the longest time since 1983 I wondered just how much they were helping and I consulted with my family doctor about tapering. As a patient partner with the Chronic Pain Research Network since 2016, I knew the evidence was unclear on the effectiveness of opioids in managing chronic, long-term pain.<sup>2</sup> The prescription required an annual special authorization and my doctor replied that The New Brunswick Prescription Drug program would not authorize 2 different dosages of an opioid. I had no option but to cut the dose in half, 100 mg to 50 mg of codeine contin twice a day with Tylenol 3 as needed. In August 2022, I tapered from 230 mg of codeine down to 130 mg. The knowledge I've gained as a patient partner in research prepared me a little for this and alternative pain management "tools" would be needed. The surprise for me was that there was no increase in my pain. The realization that the opioids were not helping anymore was the catalyst for me to continue to taper. I knew from my own research that I would have to proceed slowly, reducing by small amounts every 4 to 6 weeks. I accepted the fact a long time ago that I would always have pain. It was clear very quickly that the opioids were doing very little to help and the alternative pain management tools such as exercise

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and cognitive behavior therapy were effective but required more from me than simply taking another pill.<sup>3</sup>

The anxiety and impact on my sleep quality were the most difficult withdrawal symptoms to manage. Cannabis edibles at bedtime helped some with sleep (cannabis is legal in Canada both for recreational and medicinal use) but many patients struggle to find a dosage that works for them with an out-of-pocket cost that many cannot afford. An exercise program in the form of walking with a partner 3 to 4 days a week proved essential. I blocked this hour for walking and made it a priority. Cognitive behavior therapy reminded me that the anxiety was caused by the taper and not some unknown, imminent catastrophe.<sup>4</sup> The first 2 weeks after each taper were the most challenging, then the withdrawal symptoms would gradually improve.

In December 2022, 4 months into the taper, I went to pick up my prescription for codeine contin, and there was none available, the drug was in short supply. After some phone calls with my pharmacy and my family doctor, we found the codeine equivalent with Tylenol 3 and I began another taper. By the end of January 2023, I was down to 60 mg of codeine and 2 Tylenol 3 at bedtime. I initiated a discussion with my doctor about the challenges I was experiencing but he was focused on pain rather than the anxiety and insomnia caused by the taper. He wrote a prescription for 2 medications to try, instead both increased my anxiety and sleeping difficulties. I now believe that I've experienced significant trauma over the past 40 years of living with RA with numerous negative healthcare experiences. For the last 30 years opioids have muted my emotions, now without the opioids that filter is no longer there.

However, with the other treatment options prescribed by my doctor not helping my sleep and anxiety, my RA flared. I decided to reset to the last point where my sleep was less disturbed and I returned to 1 Tylenol 3 with the cannabis edibles at bedtime. After a 2-week course with prednisone and a joint injection in my left elbow, things are once again stable and my sleep has improved. I do not plan any changes for the next few months and then will decide whether to continue the taper. It made no sense to me to replace 1 Tylenol 3 with 2 to 3 other drugs that come with their own side effects, it is better to deal with the devil you know.

## Key Factors for Consideration

I have tapered medications before, in 2002, it took me 2 and a half years to go from 5 mg of prednisone to 0. I experienced many of the same issues with the opioid tapering; anxiety, sleeping issues, irrational thoughts, sadness, and quick to anger. My previous experiences prepared me a bit for this round of tapering but I'm much older now, and with age most things become more difficult.

The decision to take opioids needs to be carefully thought out. I kept telling myself that I wasn't addicted but dependent, which I had a clear understanding of with my prednisone experience. It really doesn't matter—addicted or

dependent—medications are powerful, can lose their effectiveness over time and all come with risks and benefits.

With the awareness the opioid crisis has brought, needing opioids in an era where the primary message is to not take them is terrifying for patients. Will my doctor continue to prescribe? Will government policies further restrict access? What about drug shortages like I experienced?

Better communication with my family doctor would have improved the outcome. I have amazing peer support through my patient advocacy work which helped immeasurably. I will probably have to take opioids again in the future. This was a major factor in my decision to taper, that, if I needed more pain management, opioids would again be effective, giving me another option for the really bad days and to be used sparingly.

## Recommendations

As governments focus on the lives being lost due to the opioid crisis, I suggest that instead of implementing policies to further restrict prescribing, there is a need to increase funding for programs for patients who are already taking opioids and who want to taper. For people living with chronic pain, opioids can return some quality of life. However, without access to evidence-based, multidisciplinary pain treatments their future is bleak; continued long-term opioid therapy with insufficient pain control.

Primary care providers need more information on the latest evidence and guidance to help their patients who wish to taper off opioids so they can be supported through the process and achieve the outcome that's best for them.

## Conclusion

I don't want to vilify opioids, they are critical drugs for many people. Without opioids, 30 years ago my life would have been unbearable and my ability to function independently significantly impacted. The main message for me through this experience is there is little chance of a successful taper for patients who do not have access to an established, multidisciplinary pain clinic and the support these clinics provide. Patients are being encouraged to taper their opioids but the support to accomplish that is simply not there.<sup>5</sup> This leaves them feeling as if they have failed when it's the healthcare system that has failed to provide appropriate and timely care. Access to a recognized pain clinic would have made my experience easier.<sup>6</sup>

I have been very engaged in the chronic pain community for nearly a decade and recognize that those individuals without the connections and resources that I am privileged to have will face even more challenges than I did, and with little chance of success.

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