

Reducing your pain medication

Information for patients



Introduction

This leaflet has been written together with people who have reduced their pain medication. We know that reducing medication for pain isn't easy. We hope it will be helpful to hear from others who have been through a similar experience.

We would like to thank Deborah, Allan, Maria and James for sharing their experience of reducing their pain medication to make this leaflet possible.

Why take medication for long-term pain?

Medication can play a role in helping to live with long-term pain; however, all medications have side effects. Some side effects can be difficult to live with. Over time you may have found that medication seems less helpful and the side effects are more of a problem.

What might be the challenges of reducing pain medication?

We know that reducing your pain medication is not easy, especially if it's the only way you know to deal with your pain. It can be hard to imagine being able to use less medication and still coping with the pain. Being afraid of what will happen if you try and reduce your pain medication is one of the biggest challenges.

I was taking a really high dose of pain medication. Whenever my GP increased my dose I would feel better for a couple of months but then I'd feel worse and need to increase the dose again. Because of this, I was frightened to reduce my pain medication. What helped me to get over this fear was setting small goals so that eventually I could feel as though I was achieving something. I didn't realise until after I reduced my pain medication that they were making me feel worse, not better.

Allan

There were lots of hard parts! When I first started to reduce my medication the pain got worse. I really wanted to take more tablets. My family were really caring in that time, although I wanted more, they knew it would be worse in the long-run and wouldn't let me take more. I appreciate that now, but at the time I would just tell them to leave me alone! It took a while for this to change but after a few weeks I started to feel better.

Maria

The hardest part for me was the afternoon time between 3pm and 7pm. That was when I felt worst... it was like having the flu. I found myself being snappy and short-tempered. What helped was distracting myself - I used to take a long, hot shower in the afternoon. I'd definitely recommend that! The other thing that helped was being able to talk with my wife about how hard I was finding it. She could see that I was really trying and could remind me of how much progress I was making when I was feeling horrible.

Allan

One of the most challenging things for me was that I didn't know the limit that I could cope with. I thought that because I still felt in pain even when taking my medication that I might not be able to deal with it getting any worse. Vivienne [Clinical Psychologist] was able to help me learn different ways of handling my pain. I found this helpful because although I know I'm going to be in pain, I also know that I'm going to be able to cope with it.

Deborah

What might help in reducing your medication?

Just as what we find hard is different for everyone, what helps is different too.

What was most helpful for me was the close support of my family. I felt really out of my mind when I was taking so many pain medications and my family could see that I wasn't the person that I used to be. My son and my husband were particularly helpful while I was trying to reduce my pain medication. My Consultant was also really helpful and let my whole family join my appointments!

Maria

For about a week after reducing the dose the pain is worse, but after that the pain levels out. What helped me the most was sticking with it! In the end when I reduced my pain medication by quite a lot, I hardly noticed any increase in pain. So it was just as helpful at a lower dose as a higher dose but with fewer side effects.

James

You may also want to speak to your own doctor or pain management team to see what support they can offer.

What might the benefits be?

After hearing how hard it is to reduce medication, you might be wondering why you would want to put yourself through that! Despite the challenges, the benefits can be worthwhile.

I am much more myself now than I was when I was taking so much medication. It felt a little bit like my brain was waking up. Whereas before it was as though it was on standby; my attention, memory and concentration were all awful. These are a lot better now, and I have been able to take up new hobbies that I wouldn't have been able to do before, like making model aircraft. My sense of humour has come back too, which means that I enjoy spending time with my friends ... While I was taking lots of pain medication I met my friend's baby, a week later I completely forgot that they had visited. I didn't realise the things that I missed but now are back in my life.

Allan

My life is completely different now that I am no longer taking medication. The pain didn't go away, but I'm more the person that I used to be. My friends and even health care professionals have told me that they can't believe I'm the same person!

Maria

I lost four years of my life being house bound, and not able to do anything... Now I'm able to drive and visit my grandchildren.

Deborah

The most positive effect has been in terms of my mental health. When I was taking a high dose of pain medication, I experienced mood swings, I was depressed and had thoughts of ending my life. I feel more clear-headed now and my mood swings are reduced.

James

Do you have any 'Top Tips'?

Here are some suggestions from people who have been able to reduce their pain medication:

- Try and approach reducing your pain medication with an open mind.
- Remember: pain medication isn't necessarily the best thing for you.
- Talk to your family and friends about how you're feeling and any worries that you're having.
- Be open and honest about how you're doing.
- Set small goals to get you through the hard times.
- Remind yourself of how well you've done whenever you reach a goal.
- It may be helpful to ask your pain team or GP for advice or support.
- Although it's scary to think that the pain is permanent, try and sit back and take on board that there are other ways to deal with pain.
- Only reduce one medication at a time.
- Take it slowly, reduce gradually.
- **Remember that there will be ups and downs when reducing your pain medication, but there were ups and downs when taking a high dose too!**

Where can I find more information?

Thank you for reading this leaflet. We hope that you have found it helpful.

Further resources you may find useful:

- The 'Free Mindfulness Project'
www.freemindfulness.org
- Breathworks:
www.breathworks-mindfulness.org.uk

Books:

- "The Reality Slap: Finding Peace & Fulfilment When Life Hurts" by Russ Harris
- "Living Well with Pain and Illness" by Vidyamala Burch
- "Living Beyond Your Pain" by Joanne Dahl