

“There are some remedies worse than the disease.”

Publius Syrus’ Maxim 301

8. BECKY AND XANAX

NEW DRUGS, NEW DANGERS, AND A NEW APPROACH

When we last visited Becky, back in Chapter 6, she was taking Sinemet, Xanax, and Benedryl. It was June of 2000. We were just beginning to understand why people were having a hard time getting off their drugs. We were just beginning to formulate time frames for becoming addicted or for the onset of withdrawal symptoms following a drug decrease. Our hypotheses about these drugs, outlined in chapter three, were only partly formed, and tested on too few subjects. The three additional hypotheses from the preceding chapter were still percolating in our minds.

However, we were utterly certain by this time, based on our own experiences and bolstered by our researches into drug addiction and the role of dopamine in addiction, that Sinemet *was* highly addictive, despite the denials of Dr. Leslie and the dozens of other neurologists that we encountered. Becky’s resumption of Sinemet was therefore probably causing semipermanent changes. If you will recall, at the end of Becky’s journal in chapter six, she had just learned that Xanax also was addictive and could cause permanent brain changes.¹

¹ Advantages of Xanax include “rapid onset...and good patient acceptance. Disadvantages noted include impaired psychomotor performance and alertness and the potential for dependence [addiction] and abuse. Treatment efficacy is therefore controversial” (*A Primer of Drug Action*, 2001 edition, p. 106). Becky’s doctor had given a presumed PD patient, one who should have some level of psychomotor inhibition, a drug that *impairs* motor performance, in addition to its being addictive. Xanax is widely advertised as being non addictive. All the scientific writing that we found on the subject says that it *is* addictive.

Because this drug is so widely advertised to the public as being non addictive, I am including in this footnote a longish excerpt from *A Primer of Drug Action*, p.107. This extremely well supported book is a definitive guide for professionals working with psychoactive drugs. This excerpt, which describes the actions of all benzodiazepines, including Xanax, may help you to understand what Becky was dealing with:

“Sleep patterns can be altered markedly. When short-acting agents are taken at bedtime, both early-morning waking and rebound insomnia for the next night are common. When long-acting agents are taken at bedtime, daytime sedation can be a problem. Impairment of motor abilities is common. This impairment is compounded by the drug-induced suppression of one’s ability to assess his or her own level of physical and mental impairment.

“The cognitive deficits associated with benzodiazepine use are significant. In both children and adults, benzodiazepines can significantly interfere with learning behaviors, academic performance, and psychomotor functioning. Cognitive and generalized intellectual impairments can persist even long after the benzodiazepine is discontinued...

“Although benzodiazepines have a reputation for causing only a low incidence of abuse and dependence, the possibility of this adverse complication of chronic use must not be overlooked. When benzodiazepines are taken for prolonged periods of time, a pattern of dependence can develop, even following only therapeutic dosages. Early withdrawal signs include a return (and possible intensification) of the anxiety state for which the drug was originally given. Rebound increases in insomnia, restlessness, agitation, irritability, and unpleasant dreams gradually appear. In rare instances, hallucinations, psychoses, and seizures have been reported.”

Bear in mind that this chapter, and even this entire book, is not written in a chronological straight line. We did not figure out what was going on with Becky as it was happening. Throughout this adventure with the medications we kept learning in retrospect what it was we had been seeing. In this chapter, Becky's journal notes will be interspersed with my reflections, many made in hindsight.

Here is Becky's next journal entry, one week after starting Xanax and restarting Sinemet:

June 27, 2000

A week's hiatus during MM's visit. Just read my previous entry and things have changed drastically. I feel much better now. My Sinemet dose has been cut to 2 or 3/day.¹ Felt rather better during tourist activities and dining out. But today I had a terrible phone fight with my son. When I was very sick I had nearly agreed to live with him, but put that on hold now that I feel better. Now he plans to come here and "see what is going on" as though he believes I am not responsible for myself. We love each other and have nobody else as family, and I don't know where it will all end. I am very upset. What can anyone do? If my son were in charge, he would count my pills and force me to take what the instructions say which is far too much. He claims that I will fall and no one will be with me to help (which is true to an extent). This is the end. I must choose between my son and my life, with no certainty either way.

Please note that she makes no comments about twitching or any other symptoms. During her first few weeks resuming the L-dopa she feels just fine. Due to her concerns about falling down with no one around, she signed up for a monitoring service that calls every morning to make sure she is OK.

June 29, 2000

Yesterday I went to the PD clinic. A visiting Japanese practitioner worked on me. I notice I type better today. The mother/son problem will be dormant for a while. I have worked my Sinemet down to 2 with no serious consequences. I take them at 8:30 and at mid afternoon. I take 1/2 a Xanax at night. Seems to work. One day at a time! This week has been "bliss and bane," in that I enjoyed having a guest but too many things happened at once. I intend to write a statement of my position for my son.

July 1, 2000

Slept well last night with the help of a calcium supplement and a Xanax. Seem to be maintaining OK on 2 Sinemet a day. Am sleeping, to the delight of the cat. Am eating at every opportunity but no weight gain

¹ Dr. Leslie had told her to start at two pills a day and increase her Sinemet daily by one pill a day until she felt better. By the third day, when she was taking four pills a day, she felt horribly overmedicated. She was confused and twitching violently. Her face was grimacing and her limbs were thrashing. She immediately cut back to 2 pills a day and felt saner.

so far, continue to look “scrawny,” a word I hate.¹ Did various small projects like organizing my rolodex phone number file, which I could not have attempted a few weeks ago. Am working up to the idea of washing out my kitchen cabinets (but I avoided this even when I was normal!)

July 6, 2000 (As reported to me.)

“I take the Sinemet at 8:30. Within half an hour all my symptoms are much worse. Then, half an hour after that, everything smoothes out. When the pill wears off, in the early afternoon, I can fix it by eating. I get a big turkey sandwich from the deli and a cold beer. I take the Xanax to get to sleep. It works instantly.”

“Within half an hour symptoms are worse.” This drug initiation and wear-off phase, a half hour or so of discomfort while the medication is starting to take effect or ceasing in effectiveness, will be described more fully in chapter 21. At this time we had noticed the switching on and off phenomenon in other patients, but had not yet named it. The unpleasant Switching occurs at the beginning or end of a dose when the body switches from native dopamine condition to the drugged condition, or vice versa. Becky had been on Sinemet 15 days when the switching started to appear. Based on the appearance of Switching, she was evidently not able to abide even this small amount of L-dopa, but we did not understand that significance of the Switching at this point.

July 8, 2000

For the past 2 days, I have not felt as well as I should. Does this mean that I should bump up the Sinemet dose to 3 a day rather than 2? Didn't sleep so well last night either. Felt the need for a second half of Xanax but didn't take it for fear of addiction. Only taking half a Xanax up until now. Got a haircut and lunch at the local deli. No appetite. Walking tired me out. I am force-feeding myself. I am so sick of the usual and don't feel like doing one of those Julia Child productions.² At 4 p.m. I watched “Oprah.” Go on, laugh, but she supports positive things. The subject was people who stand up for what they believe in the face of powerful opposition. I don't have those kind (that kind...?) of guts! I can't even stay away from harmful medications! I want my comfort. Am going to try to get into a Pilates session again but have not made the move. What does this tell me?

July 11, 2000

Had a call from XX (her son), he plans to visit for two days at the end of this month. “We must have serious talks,” (Whatever that means!). Any attempt to force me to do something will be a violation of my civil rights. What is the legal and medical record on forcing seniors to do what their children find reasonable but the seniors do not? We shall see. Felt

¹ She had lost nearly 15 pounds during her withdrawal from Sinemet. This is due to the nausea, the pacing throughout the night, and the constant shaking. She was 5'4" and down to 105 pounds.

² Julia Child is a famous TV chef.

pretty good today, but the book *Best pills Worst Pills* warns against seniors using Xanax. I only use 1/2 pill at a time and no more than 1 at most. But I already have damaged my brain with that damned Sinemet which I must now use it forever because I was casual in my use of it. I no longer have any respect for the medical profession because they clearly have no respect for seniors and just prescribe anything to get us out of the way. Yes, I am angry. Note about weight: Am keeping steady with nutrition bars and beer between meals. But what happens when I get sick of the taste (which is already happening)? A lot of weakness and not feeling well is the result of unrecognized dehydration and hunger.

In less than a month she has begun to frequently double her Xanax, from half a pill to a whole pill. However, even though she told me and put in her notes that she now takes a whole pill at times, she considers her usage rate to be half a pill.

July 12, 2000

Feel OK, but not as well as yesterday. I never feel quite RIGHT! I suppose I should count myself lucky – and I do – but it gets damned annoying. And it's all so unpredictable. The Breath Monster has been dormant for a while but who knows when it will re-appear.

July 13, 2000

Had off and on breath attacks yesterday, but they passed. Somewhat shaky this a.m. Had a late dinner yesterday which may have accounted for the breath attacks.

July 17, 2000

Slept erratically last night in spite of calcium and Xanax. Took a Sinemet an hour ago. Hasn't done much yet. News! I have gained 4 pounds! The beer and the nutrition bars are doing it!

July 20, 2000

Slept well with half a Xanax. Things are going pretty well. I take 2 Sinemet a day but I am not religious about it. Yesterday I was grocery shopping and wondered why my twitch was so active. I had forgotten about my afternoon pill and was 3 hours overdue. So I took it, late. I look back at the bad times and realize that they were really bad and that I feel so much better now. I consider the twitch minor. I feel pretty optimistic.

Her twitch had been gone, since getting off the Sinemet earlier, and a mere tremor had taken its place. She has been taking the Sinemet nearly a month now, and this is her first warning that the ticcing is resuming. Please note: the ticcing is happening because she is late with her pill, and yet, it only occurs because she has started taking the pills again. This means that the pill is causing the ticcing, even though the ticcing is most apparent (in this early stage) if she forgets to take the pill. Do you see how easy it would be for someone to assume that, since the ticcing ebbs

somewhat after taking the pill, the ticcing is proof that a person needs more pills, not less? But what is really happening is that pill-induced addiction has set in; the ticcing is now her brain's preferred way of complaining either that it wants more drug *or* that it has too much.

July 26, 2000

Read a play from the library, Marsha Norman's "'night, Mother," a play I do not recommend for anyone feeling depressed with a chronic disease, altho' it won the Pulitzer Prize in 1983. Massage this afternoon, and then on to the clinic.

July 28, 2000

Twitch is very active this a.m. Took the usual Sinemet at 8:30 but it did not improve things. Maybe the 2nd one at 2 will at least give the illusion of feeling better.

(No entries during the two days of her son's visit)

August 1, 2000

He left at 7:00 a.m. with cryptic words about "venting the past 30 years." I was not and am not the ideal mom. Enough already! Read an article this morning about Kava which is supposed to do the same thing as Xanax except it is a natural substance and non-addicting. However, you can't take both at once. Question: Is this true? If so, when can you stop taking one and start taking the other? Simultaneously? Taper off? Overlap? Feeling OK.

Over the next three weeks the entries describe the twitch as increasingly active.

August 21, 2000

I always feel as tho' I am working off surplus energy. Went on a Senior Saunter to Lake Lomond today. Fairly strenuous. Must have been 3 or 4 miles altogether up and down. Since the weekend, my twitch has been quite brisk. From time to time it stops briefly, prompting one of my fellow hikers to ask, "You don't twitch any more, do you?" I can get a measure of control over it by an iron will! But it doesn't last long. It makes me feel sort of wobbly-kneed. Is this a new phase? Walking it off helps. Strangely, in the evening, relaxing after a day of exercise, it all goes away.

August 23, 2000

The twitch continues to be increasingly active.

August 24, 2000

The twitch was very strong in my legs and hands. Breath was labored.

The twitching had now moved into her legs, a new development. Over the next few weeks she becomes concerned about the increasing breathing problems – they were the reason she had quit her Sinemet once before.

August 26, 2000

Am tempted yet fearful of eliminating one dose of Sinemet of the two I take. It seems to add to the twitch and it is certainly reawakening the Breath Monster, yet I have had such horrible experiences eliminating and/or increasing it that I hesitate to experiment. Those nights of fear and pacing, sleepless, were too ghastly. Did not sleep soundly last night. Twitch was too strong. Took half a Xanax but it did not work this time. Tossed and turned. Took some calcium. Tossed some more. 4 a.m. got up and made hot milk. It finally worked around 5 a.m. and I woke up at 6:45. All during this episode the twitch was annoyingly subliminal, rippling just under the outer skin.

This feeling of something crawling under the skin is caused by many of the antiparkinson's drugs. This movement is another way in which the brain can try to blow off excess dopamine. It is also possible that it is blood dopamine, and not brain dopamine, that causes the foul feeling of hostile electrical discharge in the skin of medicated patients.

It's now been just over a month since she started back on the Sinemet and began Xanax. She is having good days and bad days. The drugs are not having nearly as much of the desired effect as they had at first. The side effects, however, the switching symptoms, twitching, and breathing disorder, are all back.

Sept 1, 2000

I have stopped taking the Sinemet and started taking NADH, a health food store nicotine based dopamine supplement. Twitch is intensified, but no depression.

Sept 3, 2000

I just took a Sinemet because the twitch is exhausting. I began the day with NADH but it did not do anything.

Sept 4, 2000

NADH seems to stir up the twitch which makes it difficult to write this. Took a Sinemet yesterday hoping it would at least make me feel better (it did not). Took another one this morning but no results. What else can I do? J. said I would be uncomfortable if I tried to stop all at once. That is a mild description! This twitch is getting stronger and more constant. At night I take calcium, melatonin, and Xanax.

Sept 5, 2000

Yesterday it felt like the bad old days of twitching and discomfort so I had wine and cheese and then rice and chili and salad for dinner, ice

cream for dessert. Following all this the twitch and other presumable pill reactions lifted off and I felt nearly normal. Am confused. I started off the week taking 2 NADH and no Sinemet. I twitched a lot and felt symptoms like the Bad Old Days.¹ So I cut back on the NADH and added a Sinemet back in. Had “discomfort.” Is taking NADH and Sinemet on the same day a no-no? Should you substitute NADH for Sinemet? Taper off the Sinemet onto the NADH? I am puzzled by the fact that around 4 or 5 p.m. I feel better and more relaxed. Is this an unconscious relaxation or what? I think the NADH causes twitch. Or is it the length of time between Sinemets?

Feel better after a brief walk, but the twitch is doing something new – it becomes a major spasm. Whenever I woke in the night it kicked in and was very unpleasant. It seems generally worse. The twitch no longer stops.

When I asked her, she was emphatic that stopping the Sinemet did not affect her speed of movement, her voice, or result in rigidity – the classic symptoms of Parkinson’s. Also, she was certain that when she did not take the Sinemet, she had no breath problems and no facial grimacing.

During the few days when she had no Sinemet, she had no foot spasm either. The foot spasm was a brand new symptom that had started about two weeks after resuming Sinemet. Her energy was good, and only one problem was worsened because of having decreased the Sinemet a few times during the week – the Twitch.

In other words, without the Sinemet, she did not have her usual repertoire of excess dopamine symptoms. Her only problem at this time was the twitch, which, due to resumed exposure to Sinemet, now occurred whether her dopamine levels were either too low or too high. The twitch might possibly be a semipermanent condition brought on by the drugs. It also might be her addict brain’s way of calling out for more drug. We had no way of knowing.

We have seen this in other people reducing their drugs as well: sometimes, the symptoms that the body uses to protest against too much dopamine will also be employed during drug withdrawal to protest about too little dopamine.

However, as far as symptoms of Parkinson’s, which would have been characterized by poverty of movement, rigidity, or poor balance, Becky was feeling none. In fact, the NADH, a dopamine-enhancing drug, seemed to make her feel even more skittery than normal. She was walking quite a bit to use up the extra energy. She made a change in her medication: 1 NADH and half a Sinemet in the morning, and a whole Sinemet in the evening. She usually needed a full Xanax now to feel any effect. When she started the Xanax at the end of June, half a pill had worked like a miracle.

Sept 26, 2000

I notice that even the half a Sinemet seems to set off the twitch. The twitch is violent in the mornings. None of the meds help much. Sinemet tames the twitch, but it seems to cause the twitch. This week’s ear acupuncture at the clinic was unusually refreshing. [She had received a

¹ The Bad Old Days is her name for drug withdrawal.

treatment for drug withdrawal symptoms.] The twitch was temporarily subdued. But last night and today the violent right hand/left foot twitch (I will not call it a tremor) is back and very annoying. Just took the morning Sinemet but don't expect much. This has not been a wonderful week. Re-reading *Brideshead Revisited* helped. Evelyn Waugh is a great writer. Wish I could get rid of this new tendency to favor my abdominal muscles for some unknown reason. It affects my posture and walking.

At 2:00 a.m. last night the twitch was horrible, took the usual half Xanax and calcium at 12:30, but they didn't work so at 2:00 took another half.

In hindsight, the Sinemet was probably causing the abdominal spasming.

October 7, 2000

No sleep. Nothing worked, not Xanax, calcium, nor aspirin. Intense twitching, by night and by day.

On Oct 11, in clinic, she told us that since reducing her Sinemet to 1/2 a pill in the morning and a whole pill in the evening, she could stand up straight again, had no Breath Monster, no facial grimacing, and no foot spasm, but she was very grouchy. The acupuncturists at the clinic noticed that there was much less violence to her foot movements this week.

She was having fewer symptoms of overmedication with the seemingly small reduction of half a pill in the mornings. What we learned later was that this reduction of a "mere" half pill, because it was 25% of her total L-dopa amount, was probably more than her brain could handle, thus the extreme twitching and grouchiness. She was five weeks into this reduction – she was at the nadir.

On Oct 12, 2000, Becky read *Prozac Backlash* after a librarian recommended it. This book confirmed her suspicions that Xanax was an addictive drug. She resolved not to take it any more.

The following week at the clinic she reported that she felt more agitated, "yucky, with scattered thinking," and complained more about the twitch. However, our observations and hers agreed that the twitch was actually smaller in power and amplitude. However, she said that after quitting the Xanax, "every little thing is driving me nuts. The twitch is smaller, but it's bugging me more."

This was our first hint that the Xanax may have been contributing to the tremor/ticcing. At this point, I looked up Xanax in my *Physician's Drug Handbook* and found that tremor is listed as an adverse effect of Xanax.

Oct 25, 2000

I need Xanax now and then. If I don't take it every day, it works. Xanax is good for overcoming the twitching to get to sleep and stay asleep but its claims as an antidepressant are not true. I may be damaging my brain further by taking it, but I am 72 years old so who cares? Same with Sinemet; the past two days 1 pill in the afternoon perked me up. So I am a junkie, so is everybody else. We are a nation of junkies. No wonder the

Taliban declared a holy war on us! Wish I could invest big bucks in the pharmaceutical companies so I could at least profit from my own destruction. Well, enuf of this! Somebody cheer me up! I was shaking so bad and in the midst of a panic attack, I took a whole Sinemet instead of the half pills I have been taking.

Oct 26, 2000

No sleep in spite of Xanax, hot milk, and Calm R Rest (a herbal mix). It is now 5:45 a.m. and the twitch is violent. My abdominal muscles are absolutely rigid.

Oct 28, 2000

No Xanax for two days, and no morning Sinemet. Twitch has mainly disappeared but I have a spacey feeling. I am having very different can't-quite-describe-it feelings with no pills.

Oct 29, 2000

Took half a Sinemet in the morning and half in the afternoon. Twitch was fatiguing and violent all day. I've been edgy and impatient all week: apprehension, short attention span. I have to keep pacing or moving unless engaged in something like watching a movie.

At this point she was experimenting with decreasing her Sinemet to try and get rid of the twitch. She tried taking only half a pill in the mornings and a whole pill in the afternoon. She tried the reverse. She tried taking half a pill both morning and evening. Looking back over her notes, she was averaging 1.25 pills of Sinemet per day for the last two weeks.

Some days she felt horrible, hunched over from abdominal spasm and nonstop twitching, and other days she felt long periods of calm. However, the dosage didn't appear to have anything to do with that day's symptoms. Sometimes she was able to sleep, sometimes she wasn't. The Xanax was unreliable as a sleep aid. She felt certain that it amplified the twitch, because in the short term, when she stopped the Xanax, the twitch decreased. However, a few days after stopping the Xanax, the twitch was worse than ever.

The problem was, we had no idea about the delayed responses of the limbic area from Xanax. Xanax is considered to "block limbic arousal." Evidently, with the Xanax gone, her limbic zone was slowly becoming "aroused." The sleeping limbic dragon was waking. We were at that time familiar with the ten week cycle of Sinemet, but didn't realize that with Xanax as well, to best predict what sort of day she was going to have, she needed to be looking at her medication over the past 24 hours, past several days, past ten days, and past 70 days. Also, we hadn't yet figured out that the people who were decreasing without going through hell were limiting their decreases to 10% at a time. We weren't sure if Xanax, like Sinemet, might have a delayed period before the full extent of the decrease become apparent. We just didn't know.

Nov 4, 2000

Taking only 1 Sinemet a day for one week now. I now have a clear pattern of how I feel at this level. I take NADH first thing and then all the nutritional supplements and breakfast. I am uncomfortable and I twitch all morning, just not feeling well. I do not want to take on any new projects. At noon I eat lunch and take 1 Sinemet. This allows me to feel better and the twitch to diminish. It lasts until around 6:00 pm. Dinner with wine extends the comfortable period until around 8 or 9. Mild symptoms until I go to bed at 10 and go to sleep until around 1 or 2 when the night twitch pattern sets in.

Because she had reduced her Sinemet for a whole week, she is now beginning to feel the creeping dopamine deficiency. While this makes her feel lousy, it also allows the afternoon Sinemet to impart a good feeling rather than one of excess. Prior to this, the pills were increasing her twitches. Now that she is in withdrawal, the pills decrease the twitching.

Another way to look at it is this: at the previous, higher dosage level (two pills per day), the morning Sinemet was pushing her brain levels of DA up so high that her afternoon dose was in the excess zone. But this last week, because she was now re-addicted, her baseline level was low; without the drugs, she felt lousy. So now, when she took only an afternoon pill, it merely pushed her up into the effective zone, not the excess zone. Meanwhile, her overall symptoms of overmedication were decreased.

Nov 7, 2000

Got so mad at my clumsiness that I threw the roll of paper towels across the room. Good thing that nothing more breakable was handy! Since our favorite narcotic, Sinemet, gives a few hours of relief, would 2/day be a setback? Is this the junkie talking? I am sick of waking in the night. I took a Xanax, first one in weeks. I slept through until 7:00! I am feeling very down and cynical. Went to the deli for a sandwich and beer. Feel slightly better but not a lot.

Nov 27, 2000

Took an extra half a Sinemet today. Felt slightly better. Keeping to one pill a day is hard. Just reviewed entries since 11-22-00 and realized I have been taking an extra half a pill all week!

Dec 4, 2000

Took Xanax but was plagued by four trips to the toilet in the night. I can't seem to make active decisions. Feel somewhat better but kind of drained of energy. Did not take the half Sinemet in the morning though I feel less than wonderful. I don't feel like cooking.

Sinemet can cause urinary frequency. Xanax had listed adverse effects of slowed reflexes, depression, confusion, unsteady gait and impaired coordination.

Dec 12, 2000

Taking Xanax every night again for over a week, and back up to one and a half pills of Sinemet. I woke up at 1:30 and the twitch was so bad even after taking Xanax that I tossed about for another hour. Then I thought of taking more calcium tablets because I was afraid to take anything else. It worked! That, plus cuddling up with the cat. But I am very twitchy this morning. Violent twitch in the right hand and left foot all morning. I am so sick of this. Days are long.

Dec 13, 2000

I am tired of feeling like hell when I get up after another miserable night of twitching and urination (5 times!) things are not good. When I walk it is as though I am limping and my biceps spasm. I am uncomfortable sitting, standing, or lying. I try to keep active with long walks but it is a drag. I cannot reduce my medication.

Theoretically and ideally, according to Dr. Leslie, I would take 1 whole Sinemet in the a.m., another at 2 p.m. and another at 7 p.m., but past experience with larger doses were not pleasant. But maybe I have changed? Everything seems to aggravate the twitch: too much medicine or too little, too much food or too little, anticipation of any sort, any deviation in routine, etc, etc. Painter came to give me an estimate and my twitch went crazy! Am in denial about the meds and have to face the fact. I am addicted. Now what? Mornings are a dead loss because of the foggy-headedness [a side effect of Xanax]. **THIS ISN'T FUNNY ANYMORE!** On the other hand, it does have the advantage of making most of life unimportant. An attitude of "who cares?" is developing. This is not necessarily positive!

Went to the store to avoid going stir crazy. When I walk my upper arm muscles cramp up and I have to fight walking stooped (or at least it feels that way.) I took my Sinemet this afternoon and it makes me briefly less twitchy but more spacey. It keeps changing its effect over time. Now it takes 2 and a half hours for the Sinemet to kick in. It used to work in half an hour.

This delay in effectiveness is due to the combination of a dropping baseline and a rising threshold, two addiction-based brain changes. The threshold is rising and falling over twenty-four hours but also creeping up semipermanently over many weeks. The increasing night time urination can, of course, be written off to the normal weakened bladder that can come with aging, but urinary frequency is a listed adverse effect of Sinemet, and historically, bladder stimulation was one of the first known effects of blood-borne dopamine.

Jan 6, 2001

This morning I have the usual slowness, lethargy. One can argue that it is the Xanax but it is the easiest of the sleep aids. I am sick of

martyrdom. Xanax makes me feel bummed out. If I am addicted to drugs why can't they be the kind that give a HIGH! Rats! I feel spacey and wasted and lunch was of no avail.

Xanax has listed adverse effects of drowsiness, light-headedness, insomnia, and nervousness.¹

Jan 12, 2001

You can take too much melatonin! I took it several times last night, instead of taking Xanax, and I woke up slow, shaky, and slightly nauseous, and visually bothered. Pill-wise, it looks like Xanax is my only option. My pulse feels like a newly landed fish. That can't be good. I hate this life focused on my physical self! If all this is teaching me some spiritual lesson, the point escapes me. Am going to the hypnotherapist this afternoon. Will be a totally new experience. Have no expectations.

Feb 2, 2001

No more Xanax. I am learning more about it – it is a dead end. The hypnotherapy tape helps somehow. I listen to it at three in the morning; laying on the living room floor the twitching can stop for up to thirty seconds.

Feb 12, 2001

Feeling rotten all week. Got up today feeling lousy. This continued through the day. Felt like my stomach was in a vacuum cleaner. Vision was like I was drunk. Twitch was violent and relentless. Felt as tho I had gotten much worse. The Monster is lurking. I seem to be retreating to the Bad Old Days. The idea of eating gags me. General sick feeling. Mental malaise. All this in spite of taking Sinemet. Sinemet doesn't seem to work lately. Usually it kicks in an hour or two after taking it, but today was just solid discomfort. What's next?

Normally very quick witted, she is not capable at this time of understanding that she might be having drug withdrawal symptoms from the Xanax. I pointed this out to her, and she just repeated to me that she couldn't understand why the Sinemet wasn't working.

Xanax, a serotonin-enhancer, eventually causes a backlash decrease in dopamine levels. The use of Xanax had evidently lowered her baseline enough so that her Sinemet was not able to push her up above the threshold; her drugs appeared to be doing nothing.

In the short term Xanax may boost dopamine by blocking limbic arousal (preventing dopamine from being dislodged from the limbic area, so that the dopamine can accumulate there). However, the brain responds quickly to any sort of excessive dopamine accumulation by instituting dopamine reduction. Hence, the longer-term effect,

¹ *Physician's Drug Handbook*, p. 23.

and the one seen in rats after Xanax experiments, is an overall decrease in brain dopamine levels.¹

Feb 20, 2001

Isolated hours of sleep, but mostly jerking around with no relief. Nothing helps, food nor melatonin nor herb tea. Friends urge increasing meds no matter how addictive. Strongly tempted. I am too old for it to matter. Exhausted. Everything is getting worse no matter what I do. Having trouble breathing.

Feb 25, 2001

I am not twitching. I feel dull and wasted. Some choice! I feel so up and down about this whole thing. It is torture. Two nights of nearly normal sleep.

This was followed by a worsening of the insomnia – the night terrors appeared. The Bad Old Days were in full swing. They lasted for nearly three months. She was maintaining her Sinemet. The terrors this time were the result of quitting Xanax. She had been taking the smallest dose available of Xanax, .25 mg, and she sometimes only took a half of that pill – a mere .125 mg. However, three weeks after stopping Xanax cold turkey, the full battalion of withdrawal monsters attacked.

March 3, 2001

Arm is jerking violently right now. Nothing worked for helping sleep and if I dozed, when I woke up the shaking was as tho professional torturers were at work! Bad night ahead. I am scared to go to bed. It was demonic the way I was jerked into violent shakes as soon as I dozed off last night. This is definitely a repeat of the Bad Days in 1999. I took my Sinemet at 3:p.m. and it only lasted until 7:45 then things went from bad to worse. Listened to hypnotape but was jerked out of calm half way through tape by vicious shaking. The Sinemet is my only comfort. I feel very virtuous not taking more than prescribed. What would happen if I took Sinemet at bedtime? Would this screw up my daytime schedule? At least I might get some sleep.

March 5, 2001

I decided to take something – anything – to let me sleep. I took two Walgreen's sleeping pills² and actually slept. I am still afraid to go to bed. I tried sleeping on the floor like two years ago. I was in de-tox torture but it did not work. The Sinemet is no longer reliable. Muscle problems and breath problems. Breakfast gagged me.

¹ J. Glenmullen, MD, *Prozac Backlash: Overcoming the Dangers of Prozac, Zoloft, Paxil, and Other Antidepressants with Safe, Effective Alternatives*, Simon & Schuster, NY.

² Diphenyl hydramine (Benedryl).

March 8, 2001

Torture! Constant twitching. No sleep at all in spite of melatonin, aspirin, herb tea, rice cake, and finally, half a Xanax (sorry)! How long can this go on? To death? I am desperate. Without sleep, time sort of blends into one stream. Very confusing. I feel awful.

March 12, 2001

As the evening Sinemet wears off I have snakes crawling under my skin. I can't eat, sleep, or read. Lost 2 pounds. I am sick and miserable all day. The ear acupuncture is confusing; it calms my twitch but then I feel drained of any energy. I dread bedtime. The bedroom has become a torture chamber. Sleepless horror. My muscles are spasming.

On March 12 I shared our team's observation that patients seemed to do the best who never decreased a drug by more than 10% at a time, and that it appeared that there might be a ten day period before one could assess whether or not a drug change was going to bring about an effect. Her previous rates of decrease, 100% or nothing, had not been successful with any of the other pioneers. She decided that she would try a slower method of reducing Xanax. She decided to take half a Xanax, twice a week, and see if the drug withdrawal decreased in intensity. The first pill helped her sleep for a few hours.

March 16, 2001

I took a whole Xanax and got a good night's sleep. But the shaking goes on violently when I am awake and I continue to feel awful. My legs and arms are so tired. I think we are on to something with this half a pill twice a week.

March 19, 2001

Took Walgreen's¹ and got a decent sleep. It is stronger than the twitch. Felt draggy but better than with Xanax. Definite link between amounts of food and fatigue level.

March 22, 2001

Felt as near to normal as I have felt in a long time.

Violent twitch in right hand all day but I'm eating again – Gained 2 pounds! Still feel pretty good after a long day. Walked as much as possible all day. Things began to smooth towards evenings.

March 25, 2001

Two Walgreen's made me sleep "normally" but was twitchy and still am. Restless twitch during hypnotize so it was useless. I HATE MY LIFE AT THIS POINT! Unclear thinking, unclear vision, uncontrollable twitch...What is next? All I can do is primitive housework. It is God's punishment (Ha!) for being a slob all my life because I sneered at

¹ Diphenyl hydramine (Benedryl).

housework. Terrible headlines in the paper: people are damaging their livers with Tylenol! What will they discover about Sinemet?

April 2, 2001

Slept comparatively well with 2 Walgreen's and a cup of hot milk. Felt shaky in the morning but it passed. After Pilates I felt fairly decent. (Tho I still shake.) I don't have that faint nausea.

Two weeks later she had a panic attack, not unusual during drug regime changes, and two days after that she slept through the night with no sleep aids whatsoever. After that point she started noticing a slight improvement in the ratio of good nights to bad nights. She was taking Xanax twice a week.

Although the drug literature states confidently that benzodiazepines neutralize the effect of Sinemet, based on the old (and unproven) "serotonin is the opposite of dopamine" theory, Becky found that now, after a night with Xanax, her Sinemet worked better.

After three days without a Xanax, the effect of the Sinemet was lessened. When, once a week, she went four days without a Xanax, the Sinemet did not work at all: she would be in slow motion and exhausted all day. Despite the current drug theory, Xanax seemed to augment, not neutralize, Sinemet.

She was having vision problems during this time: objects would transform into fantasy objects now and then. On April 23 and 24 she slept well, two nights in a row! She had no more hellish nights until April 30. On April 30 she had all the old symptoms of Sinemet excess: breath monster, snakes under the skin.

She stopped the Xanax completely at this point since it seemed that the Sinemet was now excessive again. The Sinemet *excess* problems had been barely noticeable while she was going through withdrawal from Xanax. Now that she was sleeping better and the Xanax withdrawal was behind her, the Sinemet was once again working very consistently; in fact, she was starting to have signs of excess Sinemet. She went from .125 Xanax twice a week to none, and with the aid of various other sleeping aids, she was able to stay off the Xanax completely.

This transition from overmedicated to undermedicated during a withdrawal, and then a return to overmedication at the new, lowered drug rate, will be discussed fully in chapter 14, *Cycles of Change*. After reading that chapter, you may wish to reread this chapter on Becky and Xanax – it will make much more sense in retrospect.

Summary

Becky's drug experiences:

Spring, 1998: She started our program and immediately began making very small decreases in her Sinemet. She had mild symptoms of lethargy and fatigue that passed within a few weeks of each decrease.

First of October 1998: She was symptom free and taking no medication.

Late October 1998: She took Sinemet for one weekend; her son was visiting and she wanted optimal energy to flaunt her newly-returned health.

Late October 1998: She found she could not stop taking Sinemet.

Mid-November, 1998: She developed a ticcing pattern that is still present. She was unable to stop or decrease the Sinemet.

September 1999: She developed breathing distress. Her ticcing had become quite violent over the last year. She had tried many times to reduce her medication and failed. She had even caught herself sleepwalking to take Sinemet at night.

October 8, 1999: She abruptly stopped taking Sinemet.

October 16 to February 2000: She suffered severe withdrawal symptoms, including hallucinations, extreme insomnia, and violent ticcing.

February 2000: The ticcing made sleep difficult; she started over-the-counter¹ sleeping pills.

April 2000: She realized the sleeping pills were causing her foggy headedness and confusion. Her pharmacist confirmed that these pills did have those side effects, and that they were addictive.

May 2000: She abruptly stopped the sleeping pills. This aggravated her ticcing and the extreme insomnia returned.

Late June 2000: Her son was coming to visit. She was afraid for him to see her in her exhausted condition. Her twitching had calmed down and was once again a mild tic, larger than a tremor, but not violent. Her neurologist prescribed Xanax and Sinemet. For two weeks she slept well and she did not mind, or even notice, that her ticcing was increasing in power.

July 2000: The Xanax was no longer as reliable for inducing sleep. The ticcing was worsening. The breathing distress began to return.

September 2000: Ticcing worsened within half an hour of taking Sinemet. Severe insomnia had returned. She felt sluggish and mentally slow (side effects of Xanax). She tried to reduce Xanax intake and failed.

November 2000: She attempted to reduce Xanax and/or Sinemet. All her methods were too abrupt, and she could not sustain the reductions. She seesawed back and forth, sometimes changing her drug regimen on a daily basis in an attempt to find stability with the drugs.

March 2001: She began a slow method of reducing Xanax and started taking over-the counter sleeping pills. While reducing Xanax, Sinemet benefits diminished.

April 28, 2001: She felt that the worst of the Xanax withdrawal (dopamine deficiency) symptoms were behind her. She had two days of feeling good.

April 30, 2001: Symptoms of overmedication from the Sinemet began: dyskinesia, cramping, and breathing distress. She had not had these particular symptoms of overmedication since she began trying to reduce her medication in November, 2000.

Becky had spent nine months attempting various methods for reducing Xanax and had been in misery during most of that time. She had experienced classic symptoms of addiction with the Xanax: 1) she had needed to increase her dose to maintain effectiveness, and 2) she experienced physical, mental and emotional symptoms of drug withdrawal when she stopped taking it. (Dr. Leslie had been enraged when Becky had asked if Xanax was addictive.)

¹ Over-the-counter means non-prescription. These sleeping aids were supposedly mild.

Basically, in May 2000, to help her with her drug withdrawal from Benadryl, a mildly addictive, over-the-counter pill, her doctor had given her a highly addictive, serotonin-enhancing, dopamine-altering drug, in conjunction with Sinemet, a DED. This led to symptoms of overmedication within a few short weeks.

Following her decrease in Xanax, during the depths of the drug withdrawal (when her baseline was still very low), her Sinemet did not appear to be helping. As her baseline slowly crept back up after ten weeks of withdrawal symptoms, her Sinemet was able to now breach the effectiveness threshold, and she perceived benefits from the pills. As the baseline continued to rise, she began noticing symptoms of overmedication again, as her daily doses pushed her up into the excess zone.

Becky is a humble, wise soul. Her self-deprecating sense of humor and her determination to help others by objectively chronicling her experience carried her through. Becky was the only person in our program, at this point, who was able to survive more than two years of drug reduction trauma, and she did it while living alone. Some of our other patients who had recovered from Parkinson's and started showing severe symptoms of drug excess had been at this point in and out of care facilities or were dead.

By the beginning of May of 2001, Becky and all of the pioneers had learned a lot about the medication. She understood now that her Sinemet was causing her ticcing (twitching) and the snakes crawling under her skin, and that it was contributing to her insomnia. She understood that she would probably always have some form of ticcing – the semipermanent result of having ever, however briefly, taken a dopamine-enhancing drug when she no longer needed it. She started a slow, 10% program of reducing her Sinemet and the rest of the Xanax. After every 10% reduction, she felt on the verge of slipping into the hell of withdrawal, but instead only hovered on the edge. She fought various degrees of depression, sluggishness, confusion, physical discomfort, and insomnia, depending on where she was in the reduction cycle, plus the twitching and ticcing that may well follow her to her grave, medicated or not, but she never descended into the full demonic agonies again. Every time she began to feel the slightest bit normal, she made another 10% reduction in her drugs.

By February 2002, Becky had not taken any Xanax for over six months and had been taking only 50 mg of Sinemet *one day* a week – practically nothing – for several months. She was no longer having drug withdrawal symptoms. For nine long months in 2001, from April until December, while carefully but steadily reducing her medication no more than 10% at a time, she had been hovering near the edge of drug withdrawal.

In February she was haggard, but her voice was strong and her stride was long when she made the effort; she had been plagued by “baby steps” since the Xanax reduction. While baby steps still occurred in times of anxiety, she was usually able to prevent them by paying attention to her posture. She had no slowness of movement and no balance problems. However, she was hunched forward somewhat, and sometimes tilted to one side. She now used a walker “just in case.”¹¹ She was gaunt and had no stamina. Some days she walked several blocks to the library, the deli, or the drugstore and back, but other days she napped and pattered in her apartment. El Twitcho still appeared for five to thirty minutes when she first woke from sleep, and shook her “like a

¹¹ A “walker” is a four-legged walking aid that is pushed in front of one to provide stability.

rat” at times of great anxiety, but most of the time her shaking was once again a mere tremor.

She had aged. A person meeting her for the first time would have admired her hearty laugh and zestful appetite for life, theater, good friends and good times, but would have guessed, not incorrectly, that she had suffered much. Her eyesight had deteriorated during the preceding two years; she had been diagnosed with partial retinal detachment. Though her eyes were still bright and laughing, a gaze deep into her eyes revealed the inner weariness borne of too much pain and fear. She was easily exhausted and badly emaciated. On days of extreme weakness, it was an effort just to make herself a meal. Sometimes it took her two or three tries to hoick herself up out of a chair. But she was drug free and feeling more in control of her life than she had been in three years.

Here are her chart notes from that time:

Sleep is better, though still up every hour to pee after 2:30 in the morning. No more pacing the floor, though there is some twitching, tossing and turning in bed. There is no more of the violent shaking. It’s gone. I only have the small tremor, and even that is much smaller than it was. It’s the worst at meals – my food falls off my fork. My appetite is good but I can’t gain weight.

She felt promising surges of strength. Her eye doctor suggested that her retinal problems might respond to something as simple as an increase in leafy green vegetables. In early February 2002, she was more optimistic than she had been in years. And then, in late February 2002, her stalwart troop of friends, concerned about her frailty, weight loss, and fatigue, issued an ultimatum.

Becky’s story will continue in chapter 24.