"It is cocaine," he said, "a seven-percent solution. Would you care to try it?"

Sherlock Holmes speaking to Dr. Watson, in "The Sign of Four,"

Sir Arthur Conan Doyle

15. A TEN PERCENT SOLUTION

I have frequently alluded to "small" decreases in medication, and 10% decreases. This is the chapter in which I get specific about what, exactly, I mean by small, and explain the 10% rule. Before I tell you my ideas on "small" doses, let's see the specific recommendations the drug manufacturers have for drug reduction. Here they are, straight from the books:

Levodopa: "Because of risk of precipitating a symptom complex resembling neuroleptic malignant syndrome, observe patient closely if levodopa dosage is reduced abruptly or stopped."[1]

Sinemet (buffered levodopa): no suggestions.

Artane: no suggestions.

Eldepryl: no suggestions.

Amantadine: "If drug is being taken to treat parkinsonism, warn patient not to discontinue abruptly because that might precipitate a parkinsonian crisis."[2]

Permax: no suggestions.

Mirapex: "If drug needs to be discontinued, do so over a 1-week period.

"Neuroleptic malignant syndrome (elevated temperature, muscular rigidity, altered consciousness, and autonomic instability) without obvious cause has occurred with rapid dose reduction or withdrawal of or changes in antiparkinson therapy."[3]

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[1] *Physician's Drug Handbook*, p. 595.

[2] Ibid, p. 30.

[3] Ibid, p. 850. I am especially gratified about this warning. The original (1997) insert information for this drug did not include this warning. I wrote to the manufacturers of Mirapex in late 1998 stating that three of my patients, after rapid decrease of Mirapex, had experienced symptoms of headache, heat and/or pressure in the head, followed by symptoms of slight stroke (short-term partial paralysis, short term loss of or difficulty with speech, short-term personality change, and other symptoms consistant with mild stroke). The Mirapex people did respond and wrote asking for further details. In the next edition (2000) of the *Physician's Drug Handbook*, I saw that the available information had been amended to include the above quote.

The reason I noticed this in Mirapex patients and not in Requip patients is solely geographic; my hometown is just south of UC San Francisco, a location where Mirapex had some final years of testing. In the first few years after Mirapex and Requip, two *highly* similar drugs, were released, it seemed as if Mirapex was most often the agonist of choice on the west coast and Requip on the east coast. Most of my Requip-using patients were east coasters, visiting me only briefly. Today (2003) the drugs seem to have become generally distributed.

Requip: “Although not reported with repinirole (Requip), a symptom complex resembling neuroleptic malignant syndrome (elevated temperature, muscular rigidity, altered consciousness, and autonomic instability) has been reported with rapid dose reduction or withdrawal of antiparkinsonians. If this complex occurs, stop drug gradually over days and reduce frequency of administration to twice daily for 4 days and then once daily over remaining 3 days.”

Do you notice anything curious about all of the above? With the exception of Mirapex and Requip, not one of the drug advisories gives specifics about how to reduce the medication. I wrote to two of the companies asking for specifics on rate of drug reduction. While not identifying myself as a doctor, I did write that I had patients who were taking these drugs. One company did not answer me at all, and the other sent me the usual insert information, together with the reassuring comment that “This drug has been approved by the FDA.” In other words, most of the companies that make these drugs either do not know or do not publish information about the specific rate at which one should reduce these medications.

Only two companies made suggestions; in both cases, their suggestion that these drugs be reduced over a one-week period is ludicrous. The one for Requip is ridiculous – they suggest that if a person has already had a meltdown from stopping the drugs too quickly, then he should, after having stopped, reduce slowly. What on earth is that supposed to mean? And maybe they did not read my letter carefully; I pointed out that the three patients who had experienced stroke-like symptoms had not had these symptoms until three weeks after their precipitous decrease. Given this, what would these agonist makers have you do after your stroke: start back up on the drugs again and come off them again over a week?

It only makes it worse when they admit that the drugs can precipitate a crisis in rapid reduction, and then imply that a leisurely, one-week reduction will prevent this sort of crisis. Here’s why: this one-week suggestion comes from makers of the two antiparkinson’s drugs which specifically need a gradual build up of eight to twelve weeks when starting to take the drug in order to prevent powerful adverse effects. In other words, they know perfectly well that a person must start these drugs at levels approaching one tenth of the effective dose and work up to the full dosage over months. And yet, they suggest that a person can safely reduce these drugs over the course of a week?!

I am certain that NO testing was done to prove these reduction numbers. Since they know that over-fast reduction is dangerous, one would think that they might at least have experimented with reduction rates before proposing that, while one must increase the drugs slowly over *months* to attain an effective dose, one can safely stop taking them in a week!

One of my patients was involved in the testing that was done on Mirapex. Not one mention was ever made to her or anyone that she knew in the test group regarding testing for drug reduction safety.

Therefore, as you can guess, our little band of pioneers had to figure out the hard way just what the word “slowly” means. As already noted in earlier chapters, we found that a drug reduction of 10% appeared to be safe. This chapter is going to give details on what we mean by 10%.

10% of the current dosage

Patients who did the best usually reduced their medication by approximately 10% of their *current* dosage.[1] This means 10% of the amount the person was taking immediately prior to each reduction. This does NOT mean 10% of the highest amount of drugs ever taken. As you have guessed, this means that each reduction was a little bit smaller than the one before. Sometimes, due to the size of the pills and difficulty in breaking the pills, it was necessary for pioneers to be approximate with their reductions.

The weekly amount is more significant than the daily amount

Also, as the reductions got smaller, sometimes it was just impossible to get close to the 10% number. That was when we discovered that it really doesn't matter if the daily amount was decreased by 10%. What seemed to matter was that the overall, *weekly* amount was reduced by 10%. Because a slide into drug withdrawal usually took ten days (which is more than a week), it appeared that the limbic monster could be appeased as long as the *weekly* total of drug reduction was no more than 10% of the previous weekly amount. This finding was a huge help; in the beginning of this research project, people were literally rubbing their pills down to size with an emery board. Once we figured out that the limbic brain didn't have a clue what was going on from day to day as long as it got its ten-day supply, the pioneers had much more flexibility in their dosings. For example, in the chronicle below, watch what happens when the doses get down below 575 mg/day.

Even if you know how to calculate 10%, please read through the entire scenario below. I have tried to include many of the various irregularities that occur while people are reducing their medication. Therefore, the example below is a combination of several patients' charts, and covers a wide range of circumstances. Please do not think that anything that involves humans and drugs can ever be so simple as to conform to an exact 10% plan.

Please be aware that the example below only represents the kinds of numbers used by people in our study who got off their medication with a minimum of drug withdrawal symptoms. These numbers are not recommendations. These numbers are not supported by any drug company. You must work with your doctor. These numbers are presented as research curiosities only. They are not suggestions. Thank you. If you don't understand the significance of this paragraph, please find someone who does: maybe your doctor would be a good place to start.

This example of Waldo, a fictitious patient, is actually a composite of the reduction sagas of three patients (Hjalmar, Sonny, and Mark[2]). For purposes of this

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[1] Math question: How does one calculate 10%?

Math answer: To calculate what ten percent of a number is, multiply that number times one tenth (.1). Another name for ten percent is one-tenth.

[2] Sonny and Hjalmar were both taking slightly more than 1000 mg/day when I met them. Mark was taking 300 mg/day of levodopa and an anticholinergic.

fictitious example, we will say that Waldo was taking 1000 mg levodopa/day when he started reducing his medication:

First reduction 1000 mg/day ➔ 900 mg/day (a 10% reduction)

Explanation: To calculate 10% of 1000 mg/day, Waldo multiplied 1000 times .1 (one tenth). The resulting answer was 100. Therefore, he decreased his medication by 100 mg/day: he went from 1000 mg/day to 900 mg/day, a decrease of 10%.

Second reduction 900 mg/day ➔ 800 mg/day (11%)

Explanation: This time, Waldo multiplied 900 times .1 and got the answer 90. Another way to do this math is to remove the right-hand digit of the number. In this case, removing the zero at the right-hand edge of 900 yields the number 90. This means that this reduction needed to be a decrease of 90 mg/day. However, it is too difficult to cut a 100 mg pill down to a 90 mg pill with any sort of precision. Therefore, Waldo reduced by a whole pill (100 mg) rather than by a cut pill (90 mg). However, by checking the math, one can determine that 100 mg is not a significantly higher amount than 90 mg. In fact, a reduction of 100 mg/day, from the existing level of 900 mg/day, is only a reduction of 11%. Eleven is close enough to ten that Waldo made this reduction without going through any withdrawal problems. His decrease took him from 900 mg/day down to 800 mg/day, a decrease of 11%.

Keep in mind that 10% is an approximation. Eleven percent, or even fourteen percent, is close enough to ten percent that the limbic area probably won't notice it. On the other hand, a number like thirty percent, for example, is *not* close enough to ten percent to avoid withdrawal symptoms, in our experience.

Third reduction 800 mg/day ➔ 725 mg/day (9.3%)

Explanation: Three months later, Waldo was starting to feel good after eleven weeks of drug reduction misery. He now had two choices. He could either reduce by a whole pill (100 mg) or he could reduce by three fourths of a pill (75 mg). Most patients find that cutting a pill any finer than one fourth or three fourths is simply not accurate.

Here is the math for the two possible choices. If he reduced by a whole pill, it would be a reduction of 12.5%. Here is how he did the math. Using his calculator, he divided 100 (the amount of one pill) by 800 (his daily amount). The answer was .125. To form a percent from this decimal number, he must move the decimal place over to the right two times. Then, .125 becomes 12.5%.

His other choice was to reduce by 75 mg. He divided 75 by 800, and found that this resulted in a number .093, or 9.3%.

Wilma, his wife, decided that 9.3 was closer to 10 than 12.5, and so chose for Waldo to make the smaller reduction. From what we have seen, he could also have made the larger reduction of the two with no problem. He reduced by 75 mg/day, going from 800 mg/day down to 725 mg/day.

Fourth reduction 725 mg/day ➔ 650 mg/day (10.3%)

Explanation: This time, Wilma wondered what another reduction of 75 mg/day might be in terms of percent. When she divided 75 by 725 (his current daily amount), the answer she got was .103, or 10.3%. This was just right, they both agreed, and so on this reduction, he reduced by 75 mg/day, bringing him down from 725 mg/day to 650 mg/day.

Fifth reduction 650 mg/day ➔ 575 mg/day (11.5%)

Explanation: Waldo and Wilma were getting the hang of it now; Wilma divided 75 (for 75 mg of pill) by 650 (his daily dose) and got an answer of .115, or 11.5%. They felt that this was reasonable, as he had easily survived the preceding decreases, and so he decreased by 75 mg/day, bringing him down from 650 mg/day to 575 mg/day, a decrease of 11.5%.

Sixth reduction 575 mg/day (4025 mg/week) ➔ 525 mg five days of the week, and 500 mg two days of the week, for a total of 3625 mg/week (9.9%)

Now, for this reduction, Wilma had to take an entirely different approach. Waldo was taking 575 mg levodopa/day. If he reduced his pill by 75 mg/day, it would be a decrease of 13% (75 divided by 575 = 13%). She felt that 13% might be a bit too much.

However, if he only reduced by half a pill (50 mg), the reduction would only be 8.7 % (50 divided by 575 = 8.7%). She felt that 8.7% was too small a reduction, as she was eager to get him off the pills. She also felt that 13% might be too much. What should he do?

When she calculated how much pill he needed to reduce to make a 10% reduction, she found he would need to take 518 mg/day. Because the pills come in 100 mg units, it would be very tricky to break off 18 mg from a 100 mg pill.

Some days more, some days less

Happily, such exact breaking is not necessary. Because the limbic brain apparently only cares that it gets 90% of its dopamine pills *over the course of the week*, Waldo and Wilma only needed to figure out how to reduce 10% of his *weekly* amount, not his *daily* amount.

How much was he taking per week? In one week he was taking 575 mg (his daily amount) times 7 (seven days in a week).

575 mg x 7 = 4025 mg.

Rounding numbers

Instead of figuring 10% of 4025, which is rather an awkward number, Waldo and Wilma, who were good with math, just "rounded down" the 4025 to a nice, even 4000. It was easier to figure 10% of a nice, round number like 4000. In fact, it was extremely easy: ten percent of 4000 is 400. Now, how did Waldo reduce his medication by 400 mg during the course of the week?

Remember, because the pills come in 100 mg, the easiest way to reduce was in increments of 50 or 100 mg. The smallest possible accurate pill breakage was to 25 mg.

What Wilma wanted to do was, somehow, over the course of the week, give Waldo 400 mg less than he had the week before. They could have done this in many ways: He could have taken 100 mg less on four of the days, and left his dosage the same on the others. Since, in this particular case, he wanted each day's dose to be as similar as possible, he chose to take 50 mg/day less on five of the days (that's a total of 250 mg less over five days) *and* 75 mg less on two of the days in the week (that's 150 mg less for two days). Adding these two numbers together (250+150 = 400), he had a total of 400 mg less than he had taken the weeks before.

The weeks before he had taken 575 mg every day. This week, the week of the 400 mg/week reduction, he took these amounts: 525 mg Monday, Tuesday, Thursday, Friday, and Sunday (which was a 50 mg decrease on those days), and he took only 500 mg on Wednesday and Saturday (a 75 mg decrease). His total mgs for the week was 3625 – a decrease of 9.9%. This was almost exactly a ten percent decrease, and although his physical symptoms reflected the daily dose variations, his limbic system never even suspected that some days the dose was smaller than on other days.

Tricking the lizard

Please do not jump to the conclusion that it was always best for the daily doses to be as close in size as possible: there can be advantages in having a much smaller or larger amount on one or two days of the week and compensating by increasing or decreasing (respectively) the other doses of the week.

For example, sometimes a person realizes too late that he is in a Turnaround, on the verge of being overmedicated, and probably should have decreased sooner. Not wanting to be overmedicated, not even for a day, this person could take most of his next week's reduction immediately, over the next two days! This means that there would be two days with a greatly reduced medication level. This could prevent overmedication. Then, during the latter part of the week, in order to prevent sliding into a withdrawal, the person could take just enough medication so that the total reduction *for the week* was only 10%, even though the beginning of the week had almost a 50% reduction rate. Here is an example:

Seventh reduction 3625 mg/**week** ➔ 3275 mg/**week** (9.7%)

Return of dyskinesia!

Continuing along from the previous reduction, Waldo was taking 3625 mg/week. Five weeks after the last reduction, Wilma noticed on Sunday night that after his last dose of the evening he was twitching and grimacing. Waldo had already done the math; he anticipated that he should reduce his medication by 10%, which would be approximately 360 mg/*week* (not day, but week) for his next reduction.

Here was the plan: he was going to spread this reduction of 360 out over the entire week, and reduce by 50 mg each day: 50 mg times seven days in the week would equal 350 mg – pretty close to the target of 360 mg which would have been 10%.

He could do this 50 mg reduction easily; the pills would break into 50 mg units very nicely. This would mean that on the days when he previously took 525, he would only take 475. On the days when he took 500, he would reduce down to 450.

This would give him a reduction of 350 for the week, which was very close to his goal of 360. When he did the actual math, he found that this reduction of 350 mg/week was a reduction of 9.6%, which was close enough to 10% to go ahead. That was his original idea, before the dyskinesia appeared.

However, Wilma was deeply concerned about the sudden reappearance of dyskinesia. She vetoed the idea of a 50 mg/day decrease. He needed to take steps quickly to prevent having dyskinesia again the next day.

Times and amounts

Let's take a moment to explain the time and doses of his daily medication. His 475 mg/day would be taken in this way: 100 mg at 7:00 a.m., 100 mg at 10:00 a.m., 100 mg at 1:00 p.m., 100 mg at 4:00 p.m., and 75 mg at 7:00 p.m.

But because Wilma (but not Waldo) was concerned about the sudden appearance of dyskinesia, the next morning, Monday, he did not take his first pill of the day or his second pill. He only took his third pill of the day and his fifth pill of the day. That meant that he had reduced by 300 mg in one day! If this rate of reduction was continued through the week, he would have been reducing at a rate of nearly 60%! However, they had no intention of taking this rash and drastic step.

Because he had taken only 40% of his daily dose on Monday, he had no dyskinesia on Monday nor any on Tuesday morning after his first dose of the day. However, just to be on the safe side, and thinking that it is always better to be slightly undermedicated than to be slightly overmedicated, Wilma did not give him half of his second dose on Tuesday.

They had been planning to reduce by 350 mg over the course of the week. By reducing by 300 mg on Monday and 50 mg on Tuesday, he had finished his reduction of 350 mg by Tuesday, only the second day of the week! Over the rest of the days of the week he took the same dosages he had taken on those days a week earlier. As a result, his total reduction for the week was exactly what they had planned: a nice, safe reduction of 350 mg. But by jumping quickly into the reduction rather than spacing it out over the week, he never experienced any days with dyskinesia after making this reduction.

By Wednesday he was moving extremely slowly. On Thursday he was also moving slowly, if at all, but by Saturday he was moving so well that they realized he might need to make yet another reduction, sooner than expected.

They had been waiting to see how he felt by the end of the week; if he had been moving more and more slowly by Sunday, he was probably on a mild slide into another very mild reduction phase. If that was the case, he was right on schedule, and his 10% reduction would not be a difficult burden. If this had been the case, then over the course of the next week they could redistribute his reduction to make each day's dose similar to the other days, as they had previously planned.

If, on the other hand, he had been moving well by Saturday or Sunday, or even Friday, what might he do? If he had unexpectedly rebounded smartly from his reduction earlier in the week and was moving well by Sunday, he might need to make yet another

decrease in his drugs. This would indicate that he had gone through an entire reduction cycle in the course of less than a week!

This is often the way when dyskinesia suddenly appears at the end of a long drug withdrawal phase: there may need to be one, two, or even three rapid (less than ten weeks apart) reductions in a row to prevent overmedication. Had he been having dyskinesia by Thursday, after making those powerful reductions on Monday and Tuesday, Wilma might have suspected that he was not Sliding down, but was actually recovering dangerously quickly from his Parkinson's and his addiction; he might even need to have a day or two with no medication to see what was going to happen next. We will consider that contingency in depth later on, when we look at the case study of Viktor. For now, since he was moving somewhat slowly again on Sunday, he stayed at the level of his seventh reduction. He continued at that level for three weeks.

After that first week with all the reduction occurring on Monday and Tuesday, he switched over to a more consistent schedule: for the next two weeks he made the 50 mg/day reduction each day, as he had originally planned. In other words, since after the sixth reduction he was taking 525 mg on five days and 500 mg on the other two days of the week, this time, for this seventh reduction, he took 475 mg on five days of the week and 450 on the other two days. This kept him at 3275 mg/week, as planned.

The reduction was more painful than some of the others. For several days, Waldo was sobbing from pain and immobility. He called out for Wilma to help him all night long. Her journal shows that he called to her for help more than six times an hour throughout the night. He was sleeping in the lounger chair in the living room. He couldn't move by himself at night, and needed help to use the bathroom or to shift from his always painful (despite advil and bedtime brandy) position to another one, equally painful. This extreme level of disability and pain is not unusual with safe, slow drug reduction. He was abjectly miserable, but not psychotic nor suffering life-threatening symptoms.

Only at the end of three weeks at this reduced level of 3275 mg/week was he feeling *almost* good: he wasn't having dyskinesia, his appetite was good and he was finally sleeping again, getting up to five hours of sleep a night. He would have preferred to be getting more sleep, but he realized from talking with other people in the clinic that 5 hours is actually pretty generous during a drug reduction. Waldo did not feel ready to make another drug reduction. Wilma decided he should.

Eighth reduction: 3275mg/**week** ➔ 2925 mg/**week** (10.6%)

Explanation: This week Waldo again reduced by 350 mg/week. Wilma wondered what percent it might be this time if he decreased by half a pill per day again. When she did the math, she found that 50 mg/day was equal to 350 mg/week. When she divided 350 by 3275 the answer was 10.6%: just right! He had been taking 475 mg on five days and 450 on two days of the week. For his eighth reduction, he decreased by 50 mg/day, which put him at 425 mg/day five days of the week, and 400 mg/day on the other two days of the week.

Ninth reduction: 2925 mg/week ➔ 2800mg/week (4%)

Explanation: On this reduction, Waldo and Wilma both wanted to get rid of the annoying quarter pills. They wondered if there was some way he could take the desired amount and be using whole pills or half pills. They figured that, if on the five days when he was taking 425 mg/day, he went down to 400 mg/day, that would be a decrease of 25 mg times 5, or 125 mg. However, a reduction of 125 mg/week was only a 4% decrease. That would not be enough of a decrease to keep with their 10% plan.

However, they considered how he was doing in general; on average, he was making a reduction every two to four weeks, based on the fact that he felt somewhat OK by the end of two or four weeks, experiencing neither Build Ups nor severe withdrawal symptoms. They decided that, rather than wait a full four weeks to make this 4% reduction, one that would bring him down to 2800 mg/week (a neat 400 mg/day with no messy pill breaking), and he would make this small, 4% reduction just ten days after his last reduction.

The reduction went well. However, within a week after making this small, 4% reduction, he had a bit of twitching and dyskinesia on the Sunday evening. Wilma immediately set in motion his tenth reduction.

Tenth reduction 2800 mg/week ➔ 2500 mg/week (10.7%)

Explanation: Wilma enjoyed not having to break the pills into quarters, and so she wondered whether or not he could manage this reduction using only whole pills and half pills. She decided that by reducing by 300 mg this week, he could make this work. To reduce by 300 mg, he could make a decrease of 50 mg on six of the days of the week. That would make it easy: he had been taking 400 mg every day; now he would take 350 every day for six days, and on the seventh day he would take 400. He would be taking four doses a day on most days: three doses of 100 mg and one dose of 50 mg. He decided to take the smaller, 50 mg dose in the evening. This way, he would have more time to rest his brain during the night. Though the smaller dose at bedtime might mean difficulty falling asleep, they planned to have a dinner high in carbohydrates and possibly a cup of hot milk at bedtime. These tricks sometimes enabled him to get to sleep even when his brain was cranking and his body stiff from the lowered dose.

However, because the dyskinesia had reappeared, they had to abandon this nice, neat plan. Instead of spreading this decrease out over the week, he made most of the decrease over the first two days of the week. On Monday, though he did not much like the idea, he only took one dose of medication: his afternoon pill.

We need to pause in this chronicle and take a side trip into dosage timing and amount before we can continue Waldo and Wilma's story.

Times and amounts

When he had gotten down to 400 mg/day, during his ninth reduction, they had rearranged his dosages. Before this, he was taking pills five times a day, every three hours. At the ninth reduction, he started taking his pills four times a day, 100 mg at each dose. He spread the pills out so that he was taking them every three and a half or four hours instead of every three.

Shortly after this time he had started having the extreme fatigue in the mornings that is typical of recovery from Parkinson's. No matter what he did with his drugs, he

simply could not rouse himself at 7:00 a.m. He was terrified, but to Wilma it looked as if he might be in the Deep Sleep stage of recovery. This was exciting: if his body was doing such a lot of repair work, then this was further confirmation of recovery. This was also frightening because he was still taking a considerable amount of medication, and Wilma knew that he needed to be off his medication before his brain started making its own dopamine. He was still taking 400 mg/day, and it might take quite a while to comfortably reduce down to nothing.

Because he was not able to move in the mornings until he abruptly sprang to alertness at 9:30, she stopped giving him his first dose of the day at 7:00. She figured it was just a waste of a pill and a strain on his body to be ingesting stimulants when the body was clearly trying to rest. He started taking his first dose of the day at 9:30 or 10:00 and taking the rest of the day's pills three hours apart. He took a pill at 9:30 a.m., 1:00 p.m., 4:00 p.m., and 7:00 p.m. By having a big lunch at 2:00, a light dinner at 5:30 and a snack at bedtime, he was able to have plenty of protein at these meals without interfering with pill metabolism.

Now, back to their response to the dyskinesia.

Monday decrease (continued)

Because this tenth reduction coincided with the reappearance of dyskinesia, together with the onset of Deep Sleep in the mornings, Wilma felt he needed to try something drastic to bring his drug levels down quickly. The dyskinesia had appeared on Sunday; on Monday, instead of taking his first dose of the day at 9:30, he waited until mid afternoon to take his only dose of the day. In other words, to prevent overmedication, he only took 100 mg for all of Monday.

This certainly worked – he was barely able to move or speak on Monday or the next day. This was uncomfortable, even painful, and he wanted his drugs. Wilma kept reminding him that it could have been much worse; after all, moving and speaking are just functions of his brain's motor area. His limbic zone, the zone that could have sent him into terrors and hallucinations, simply snoozed through the whole thing. He was cranky and in pain because of his relative immobility. His extreme leg pain sometimes reduced him to tears. Even so, Wilma pointed out, he was not in the agonies of withdrawal.

They had planned to decrease by 300 mg this week. Had there been no appearance of dyskinesia, he would have taken 350 mg on Monday. Instead, because of the Sunday evening dyskinesia, he only took 100 mg: a reduction of 250 mg for the week, all taken in one day!

On Tuesday he cautiously took his pills as planned, at 9:30 a.m., 1:00 p.m., 4:00 p.m., and 7:00 p.m., reducing the evening dose, as planned. He had no dyskinesia, so on Wednesday, he started in again to take four doses. However, after his Wednesday 4:00 p.m. dose, he was dyskinetic. They had no idea what to do: if he decreased again, he might risk the withdrawal symptoms that he was trying so hard to avoid. If he failed to reduce and let himself be overmedicated, he would certainly have more problems down the road, as he became addicted.

Social crisis

To make matters worse, his 65th birthday party was planned for the following weekend. Everyone was coming to visit. If he decreased rapidly, he might be a drooling, immobile blob over the weekend. His wife wondered if he should take extra medication over the weekend to be at his "best" for the company, and to take some of the hospitality burden off of her. What to do?[1]

A major social event looming at the same time as dyskinesia appears is a fairly common occurrence. This may be in part because the anticipation of a social occasion can cause an increase in either adrenaline, if stressful, or dopamine production, if joyful. Given this natural increase in mobility during times of emergency and times of gaiety, several people have taken advantage of the upcoming social event to initiate an early drug increase, or even a slightly larger one than usual. I have many such instances to choose from in this composite example that I am writing up here, so I will use in this example the path followed by the person who had the fewest problems.

Brave decision

Wilma and Waldo decided to decrease his medication again. Evidently, even with the large decrease on Monday, he was still showing faint hints of dyskinesia by Wednesday. He was not sure how to proceed at this point, so he averaged the amount of medication he had taken in the last ten days, including his Wednesday medication that had started him twitching. He used the last ten days because that is the average length of time of a Slide, and he wanted to know whether or not he was sliding. Here's how he figured this:

Wednesday	300
Tuesday	350
Monday	100
Sunday	400
Saturday	400
Friday	400
Thursday	400
Wednesday	400
Tuesday	400
Monday	400

His total for these ten days was 3550. His daily average over these last days was over 350. Due to his extreme decrease on Monday, he was already, over the last ten days, averaging 350 mg/day, which had been his goal for this next reduction. Therefore, he might safely assume that he was done sliding, and was nearing equilibrium with the

[1]All three of the people on whom this composite example is based had memorable social crises during their drug reductions. Hjalmar had his 70th birthday party, attended by friends and family. He took an extra 50 mg of levodopa that day though he knew he would be dyskinetic the next day.

Mark had a daughter receiving her Master's degree in two weeks; his wife Margaret said, "I don't care if Mark has to go in a wheelchair, he needs to make another reduction and he will do it. But no matter what condition he is in, we are GOING to that graduation; we wouldn't miss it for the world.

When Sonny started having dyskinesia three weeks before Christmas, his wife Evelyn announced that they would make no decreases until after New Year's Day, because "the holidays are hard enough without having to deal with Sonny going Off all the time."

350/day amount. And yet, even with this new low average, he was having dyskinesia. Maybe they needed to rethink this reduction and do another one immediately. It does often happen that two or three quick, back-to-back reductions in a row might be needed. Maybe this was one of those times.

Why was Waldo so overmedicated, and so suddenly? It could be that the ninth reduction, the one before the last, of only 4% was not adequate. It could be that the upcoming birthday party, complete with grandkids and chocolate cake, was causing him to produce more dopamine than usual. Maybe, compared to his rate of drug decrease, he was recovering far too quickly.

Once the recovery is set in motion there is no way to slow it down. Ceasing treatment will not help. Once the body is given permission to fix the old injury, it charges ahead like a child running to the ice cream truck. Once a person starts to recover, he is going to recover. About the only thing a person can do to slow this inevitability down is take dopamine-enhancing drugs, thereby doing himself a mischief and causing permanent brain damage. In such a case as this, the patient will still recover from Parkinson's, but he will possibly continue having symptoms due to drug-induced parkinson*ism*. Waldo didn't care one way or the other, but Wilma wanted none of this parkinsonism stuff. He reluctantly agreed to make a big reduction in his medication.

Completely ignoring the math, Waldo did not take his morning dose for five days, and he did not take his afternoon dose every other day for these five days. This became his 11th reduction. After his 10th, brief reduction (which had lasted only three days before he was dyskinetic again), he had been taking pills at a rate that would have been 1750 mg/5 days. During these five days of rapid decrease, he only took 950 mg/5 days. This is a decrease of a whopping 46%!

Eleventh reduction 1750 mg/ **5 days** ➔ 950 mg/ **5 days** (46%)

Explanation: In order to be certain to avoid the dyskinesia, which had reared its ugly head within two days of a large decrease, Waldo took the drastic steps described above for five days. Over these five days with the greatly reduced doses, he was not moving well and he was in pain.

Part of the pain was the horrible throbbing he was starting to have in his legs as he regained sensitivity in his extremities.[1] This painful part of recovery seemed all the worse because his brain was accustomed to use levodopa to mask the incoming pain signals.

Levodopa is a mild anesthetic: in addition to weaning his motor area off the stimulation of the drugs, Waldo was also weaning himself off of the sedative effect of the medication. Therefore, in addition to undergoing bouts of immobility and tightening of his muscles (reduction symptoms), he was also experiencing the sharpness of hundreds of reawakening nerves, nerves previously pacified in part by the medication.

This heightened sensitivity, the exact opposite of Parkinson's, prevented him from sleeping. He was becoming exhausted, and Wilma was at the breaking point. Wilma decided to give Waldo a glass of brandy at bedtime.

[1] Restoration of blood vessels, proprioception, and temperature sensitivity in the extremities are some of the most painful aspects of recovery. Unmedicated patients may find these recovery symptoms very painful. A recovering person who is reducing medication may find them even more so.

Alcohol is a very mild dopamine enhancer, compared to levodopa. She was deeply concerned about his developing another addiction, and therefore worried about him drinking the brandy. But when she thought it through, she decided that alcohol, though famous for its addictiveness, would not cause parkinsonism and tardive dyskinesia – two forms of permanent brain damage. Alcohol might affect his liver, but so might levodopa affect his liver. He was up against what she saw as two evils, and alcohol was clearly the lesser of the two. They were both quite gratified to find that he was able to drop off to sleep more easily after a snifter at bedtime. He was able to get several hours of sleep before starting in on calling to Wilma for help "every #%*! ten minutes!"

The Alcohol question

Had Waldo and Wilma thought more deeply about the addictiveness of alcohol, they might have realized that, since he was in a condition of dopamine deficiency during his drug reductions, he was most likely not risking any addiction at all from the alcohol: addiction only occurs when one goes over the Safety Limit, and on these days of extreme drug decrease, with their immobility, pain, and insomnia, he was not anywhere near the Safety Limit. He was on safe territory, as far as addiction was concerned.

Back to Waldo.

Waldo, despite his very large medication decrease, did not fall into the dreaded abyss of drug withdrawal. Maybe he was being helped more than he realized by his slow but steady apparent recovery from Parkinson's. Instead of withdrawal, he merely went through the usual symptoms of extreme pain, feeling helpless and scared, and calling for his wife to help him shift positions throughout the night.

Waldo was in a lot of pain, especially in his legs and shoulders, but everyone else in the clinic who was at his stage in recovery, *whether medicated or unmedicated,* was also experiencing new pains very similar to Waldo's. Wilma decided that the achiness and stabbing sensations in Waldo's legs, his frequent urination, his inability to support his own weight (he was starting to become limp), and his emotional fragility were coming from the recovery and not merely from the drug reduction. He did not have nausea or hallucinations, nor was he shaking violently from terrors. Wilma decided that he was experiencing recovery, primarily, and secondarily experiencing drug reduction. She couldn't be sure, but after meeting with and hearing stories about patients going through addiction and actual drug withdrawal symptoms, she did not feel that Waldo was going through over-fast reduction or drug withdrawal.

Twelfth "reduction" 950 mg/ **5 days** (190 mg/day – his quick, emergency reduction) ➔ 250/**day** (which is equal to 1250/5 days) (This constituted an increase of 31% over the preceding five days, and a decrease of 29% compared to the five days before that.)

Explanation: This was an attempt to moderate between the radical reduction of the last five days. The twelfth "reduction" was actually a slight increase over the amount he'd been taking for the preceding five days. However, compared to the amount of medication he had been taking *ten* days earlier, it was still a substantial decrease. In fact, compared to the amount he was taking after his tenth reduction (2500 mg/week), his new drug level of 1750 mg per week (250 mg times seven) was still an overall decrease of

29% for the last two decreases. This was an average of 15% for each decrease: slightly on the high side, but not extremely so. And now he was down to 250 mg/day, after originally having been taking 1000 mg/day.

He felt he was almost done with the medication. Wilma decided to not give him his morning dose and reinstated his afternoon dose in its place. She used his unmedicated mornings to give them both a more accurate picture of what was really going on in his body than she could have seen had he taken drugs first thing in the morning. He was still sleeping a tremendous amount, and often slept past what would have been his first dose.

Of course, the hardest part was yet to come. We will leave Waldo at this point, because individual cases diverge very quickly from any generalization when the dose gets down to the last little bit. Lets give thanks to Sonny, Hjalmar, and Mark who merged into Waldo while demonstrating the 10% principle and the equally important principle that, despite good intentions and good solid theory, the safest drug reductions do not always occur in a neat straight line.

The last little bit

The reduction of medication from approximately 300 mg/day of levodopa down to zero is a special range. Some people try to go quickly through it. Some people struggle mightily, getting down to zero and then going back to 200 mg/day, and then back and forth between zero and 200 mg several times before they finally stop for good. Others get to 100 mg and go crazy.

In our experience, the most dangerous time is when a person is taking approximately 100 mg/day levodopa or similarly small doses of the other anti-PD drugs. This is when our patients were most likely to want to drop out of the project.

Curiously, this is also the time when spouses and friends would remark, "His brain is back!" It was as if the curtain across the mind that is created by the drugs begins to part, just a bit, when the medication is reduced down to about 100 mg/day of levodopa.[1]

At this terrible stage, a person retreats behind the familiar curtain of drug haze when the drugs kick in and is painfully jerked back to reality when the drugs wear off. This is a different reality than a person had during Offs and times of undermedication when taking higher over-all levels of the drugs.

At higher levels, even though the motor area staggered through Ons and Offs, the frontal lobe of the brain was never actually clear of drug-induced mists. However, when the daily average of medication is at 100 mg/day or less for more than a few weeks, the brain may be somewhat free of the drug now and then, and especially during Off times. These flashes of reality can be very painful for the patient, both emotionally and physically. On the other hand, friends and family are often thrilled or else uncertain how to react to this mixed blessing: the return of the consciousness, the return of "the man I fell in love with," combined with the obvious psychic, physical, and emotional pain being experienced by the loved one. So we will tackle the "last little bit" in a chapter all its own.

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[1] For other medications, please see the individual drugs in the appendices and chapter 17, The Last Little Bit.

Conclusion

In the meantime, I hope that this composite journal chronicling the drug reduction adventure of our fictional Waldo has opened the eyes of anyone who said to himself "10%? OK, that will be simple enough." For anyone who imagined that he could simply do the math, multiply by .1, count fourteen days, do the math again, count to fourteen again, one two buckle my shoe, three four out the door, knit one purl two and be home without a hitch, I hope that this chapter has given you pause.

One test reader asked why I had written the above sentence in closing this chapter, as it made no sense to him. So let me put it another way: if you think that there is an easy, formulaic way to neatly and simply get off the medications, that it will have a neat rhythm to it, like a poem, or that it will be as easy as following a recipe or a knitting pattern, you are wrong.

Reducing dopamine-enhancing medication is very difficult. The brain does not respond the same way every time to the same process. The timing and symptoms of each reduction cycle can be different from the ones before.

Most people cannot do it alone.

Legally, only a doctor can help you and advise you in this extremely difficult process.

What your doctor recommends may be harmful.

If you are taking medication, you are not a good candidate for recovering from Parkinson's disease; you may be better off having Parkinson's disease than recovering from Parkinson's while using drugs and thereby becoming addicted.