

Questions about
OPIOIDS
and the answers that may
SURPRISE YOU

A booklet for people who
may benefit from reducing
or stopping their opioid



You are currently taking one or more of the following medications:

Generic Name	Brand Names
morphine	STATEX, M-ESLON, KADIAN, MS-CONTIN
hydromorphone	DILAUDID, HYDROMORPH CONTIN, JURNISTA
oxycodone	OXYNEO, PERCOCET, TARGIN
tramadol	ULTRAM, ZYTRAM XL, TRIDURAL, RALIVIA, TRAMACET, DURELA
codeine	CODEINE CONTIN, TYLENOL #1, TYLENOL #2, TYLENOL #3, TYLENOL #4
tapentadol	NUCYNTA
buprenorphine	BELBUCA, BUTRANS
fentanyl	DURAGESIC

These medications are known as *opioids*, or *narcotics*. They are sometimes prescribed to treat pain.

I've heard in the news about an "Opioid Crisis" ... could my opioid hurt me?



WHAT WOULD HAPPEN TO ME IF I WENT ON A LOWER OPIOID DOSE?



WILL I HAVE TO TAKE MY OPIOID FOR THE REST OF MY LIFE?



Why do I still struggle with pain even though my dose of opioid keeps going up?

Can you tell which of these are **FACTS**, and which are **MYTHS**?

1. If I take my opioid exactly as prescribed, I won't have any side effects.
2. If my opioid isn't helping my pain any more, it means I need a bigger dose.
3. If I stop my opioid suddenly, I will be in pain.
4. An opioid is always the best medication to treat pain.

1. If I take my opioid exactly as prescribed, I won't have any side effects.

This is a myth. Even people who take their opioid exactly as prescribed can get side effects. In fact, at least 80% of people taking an opioid will experience some type of side effect.

Some side effects of opioids are noticeable. These include things like constipation, nausea, sweating, or itchiness.

But other side effects are less noticeable, such as fatigue, lower hormone levels, "brain fog", and disordered breathing while sleeping. Sometimes when people decrease or stop their opioids, they are amazed at how much more alert they are and how much better they feel. This is what Rita found out. You can learn about her experience on page 6. And you can learn more about the hidden effects of opioids on page 10.

2. If my opioid isn't helping my pain any more, it means I need a bigger dose.

This is a myth. For many people, opioids seem to work, but then become less effective as time goes on. This may be due to tolerance and can lead to higher and higher doses of opioids.

There are problems with high doses of opioids.

1. Side effects are more likely.
2. Your pain may actually get worse. This is called *opioid-induced hyperalgesia*. It may seem hard to believe that a medicine for treating pain can actually cause more pain, but it really can happen! Many people find that when they slowly reduce their opioid dose, for a little while the pain is worse, but in the long run their pain gets better or at least stays the same.

3. If I stop my opioid suddenly, I will be in pain.

This is a fact. Almost everyone who takes an opioid for a long period of time will develop physical dependence to it. This means that when the opioid is suddenly stopped, you experience unpleasant symptoms called withdrawal. Withdrawal causes pain.

Withdrawal can fool people into thinking their opioid is working. If you are a little late taking a dose, and your pain gets worse, but then gets better again after taking the opioid, you may think the opioid is helping with the pain. However, the opioid may only be helping with withdrawal pain rather than helping with the original pain. A diagram on page 11 helps explain this idea.

Withdrawal pain doesn't necessarily mean you are addicted to the opioid. It just means your body is used to having the opioid there, and misses it when it is suddenly gone. Going off the opioid slowly can help prevent withdrawal. To learn more about preventing withdrawal, see page 9.

4. An opioid is always the best medication to treat pain.

This is a myth. In the past, it was often thought that opioids were the strongest medication we had for treating chronic pain. However, over time we have learned more about pain, and today have more options for treating it. For example, opioids are not recommended as a first choice for low back pain, fibromyalgia, or osteoarthritis. Other therapies often work better.

Your healthcare provider likely can help you explore the options available to treat your particular type of pain.

Many people report a better quality of life after they gradually lower or taper off their opioid. Turn the page to read Rita's story. Sometimes it is only after the opioid is gone or reduced that people realize how it was hurting, rather than helping, their life.

I felt like a person again

RITA'S STORY

RITA IS A RESIDENT OF SASKATCHEWAN.

I started having pain issues when I was 17, off and on. Then when I was 19, the pain got severe, and I needed something all the time. I took Tylenol 1's, then Tylenol 3's, then OxyContin, and finally morphine. All through this, the dose kept increasing, because the pain was never controlled. At first a dose increase would feel better - but only for a while.



I was on opioids for 10 years, and things were not getting better. My doctor didn't want to go any higher with the dose. She kept encouraging me to reduce. And eventually I realized - the morphine was making me sicker, not better.

Back when I was on morphine, for a long time I thought I was doing OK. But I wasn't functioning normally at all. I was blind to it, I couldn't see it. Once my dose got low enough - I can only describe it as an awakening of the body and mind. I felt like a person again. I could feel pleasure again - I hadn't realized that the opioid was doing that to me.

I think now that my pain was getting worse because I continued to use opioids. My neighbour was on opioids, and she watched me go off, and then she used my tips to help her get off. Now she's a completely different person.

Tapering was really hard. It was like having a severe flu. It took me 2 years to taper - I felt horrible, but I felt like I was doing something that was going to help me. My doctor told me I didn't have to go all the way, that I could stop the taper - but I wanted to get off. She prescribed some medications that really helped with the withdrawal.

It's been over 2 years now since I was on opioids. The taper was 100% worth it. People don't know how much better things can be. The more people who try, the more people who will see that it's possible. That you don't have to be stuck. **I FELT LIKE A PERSON AGAIN.**

Note: Rita worked with her family physician and pharmacist to implement a successful tapering plan. Her name has been changed to protect her privacy.

RITA'S TIPS FOR TAPERING

You'll need to have help - there's no way to do it by yourself.

If you have a plan and schedule in place, it can keep you focused.

Medications can help with withdrawal.
In my case, clonidine and melatonin were especially useful.

To help with hot and cold sweats in withdrawal, I would get into an empty bathtub and fill it with hot water - once the tub got full my temperature would reset.

It's OK to slow the taper down if you need to, if the withdrawal gets too uncomfortable.

The days right after you reduce a dose are going to be hard - be ready, and remember the increase in pain is only for a few days.

Stay determined. It's hard, but it's worth it.

Questions About Opioids

*I started my opioid because we tried everything else.
So what am I supposed to do now?*

In some people with chronic pain, over time their pain has improved, but this improvement has been masked by opioids. This means that when the opioid is lowered or stopped we find their pain doesn't get worse. In fact, it may get better. More importantly, their ability to function may also get better.

Another thing to consider is that opioids tend to work well in the short term, but often lose effect in the long term. In other words, opioids may not be as good for long term pain as we used to think. A dose decrease could help find out if opioids have lost their effect on you.

Some people may find that the side effects of an opioid are just too unpleasant, and so they want to try something else but are not sure what could work. Some opioids can have more side effects than others – it may even help to switch to a different opioid. What could be useful is for your healthcare provider to do a full review of what has been tried to treat your pain. Some of our medications or therapies for chronic pain take time to work (2-3 months or more). So even though a therapy may have been tried in the past, trying it again at a good dose for a little longer could help.

**Even the best treatment available
may leave many people with
bothersome pain. Try to live beside
the pain rather than in it.**

*How would I know if my
opioid is doing more to me than for me?*

YOU MAY ASK YOURSELF:

- Is my pain any different today than when I started my opioid?
- Can I do more activities around the house, exercise more, or do the things I care about since I started my opioid?
- Have I noticed any side effects from my opioid, like grogginess, fuzziness, tiredness, depression, constipation, low sex drive, or nausea? Am I experiencing problems breathing at night or sleep apnea?
- Has anyone around me noticed that I've been different since I started my opioid – such as more forgetful, more moody, or less safe while driving?

Does everyone get withdrawal when they lower their opioid?

If an opioid is stopped suddenly, nearly everyone will develop withdrawal symptoms such as anxiety, pain, trouble sleeping, sweatiness, diarrhea, or cravings. However, if an opioid is gradually reduced, withdrawal symptoms are lessened.

Some symptoms of withdrawal can also be managed with medications. By prescribing these medications, your healthcare provider can help withdrawal feel a lot more comfortable.

Some people who decrease the dose of their opioid do not experience any withdrawal symptoms at all. Unfortunately, this will not happen for everyone. If you do experience withdrawal during your opioid taper it is important to know that these symptoms are only temporary, and to speak with your provider to help make these symptoms more manageable.

Could I really be having side effects and not know it?

Rita's story is on page 6. When she was on her opioid, for a long time she didn't think she was having side effects. But when Rita reduced her opioid dose, she noticed big changes in her life. After she stopped taking opioids, she told us about giving someone a hug and feeling happy, and how good that felt. But the shocking thing for Rita was that she hadn't realized the feeling of happiness was missing. **She had forgotten the way hugs used to make her feel.**

Sometimes people can be experiencing side effects to opioids, but not realize that anything is wrong until they try reducing.

OPIOIDS CAN
LOWER SEX HORMONES
AND LEAD TO
SEXUAL DYSFUNCTION.



PEOPLE WHO TAKE OPIOIDS ARE
MORE LIKELY TO BE INVOLVED IN
CAR ACCIDENTS

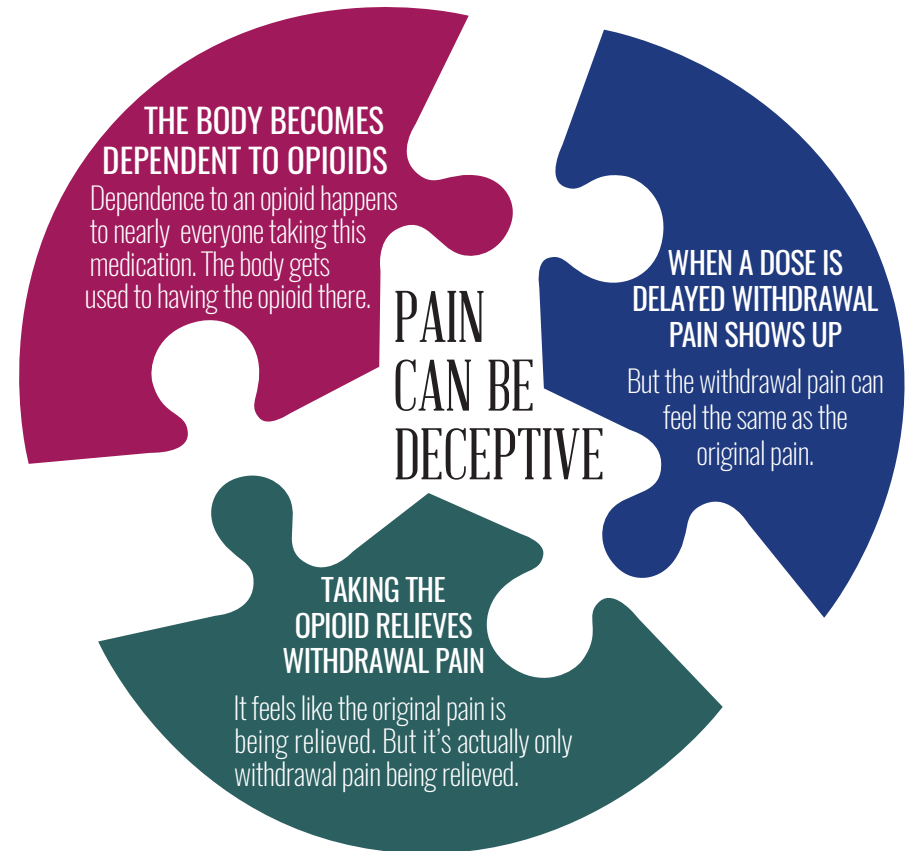


Using opioids for a long time could weaken the bones, and lead to osteoporosis & fractures.

Even though opioids make people sleepy, they also disrupt the quality of sleep. People may find that without the opioid, their sleep is actually deeper & more restful.

Opioids may be helpful for some, while being harmful for others. Figuring out where they fit for you isn't always easy.

Could my opioid be tricking me?
Sometimes opioids can seem effective even though they are not really helping.



If you have been on opioids a long time but your pain and function is no better or even worse, it may be time to talk to your healthcare provider about planning an opioid taper. You could be one of those people who ends up living a little better - maybe even a lot better.

This is a note from one patient whose opioid was doing more to her than for her. She stood to benefit from reducing her opioid and as you can see, she was successful.

Hi Everyone,

My name is Heather and I am an Fentanyl Survivor. With alot of will power & support from my doctors and family, I am now Fentanyl free!!! This was not easy... not by a long shot. I came down at a slow, steady pace and with the help of Hydromorph + Hydrocortin to ease the withdrawals which was very minimal. At the end of this I weaned myself off the Hydrocortin over the span of a month. And I am free of that also. This is not as hard as it sounds. You must be determined to get off that deadly drug. It will save your life. Best decision I ever made!!!! Best wishes to all!!!

Heather



HEATHER'S STORY

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and Nutrition

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