

Pain

One of the most difficult aspects of my illness is the pain.

Because of MPN I regularly have bone, muscle and joint pain. In addition, I recently learned that I also suffer from neuropathic pain caused by small fiber neuropathy. And then there's the headache, due to the leakage of spinal fluid and the MPN.

Most of the time I can take things easy and then the pain is bearable, but it is never gone.

Sometimes the pain is very pronounced, for example when I go to a party or when I've been doing chores. That can be so frustrating. Yes, I make the choice in advance to go to that one party or do that one job, knowing I'm going to pay the price. Either way, pain takes a lot of energy and also means that sometimes I am not so nice to be around. Sometimes I can push pain in my body to the background by seeking distraction, but with a headache I find that harder.

I actually find the mental pain more difficult to cope with, but overall I've found a way to live with and enjoy my current health situation.

Sometimes, however I hear some news that pains me, for example from my old employer or from a friend who has found a nice new job or is going to study. I would love to have continued with my career and have always been looking for new courses to further develop myself. That would have been fun!

That these doors are now closed to me I find painful and sad.

But enough of complaining. With a little contemplation I still manage to see the positive things in my life. To look at what I do have.

In the end, I also allow myself to occasionally reflect on the pain.

Embracing it usually works best. Resisting it produces more pain and frustration. And, despite the pain and other inconveniences, I am happy. I do nice things and have nice people around me.

Emilie Rozendaal, November 2021