

## Appendix 9

### ANOTHER SINEMET CASE STUDY

These emails from Taylor Paul have been appended in this book because the most frequent request I get from patients is, "Give us more case studies! More individual examples!" Hopefully, with every new edition of this book, I will find time to type up a few more case studies. Maybe someday, an entire book of case studies relating to antiparkinson's drugs will be published.

Do bear in mind that every PDer is different, but that the general principles demonstrated by this case may be helpful.

#### *Taylor Paul*

These are some emails that I got from Taylor Paul when he was nearly off the medication the first time. (Taylor Paul is introduced in chapter 21 of the text.)

These notes describe his experience with the vacation – the fleeting feeling of peace that can occur immediately following a drug reduction. The first email states that he had just quit taking his meds altogether, as of a few days ago. He had been slowly reducing his medication (from a high of 450 mg/day) down to 150 mg/day of L-dopa. He had just decided that he was going to quit altogether, since 150 mg a day was practically nothing, and he had taken no medication for three days and was feeling great. I sent him some frightening case studies of people who had just stopped cold from 150 mg, and even 100 mg/day. He evidently decided to reduce his drugs more slowly after that. He went back up to 150 mg/day.

In the second email he had just reduced from 150 mg/day of L-dopa down to a reduction in which he took 100 mg/day on two days of the week, and took 150 mg/day on the other five days of the week. He was spacing the low-dose days a few days apart.

Here's his missive:

*Hello:*

*I'm back on 150 mg per day. 50 mg at 7:30 AM; 50 mg at 11:30 AM and 50 mg at 5:00 PM. I was planning on cutting off the 7:30 AM morning dosage for a couple of days next week because I am definitely having meds dyskinesia after taking these doses (most of the time). I am not feeling great but OK or as normal as I can feel with this PD. I haven't felt "really good" since going back on the Sinemet.*

*Yesterday I went to see my doctor. I gave him an update on what I am doing. He is a great guy. Very attentive and compassionate but he loves drugs. He loves Sinemet as he has used it for years with his PD patients. I asked him...what about when Sinemet quits working and dyskinesia sets in? He said then it is "awful." I told him about my experiment of going off Sinemet for a couple of days. He asked me why I didn't just stay off the drug (cold turkey). He has never taken anyone off Sinemet because none of his patients have ever requested it. They have all been so "happy" with the drug. Sound familiar?*

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*The only big change I have observed (other than my PD symptoms gradually worsening) is that I have a sleep interruption at 2:00 AM mostly every morning. I am usually awakened by shaking and neck pain and general weakness. When I first started FSR, I was able to sleep thru the night for a long time. Quite a blessed change. But a month after I dropped the dosage of Sinemet to 150 mg was when the sleep interruption started again. You mention in your book to try a sleeping pill or Benadryl to get by. (Author's note: I no longer make this recommendation. Too many patients became addicted to their sleeping pills.) My Dr. suggested that I go on Amitriptyline. No thank you. I have used Tylenol. But I don't like using it often.*

Two weeks later

*Hi:*

*I have for the last two weeks dropped two doses (total of 100 mg) of Sinemet per week (two days). The first week...no problem. The second week after the second reduction day (spaced two days away from the first day of withdrawal), I experienced a sleeping deprived night and uncontrollable shakes day and night. After resuming 150 mg per day (for the past two days) I am OK now. Wow!*

*Isn't it strange, I can go off the drug cold turkey for three days and feel wonderful...but two weeks later...*

*What do you attribute my right arm pain – shoulder, arm and hand too? I remember my dad complained about pain in his shoulders too. Anything I can do about it? [Now that the meds are so low] I am FEELING the numbness in my feet and legs now.*

*Love,*

*Taylor Paul*

In review, two and a half weeks earlier he had gone from 150 mg/day to none, and stayed at that level for three days. He had felt great during that time. He then started taking 150 mg/day again. For the next two weeks, he took 150 mg of L-dopa on five days of the week, and only took 100 mg on two of the days of the week. After one of the days when he took only 100 mg, he had two days of powerful drug withdrawal symptoms. After that, he felt “normal” again.

And here was my answer to him:

“Dear Taylor Paul,

“It actually takes nearly ten days for the limbic part of your brain to realize what is going on at the head office. That's why there was a delay in noticing the three days when you went cold turkey. What you were probably feeling when the shaking set in that night was the result of taking no pills, for three days, almost two weeks earlier!

“Repeat: the uncontrolled shaking was probably coming from the cumulative effect of not taking any meds at all for three days, back when you quit cold turkey ten days ago. You are lucky; a night or two of shaking is not very bad, in terms of what drug withdrawal can potentially do. Sounds as if you got off easy. And you might not be done with the withdrawal. It will be some days before you really know if you are finished responding to your three day hiatus, and if you have adjusted to your new, lower weekly level already or not. The shaking response tells you that you were overmedicated, or at

least mildly addicted, at your previous dose level. If you had been mildly undermedicated at the time you made the further reduction, you would merely be even more undermedicated and moving slowly, looking more PDish. But if your brain is slightly addicted, so that when you reduce, your limbic area was exposed, showing a drug-induced deficit, that's when the brain will do the withdrawal tantrum – the shaking that you had – as an attempt to get its goodies back (the L-dopa pill) without having to grow the dopamine itself. Those three great days when you stopped your pills and had no problems at all, that was just a little vacation. Most people love the clear-headed feeling that they get when they stop the pills briefly, even though they don't move too well. But clear-headedness doesn't compensate for the hellish drug withdrawal symptoms, once they begin. That's why most people choose to go slowly instead of going cold turkey.”

So that demonstrates the vacation. He felt just fine for nearly ten days. And then, boom!

### ***Taylor Paul, the second time around***

The following brief description of a drug reducer's dilemma is taken from Taylor Paul's second round of getting off Sinemet. As you may recall from chapter 21, his doctor had mistakenly put him on Sinemet during a hospital stay for what it turned out was not Parkinson's but a life-threatening bacterial infection.

Taylor Paul had come to a difficult point in the reduction and was uncertain whether he was getting better or worse, or needing to decrease his drugs or increase them again; he wanted advice. His adult children were supportive of his plan to reduce his medication, but his wife had passed away a few years earlier, so he lived alone and was very much alone in his drug decisions. He wanted an answer from me but, as you know, I cannot advise. I asked him to describe his situation in hopes that, while describing it, it might become obvious what he should do next.

He described himself thus: he was at the point where he could function slightly better every day. He was down to 100 mg levodopa/day from a brief, post-hospital high of 500 mg. He was driving his car again and had recently moved back into his own home after staying with his daughter during his weakest phase. However, every night at around 4:00 a.m., he would startle awake and proceed to shake violently until 6:00, when he got out of bed. He asked me if this meant that he had decreased his drugs too abruptly.

I asked the following questions: Was he once again able to initiate movement? Yes. How was his balance? It was improving daily. Was his stride lengthening? Yes. Was he able to resume his daily walks? Yes. Was he having dyskinesia? No, and the facial grimacing had ebbed. He had normal facial expression. Had he fallen recently? No. Were his arms swinging? Yes. Was there anything that he could do, short of taking medication, to reduce the shaking from 4 to 6 a.m.? Yes: he had tried taking Tylenol and that would put him right back to sleep, but, he asked, wasn't it bad to take Tylenol every day?

My answer was, “Yes, it can be hard on the liver to take Tylenol every day.”

He mused for a bit. He then proposed that he try having some toast at 4:00 in the morning. He also suggested that a bit of wine would probably knock him right out, and he would sleep like a baby if he had a bit of wine at 4:00 in the morning.

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I told him that if he could deal with his shakes by eating some toast or having a drink of wine, then those might be healthier options in the long run than using L-dopa to deal with his 4 to 6 a.m. shaking. Considering that in every other way, he was doing better and showing marked improvements in his symptoms, he might want to think about the possibility of overmedication rather than undermedication. (To me, though I was not able to give advice, his overly bright eyes and overquick smile seemed more of a concern than his shaking in the night. He seemed slightly stoned to me, but I couldn't mention it.)

He tried the toast; it worked. The old Ayurvedic saying, "Never use medicinal herbs when food will suffice," applies neatly in this case.

A month later he made a further decrease, taking only 50 mg two days a week and 100 mg on the other five days. The stoned look in his eyes faded away. He may always need a small amount of dopamine-enhancing medication due to the damage he has done to himself. In order that the needed pharmaceutical dopamine never exceed his Safety Limit, he may always need to be careful that he takes just enough that he never feels really good, but enough so that he doesn't fall into a Slough of Despond. He is determined to use spiritual inspiration to make up the dopamine difference between the sub-feeling-good drug amount and the way that he really wants to feel. I supportively include him, and all my patients, in my prayers.