

“The difficulty in life is the choice.”

“The wrong way always seems the more reasonable.”

The Bending of the Bough, play by George Moore (1852-1933)

20. TOO MUCH PAIN

THE DRUGS AS SOLACE FROM ERUPTING PAIN

This chapter about Rudyard, like the preceding chapter about Coach, is a single case study. Rudyard’s experiences contributed to our growing body of evidence that, once a recovery program has been started, medication may no longer be a safe option.

Rudyard - Eldepryl, Mirapex

A study of “harmless” amounts of Eldepryl and Mirapex

Rudyard was taking Eldepryl and the health store supplement, NADH, when he first came to our clinic. He had been diagnosed one and a half years earlier, at the age of forty-six, but he already had fairly advanced Parkinson’s at that time.

He had had symptoms of Parkinson’s since age twenty-six: his tremoring was significant at that early age. By the time I met him, his posture was hunched to the point of deformity, including a frighteningly severe reverse curvature of the cervical vertebrae. His feet were grotesque, bluish-grey, gnarled, and utterly numb, with extreme deformities of the toenails.¹ His personal hygiene was appalling due to his inability to wash himself thoroughly. His hands were quite rigid, with all five fingers pressed together, fingers extended. His legs were rigid, as were his torso, shoulders, and neck. He had no arm swing and his left leg dragged badly. He was certain that, because he was only diagnosed a year and a half ago, his was a case of “early” Parkinson’s and should respond quickly to treatment.

I did not consider him to be “early Parkinson’s.” Even with Eldepryl, he had trouble performing small motor tasks, including eating, putting a key in a lock or washing his hair; his balance was very bad and he had had many falls; his whole body was tense and rigid to an extreme degree. It seemed to me that the reason he had only been diagnosed a year and a half ago was that he had only seen the doctor for the first time a year and a half ago. Considering that he had had most of these symptoms, albeit to a lesser extent, for nearly twenty years, and the tremor for a full twenty, and especially in light of the fact that he was to need to move into a care facility in less than a year, I would say that, at the time I met him, he was probably approaching an advanced condition. However, I would have to say that he had done very well, considering that his symptoms had appeared twenty years earlier.

Usually, a person who has symptoms prior to age 55 tends to have a more rapidly progressing form of the illness. I can only attribute much of his success in living for so

¹ Toenail deformities are common in Parkinson’s, as is toenail fungus. Happily, this fungus and the deformities go away as a part of the recovery process. As circulation to the feet is restored, the body is able to recognize and kill the fungus.

well for so long with encroaching PD to the facts that he was not oppressed by the knowledge that he had PD and he was not taking any medication.

He had started taking Eldepryl at the recommended dose, 5 mg two times a day, when he was first diagnosed. One month after starting the drug, he started receiving treatments from an east coast practitioner who was using our methods, and, in anticipation of a quick recovery, reduced his Eldepryl to a fourth of a pill, twice a day. He took this dose for a year and a half. He insisted when I met him, after a year and a half of this low dose of Eldepryl, that the drug did nothing for him. He could take it or leave it, he claimed, and only took it out of habit. He became annoyed when I suggested that it might be addictive, and two weeks after starting to work with me, he quit taking his “insignificant” dose of Eldepryl and reduced his NADH to 5 mg a day from 10.

Over the next ten weeks, he went into a tailspin. Five weeks after stopping the Eldepryl, he reported that he was freezing constantly and he couldn't catch his breath. He couldn't sleep, he could not turn to one side or the other, and his balance was completely gone, frequently causing him to crash into walls. His left leg was utterly useless – he had to lift it with his arms to move it – and his left calf and hamstring were painfully cramped. His tremor was “deeper” and dominated his every moment. He could barely eat and he had to spend long minutes calculating how to get up from a chair.

By week six, he said, “I'm not better but not worse, and although mornings are bad, once I start walking I can keep going.” After several more weeks, he said he had “turned a corner. I'm doing better, I have to admit it.” He was less frequently “paralyzed,” and “not needing to lift my feet thirty times to move three feet.”

Ten weeks after stopping Eldepryl

After a full ten weeks, he noticed that he was doing much better. He went running twice during the week, and he was sleeping well, only getting up twice at night to urinate. He had only had one episode of hand clenching (dystonia) and the freezing was much less frequent – and when it did appear, he could easily break up the freeze and keep moving. He was angry when I suggested that the ten weeks did correspond to the amount of time that most people need to complete a withdrawal from dopamine-enhancing drugs. He was adamant that he had not been taking enough to make a difference. However, he was surprised when I read to him his weekly notes and pointed out that at five weeks after the reduction, he had been at his very worst, and at eleven weeks he was running again and pretty much behaving as he had been prior to the drug reduction.

Two weeks later, he noticed that his arms were starting to swing, and that he was starting to have sensation in his scalp. After that he started having recovery symptoms, including a sense of tremendous heaviness at nighttime, as if he was sinking into his bed and down into the earth, as if his bed had an enormous gravity and he was of supreme density. This feeling, which he named “being buried alive,” understandably terrified him, even though I shared with him similar descriptions from people who were starting to experience the Deep Sleep and extreme weakness that accompany recovery. Even more horrifying, however, was the pain that accompanied the return of sensation in his extremities.

Pain

Foot pain

For over a year and a half, Rudyard took no medication and noticed increasing signs of recovery from Parkinson's. However, over time, as sensitivity returned to many parts of his body, he regularly (daily) considered taking drugs again. When he first regained feeling in his feet, he was so panicked by the extreme burning and the alarming return of pinkness (which he assumed to be an infection) that he went to the emergency room. They offered him L-dopa. He took one dose, felt completely stoned, and decided that he could no longer tolerate this particular drug. (When he had taken L-dopa at the time of his first diagnosis, it had done nothing dramatic for him and so, after a week, he had stopped taking it.) However, concerned by the pain and rosy color appearing in his feet he started toying with the idea of trying some new Parkinson's drugs.

I asked him at his next weekly visit why he had not considered taking aspirin or Tylenol for his foot pain, and he told me that the pain was so severe that these mild remedies could not possibly have helped.

Hand pain

Several months later, after his feet were no longer burning, he started to have restored feeling in his hands. He again went to the emergency room, this time for hand pain. When he told the doctors that he had been diagnosed with Parkinson's, the ER doctor (clearly not a PD specialist) told him that abrupt hand pain and a return of healthy color in the hands was a symptom of Parkinson's disease. He suggested antiparkinson's medications and also told him that the emergency room was not the appropriate venue for getting treated for Parkinson's disease, and to stop coming in.

Rudyard again refused to consider taking mild anti-inflammatory medications such as aspirin. He actually tried taking one aspirin once and, since he still felt pain in his hand, he announced that anything short of anti-PD drugs would be worthless.

After the emergency room asked him not to come back, he asked me every week whether or not he should start taking some antiparkinson's drugs for the pain. I replied every time that I no longer worked with medicated patients. He was certain that only anti-PD drugs would be strong enough to ease his pain. He refused to even try over-the-counter pain pills, massage, meditation, or anything that might possibly have helped his throbbing hands, and instead took nothing for the pain. After several months, the burning in his hands, which was quite severe, preventing sleep and nearly crippling him with pain, began to ebb. The worst was yet to come.

Elbow pain

About two months after the hand pain began to ebb, it appeared in his elbow. On days when the pain was extreme, he felt he was dying, but sometimes, on days when the pain started to ebb, and particularly after nights when he slept well, he felt much better and not at all like he was suffering from PD. Here is a quote from him at this time:

“Interesting week. Yesterday was the worst day of my life, the worst week, the worst everything, but I slept well, and today, I don't feel that way at all. The new thing is my arms are dead, just like my legs used to be dead when the pain first left them. This makes me panic, of course, and the elbow pain continues, but it's less. The problem now

is that the hands are weak and limp. I'm not dizzy this week, but I'm getting a red rash on my feet and torso, and a feeling of bugs all over my skin."

And so it went, alternating between recovery symptoms, which were quite painful, and days when he felt much better, and his increased flexibility made him appear much less like he had PD.

Neck pain

The worst was still yet to come. He started to have feeling in his grossly contorted neck. I can well believe that this pain must have been excruciating. He insisted that what he needed to help with the neck pain were antiparkinson's drugs. Again, he refused to consider any treatment or pain reliever except for anti-PD drugs.

I asked him to try a chiropractor to see if anything could be done about his neck. The chiropractor said that his neck bones had grown into the distortion, and there was nothing that he, the chiropractor, could do about it. This threw Rudyard into an emotional tailspin. He was in great pain. He could not be consoled with the fact that his feet no longer hurt, that they were now flexible and warm and his toenails were growing in normally. He was not consoled with the ebbing of pain and the return of feeling to his hands, or the ability to move his fingers.

Dopamine depletion from pain

Rudyard started exhibiting postural symptoms of dopamine depletion. Pain is modulated with dopamine, and in times of great pain, one needs either increased adrenaline or dopamine to saturate the limbic zone against the incoming onslaught of pain signals. Rudyard didn't have enough of either.

Rudyard was in extreme pain. This pain had him awake most of the night, curling his body into a protective fetal position, and staggering about, losing his balance and crashing into walls – symptoms of pain-induced dopamine depletion.¹

He announced that he would take some antiparkinson's drugs for a few months. Having experienced similar burning in his feet and hands, he was certain that he would only need the drugs for a few months until his neck pain also went away. I was concerned that he might become addicted if he started taking the drugs; I had seen this happen several times before. However, he was adamant.

I had shared with Rudyard, just as I shared with everyone, the case studies of his fellow pioneers. Rudyard fixated on Coach's recent success with a low level of Mirapex. He completely disregarded the discrepancies between their cases: Coach was now 76 years old, had been suffering post-traumatic-stress depression and addiction-induced dopamine deficiency; Rudyard was now 47 and suffering from a debilitating level of pain. Their cases did not seem to me to be similar.

¹ For that matter, infectious illness also depletes dopamine; I had a high fever and sinus infection only last week, and I was shuffling around the living room, nearly losing my balance several times, and tripping over the furniture. My arms were clenched in a fetal position. I felt incapable of any speech louder than a moan. I mention this merely because I am trying to make the point that there are many syndromes besides Parkinson's disease that can deplete dopamine and cause the sufferer to revert to a hunched over, staggering hulk who is incapable of taking care of himself. However, most people do not treat extreme pain or febrile illness with antiparkinson's drugs. To do so would be, in the phrase I learned in school, "killing a chicken with a buffalo ax."

It did appear as if, when the pain ebbed, Ruyard was able to produce dopamine. He was in fact starting to have more episodes when he would suddenly find himself relaxing down into his chair, and even relaxing emotionally. He was starting, for the first time in his life, to be able to have a circumspect attitude about his condition and about life in general. Prior to this he had always been intense, driven, and demanding. I remember, right around this time, that he amazed the two people who were treating him in the clinic when, in response to their warning that it might take a long time for the neck pain to begin to heal, he shrugged his shoulders, smiled at them, and said, “Whatever!”

Even he was amazed. Immediately after he said it, he sat halfway up from his treatment table and chuckled, “Did I really just say what I think I said? Omigosh! I *am* changing!”

But despite these indications that dopamine was returning, and despite the differences in their ages and case histories, Ruyard compared himself to Coach and asked his neurologist for a prescription for Mirapex.

Mirapex

He started taking Mirapex at the lowest level, .125 mg (an eighth of a milligram), three times a day, for a total of three eighths of a milligram per day.

I did continue working with him, despite my concerns about drugged patients in the recovery program, partly because of legal restrictions on “patient abandonment.” I also saw no point in abandoning him as a patient: at this point, he was already getting better and there was no way for me to turn off the recovery. I stopped doing Tui Na, however, and limited my treatments to mostly talking about his week, or very simple acupuncture treatments for reducing dopamine levels if he appeared too overmedicated.¹ I figured that there was a chance that he might be able to use the medication to get through this period of extreme pain and then get off the medication, so I kept meeting with him. At the clinic, the practitioners mostly held his hand or massaged his neck while he talked about his week. We did not want to do anything that might accelerate his recovery.

Despite my misgivings, we were all curious as to the relative addictiveness of the new agonists when compared with levodopa. We were to learn that the agonists are just as damaging.

One eighth the normal dose

Within two weeks, he was somewhat better, having two periods of over an hour when he was perfectly “normal.” I pointed out to him that he wasn’t supposed to feel this much better at this starter dosage – these drugs are supposed to be increased up to somewhere between 3.0 and 4.5 mg/day before the patient feels better, and here he was feeling greatly relieved at one eighth of the so-called therapeutic dose. He was taking a third as much as Coach. Didn’t this suggest to him that he should be trying something a little less powerful?

He felt that I was being melodramatic. He pointed out that he was taking so much less than the therapeutic dose that the drug could not possibly be addictive at this level. I

¹ A needle jabbed deeply and painfully into KI-1 (on the sole of the foot) can waken the sympathetic system, bringing energy down from the head during episodes of mania or overmedication from dopamine-enhancing drugs.

countered that, since the drug was clearly masking the pain at this minute dosage, maybe it was more powerful than he was giving it credit for.

Doubled dose to .75

After two weeks, he decided that, since he was feeling better with the Mirapex, he should increase his dose. He doubled his dose, as recommended by his doctor, up to .25 mg/three times a day, for a daily total of .75 mg. Within two days, he felt much better, with increased range of movement and much less pain.

Ticcing and dyskinesia

However, he noticed that he was having an increase in tremoring, even in his left hip, which had not tremored in many months. Within two weeks, he said, “I feel fantastic, but the tremoring is getting very powerful, more so than ever before.” He also had cramping in his legs (dyskinesia) just like he had when had taken Eldepryl. Within four weeks at this level, he told me that moving to alleviate the cramps would cause worse cramping. Also, after doing his jumping jacks, he had cramping in his pectoral muscles. Most frightening was the extreme cramping in the neck and facial spasms, which, in his words, “makes me feel like Frankenstein’s monster.”

33% reduction

Mirapex is well known to cause cramping in the muscles along the front of the neck. In fact, I should not be surprised to learn that it is this cramping along the front of the sternocleidomastoids that is responsible for the drop in blood pressure in Mirapex patients.¹ He reduced his medication. He started taking the .25 mg pills only twice a day, instead of three times. Now, at this reduced level, he saw the benefits of the medication ebb. Within a week, he had lost most of the benefits that he had gotten when he started the drug. When he had first started, at three eighths of a milligram a day, he perceived benefits. Now, just two months later, he perceived no benefits from the drug at half a milligram per day, a slightly higher dose.

Worse, he continued to have the powerful tremor and the cramping, both of which are listed as adverse effects of the medication. Although the tension in the neck decreased and the facial spasming stopped, he felt weaker than ever, lurching from spot to spot, with a tendency to fall over backwards and, in his own words, “paranoid” about the sudden increase in weakness.

The next week, he felt much better at the lower dose: although his tremor was increased, with greater power, he observed that his sleep was better, he had increased feeling in his low back and could even stretch the muscles of his low back, something he had not done in years. He was lurching less, getting up out of chairs more easily, and his

¹ The pressure along the SCM muscle pushes on the carotid sinus, where the barometer for determining blood pressure is located. The increased pressure on this sinus may be mistaken as a signal of excess pressure by the sinus, which then, appropriately, sends a “Reduce pressure” signal to the body. The corresponding lack of pressure causes the orthostatic hypotension that is particularly severe with this agonist. Conversely, when decreasing this drug, the temporary collapse of this muscle that follows the decrease may send a false “Low blood pressure” signal to the sinus. The sinus then responds with a surge of increased blood pressure via vessel restriction and increased heart rate. This would certainly account for the feeling of pressure and heat in the head experienced by people who reduce this drug quickly, and it may also account for their symptoms that resemble mild stroke.

small motor function was better than it had been in a long, long time: he was now able to floss his teeth and was doing it three times a day.

A slight decrease

At this point, feeling better at .5 mg/day than he had at .75 mg/day, he felt that it had been a mistake to take the Mirapex, and he decreased again by a tiny amount, taking only .25 mg/day on Thursday, though he continued taking .50/day the other days of the week.

Within a week, he was feeling depressed. He reported, “I’m getting weaker, my energy is fading, but a lot of it is depression; I’m laying in bed when I don’t need to. I can still get out of chairs and I’m still able to feed myself, but I just don’t feel the same about it.”

He continued with the above dose: .5 mg/day every day but Thursday, and only .25 mg on Thursdays. He felt “no marked difference on the days with only .25 mg, and the cramping is easing up. I can relax again. I can feel myself sinking my head into my pillow, and it feels so good. When I’m in bed, I feel so relaxed that I think I will be able to be fluid and graceful when I get out of bed, but I can’t. Since decreasing the pills, the sleep is continuing to improve. I can stop the tremor now by concentrating on it. I have less choking and tension in the front of the neck, I’m regaining feeling in my stomach and low back, and I can stretch this area. I’m having ants crawling on my face and twitching or shivering in my facial muscles. I was so relaxed that I was able to lie in bed and read a book, and I haven’t done any reading in a year. My arm gets tired from holding the book, but my ankles are so relaxed I can lie on my bed with my sneakers on and not get ankle cramps or pain.”

The next week, he reported that he felt distinctly “looser” on Friday mornings, after having only .25 mg on Thursdays. However, his throat spasm, though it changed from hour to hour, was starting to frighten him. He reduced his medication again, taking the small dose of only .25 mg on Sundays as well as on Thursdays. After making this extremely small reduction, he felt “a head shift (an attitude shift) this week. I’m seeing each moment as an opportunity to stretch, grow, practice. I am starting to realize now that any improvements that I’ll get now will come from me.”

He noticed that on Fridays and Mondays (the days that followed his smaller dosage), he had “a clean feeling, with better alertness. But two days after the smaller dose days (on Saturdays and Tuesdays), I have a mild crash.” He wanted to stop taking the Mirapex now, as he felt he had made a mistake in starting it, but these mild crashes worried him. He was afraid that if he stopped taking the Mirapex altogether he would be much worse than he had been before starting it. Also, I had warned him that Mirapex has a delayed effect, about three weeks longer than Sinemet. While Sinemet has a ten-day slide, the Mirapex slide is nearly a month before the real withdrawal begins.

Another very small decrease

Nevertheless, he decreased again by reducing to only .25 on a third day of the week. At this point, almost four weeks after his first Mirapex reduction from a “sub therapeutic dose,” he started experiencing drug withdrawal symptoms: “Depressed all week. I feel as if I’m lacking serotonin. Balance is worse, freezing is worse. I’m back-pedaling when trying to walk forward, my neck pain is worse, and the throat strangling

feeling is back. It's harder to get in and out of chairs, and I'm feeling weaker every day. I'm still having the ticcing – it hasn't stopped since I started the Mirapex – and I'm starting to have cramping in my legs even at this low dose." After two weeks on this drug regime, his insomnia was back and the depression was very bad. He was experiencing a devastating loss of energy and having dizziness with a horrible new sort of head tremor. In the past, when taking levodopa and later when taking Eldepryl, he had experienced dizziness. Dizziness is listed as an adverse effect of Mirapex. However, from deep in his drug withdrawal haze, he fixated on the dizziness, decided it was the most significant of his Parkinson's symptoms and it could only be helped by the medication.

Return to .75

Over the next several weeks, he went back up to .75 mg/day, his previous highest level. His memory of this level of drug use was that it had felt like a golden time, a time of energy and gracious movement. I pointed out to him that, in fact, it had been a time of severe ticcing, cramping and feeling like Frankenstein's monster, and that was why he had decreased the drugs. He disagreed and said that he had decreased the drugs because he felt so good that he had imagined he was recovered, when, in fact, it was obvious that he was not getting better, as evidenced by how bad he felt with the reduced dose. In fact, he pointed out, he had never felt better than when taking .75 mg Mirapex a day, and he had never felt worse than he did when alternating between .25 and .5 mg per day.

Return of adverse effects

Within two weeks of taking .75 mg/day, he was having strong cramping, increased tremor and dangerous, choking throat spasming again. Worse, he felt none of the benefits of the medication. He could not understand why, only a few months earlier, he had felt on top of the world while taking .75 /day (his faulty memory of those "golden days"), and now he felt only tension and pain. The throat spasms became so severe that he dropped back down to his previous pattern of alternating .5 mg days and .25 mg days.

Decreased dose, withdrawal symptoms

He soon became severely depressed. He could not get out of a chair, feed himself, or sleep. "I'm in bed, tired, but not sleeping well, and every day I'm more weak, with less balance. The depression is *very* bad." He started having leg and throat cramping even at these lowered doses.

The cramping, especially the throat spasms, was so frightening that he decided he needed to increase his medication. He felt that the throat spasms were being caused by the Parkinson's returning, and the only way to make them go away was to increase his medication.

Return again to .75

He increased back up to .75, and the cramping became truly agonizing, but he felt that the increasing dizziness was even more of a concern, as he was starting to crash into things.

After several weeks of frightening dyskinesia he decreased again, down to .5 mg/day, but the tremor and crashing into walls continued to build in intensity.

At this point, I had yet another long talk with him, in which I read to him again from the list of adverse effects of Mirapex. I asked him, "If the drug causes throat spasms, and you do have worsening throat spasms when you increase the drug, what do you think you should do?" He answered, "Increase the Mirapex." Two of my colleagues who had been invited to observe this session exchanged glances.

I asked Rudyard, "If the drug warning says that this drug can cause dizziness, and if you have increasing dizziness when you increase your medication, what do you think you should do?" He answered, after a thoughtful pause, unaware that I was asking him essentially the same question, "Increase the medication." My colleagues cocked their heads and looked at me, puzzled.

"Rudyard, if this drug *increases* tremor, and if your tremoring started up again after you started taking this drug, and if the tremor is worse at higher doses and decreases at lower doses, and you are having worsening tremor at .75 mg/day than you did at .5 mg/day, what do you think you should do to ease your tremor?" This one required no thinking at all. Rudyard smiled and answered quickly, "Increase the Mirapex." He continued, "I feel so bad now, and I remember so clearly, the first time when I went up to .75, I felt so good. I've never felt so good in my life. I could move, I had confidence, and all my pain went away. I just want to recapture that. I know how I felt at .75 and that's how I want to feel."

I suggested, "Within a week or less of being at .75, you have horrible, choking throat spasms and your tremor increases."

Rudyard returned, "No, my tremor is bad now. It was fine at .75. And I never had cramping at those levels"

"Let me read to you from your chart," I said, "where I have it in your own words. 'It makes me feel like Frankenstein's monster...'"

"Oh that. Well, that was just because I increased too quickly."

"No, Rudyard, every time you've been at .75, you've had to decrease soon after because you feel you are choking to death, and your tremor gets violently worse."

"What do you mean, 'every time'?" he asked. "I've only been at .75 one time, and it was wonderful, and I only decreased my medication so I could stay in your program."

"Rudyard, you have been at .75/day three times now, and you've had to decrease every time because of the cramping and choking, as well as your tremor getting so violent that it shakes your whole body. I have never threatened to throw you out of the program. We're learning from your experience."

"My tremor is shaking my whole body now, and I'm only at .5." he countered.

"That's because you are now addicted. Your body developed a tic in response to the drugs, it's most powerful when your dose is working, and since you are now addicted, your body is screaming for more medication, and it will tremor until it gets it."

"So then let's give the body what it wants, which is .75...or maybe more!" At this, he smiled hopefully.

"But at those levels adverse effects of the medication develop rapidly: cramping, frantic shaking, and choking."

"Then what I need is more medication, so that I don't have the adverse effects. The whole point of the medication is to overcome the adverse effects, correct?"

I want to make it very clear to the reader that, prior to starting the medication, Rudyard was a very thoughtful person who seemed to understand completely the risks and problems associated with addictive drugs, including the worsening of side effects even as the body becomes inured to the drugs and the beneficial effects fade away. He understood this completely.

Anyone reading this who is living with a medicated patient who is starting to not make sense will understand completely what I am talking about. PDers, for the most part, are extremely intelligent, and very often they are keen analytical thinkers. However, these drugs can curdle their brains so that they no longer think straight. And worse, when it comes to their medication, they can be blinded by love – a love for the drugs. So many of them, especially those who have taken the meds, however briefly or at however small doses, for even a few days, at any time *after* the recovery has begun, only remember that the meds, however fleetingly, made them feel “better than I ever felt before.”

As the conference with Rudyard drew to a close, I asked Rudyard a final question: “If your medication makes you feel worse, and not taking it makes you feel better, what should you do?” He thought for a moment and suggested, “Increase the medication more slowly.” I turned to my colleagues with a sinking heart. “This is what I mean by drug-addled and addicted,” I told them. Rudyard also turned and smiled at them, as if he had just aced a quiz show and it was time to collect the prizes.

I was leaving the country at about this time to write up this book. I left Rudyard in the care of my locums. I have since heard that he is moving better than ever: he has much less pain and newfound agility in his torso and limbs. He does appear to be recovering nicely from Parkinson’s.

He never decreased the medication again: he recently increased it to help with his moods and what now appears to be permanent shaking. The increase appears to have increased his ticcing and dyskinetic cramping.

However, the horrible neck pain stage seems to be finished, and he is moving quite well, better than he has in many years, even in the years when he was taking Eldepryl or feeling “great” when he started the Mirapex. We are assuming that he will need ever-increasing amounts of Mirapex to keep his mood up, especially in light of the constant ticcing and spasms, but we are pleased that his previously distorted body has responded to Tui Na treatment by becoming supple, and that his circulation has been restored.

He also appears to be ferociously addicted to the medication. I have also heard that his conversation is highly illogical, and that he has difficulty following a train of thought.¹

¹ As this book is being published, I just learned that Rudyard has tripled his Mirapex in the last four months, up to 3.0 mg/day. My colleague says that he’s “completely nuts.” His dyskinetic cramping, choking, and ticcing are severe, but he doesn’t seem to notice them. He announced that he is only taking the Mirapex until he begins to have signs of recovery, and then he will quit. He is moving back to New York to show his old friends how well he is doing...

Summary

Very often in our limited experience, a recovering PDer who is taking only a “little bit” becomes extremely addicted and is trapped with the medications for what appears to be a life sentence. If a person has started to recover from Parkinson’s, these medications, even “just a little bit,” appear to be at least ten times more powerful, and more addictive, than “just a little bit of cocaine” or “just a little bit” of heroin.

I also included this story to make the point that *all of the dopamine-enhancing drugs*, not just levodopa, are capable of quickly setting in motion a very powerful addiction. A colleague who was working with Rudyard after he started on the Mirapex once asked him if he had read the materials that I had been writing up about the dopamine-enhancing drugs, materials that were available to my own patients and also to Internet patients who had specifically inquired. (This was, at the time, a series of short chapters that have now evolved into this book.) Rudyard said, never having cracked it open, that there was no point in him reading it. Despite our assurances to the contrary, he was adamant. “I won’t read it. I’m taking Mirapex. Her writing is sure to be about levodopa.”

Rudyard probably would have been best served with some sort of pain relieving medication. However, the lure of the medication was always nagging at him. From the time he first got off his Eldepryl, he was always asking me if “just a little” medication might not help. This “looking back with longing” at the happier times with medication – even if those “happier times” were filled with pain, rigidity, and the full spectrum of Parkinson’s disease symptoms – is not uncommon in those who have ever, however briefly, taken medication.

Rudyard was starting to experience glimmers of dopamine even before he started taking the Mirapex. We have not really broached this subject yet, the complications that can arise if a person is still taking medication when these first glimmers of native dopamine appear. So in the next chapter we will discuss some complications, such as glimmers of native dopamine, that can arise during recovery or addiction, complications that can add still more layers of confusion and mystery to the subject of drug use in Parkinson’s.

