OPIOIDS

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:

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

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

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

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, impaired breathing while sleeping, and/or “brain fog”. Sometimes when people decrease and 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 two problems with high doses of opioids.

The first problem is that the higher the dose, the more likely it is that side effects will occur.

The second problem is that, especially as doses go up, opioids can actually cause your pain to 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.

Just because you are having physical dependence and withdrawal pain does not necessarily mean you are addicted to your opioid. Rather, these symptoms mean that your body has gotten used to having the opioid there, and misses it when it is suddenly gone. Many people find that if they follow a gradual reduction plan, they do not run into withdrawal symptoms. Your healthcare provider may also give you medications that can help with withdrawal.

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 medications and other non-drug 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 taper off their opioid. Turn the page to read Rita’s story. Sometimes it is only after the opioid is gone that people realize how it was hurting, rather than helping, their life.
RITA’S STORY

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 opiates. My neighbour was on opiates, and she watched me go off, and then she used my tips to help her get off. Now she’s a completely different person.

RITA’S TIPS FOR TAPERING

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. YOU CAN FEEL 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.
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 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. What could be useful is for your healthcare provider to do a full chart review of what has been tried to treat your pain. Many of our medications or therapies for chronic pain take a long 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.

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

• 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 gqogginess, 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 quit 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.

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

Could my opioid be tricking me?

Sometimes opioids can seem effective even though they are not really helping.

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

The body becomes dependent to opioids

Dependence to an opioid happens to nearly everyone taking this medication. The body gets used to having the opioid there.

When a dose is delayed withdrawal pain shows up

But the withdrawal pain can feel the same as the original pain.

Taking the opioid relieves withdrawal pain

It feels like the original pain is being relieved. But it’s actually only withdrawal pain being relieved.

Pain can be deceptive

Opioids can 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.

Using opioids has been linked to depression.

People who take opioids are more likely to be involved in car accidents.

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.

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

If your opioid dose has gone up and up, but your pain and function is no better or even worse, it may be time to consider a well planned 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.

HEATHER'S STORY

Hello everyone,

My name is Heather and I am 47 years old. I started on Vicodin, with a lot of work, pain, and support from my doctors and family, I am now on Tylenol. This was not easy... not by a long shot. It came down at a slow, steady pace and with the help of Hydrocodone and Tylenol to ease the withdrawal, which was very unimpressed. At the end of this, I went and myself off the Hydrocodone, over the span of 2 months. And then five months after that, I did not feel it. You must be determined to get off that deadly drug. It will save your life. Best decisions I ever made!!! Best wishes to all!!!

Heather

http://www.rxfiles.ca/PainLinks