

*“O Sleep, O gentle sleep, nature’s soft nurse!
How have I frightened thee,
That thou no more wilt weigh my eyelids down...”*

Shakespeare’s King Henry IV

6. BECKY’S JOURNAL

HER WORDS, HER DRUGS, HER SLEEPLESS HELL, HER HOPE

Now that we have a shared vocabulary, we can continue with Becky’s travails from chapter 4. The following is Becky’s journal notes, interspersed with my notes.

December, 1999¹

12-12-99

Took a total of 4 TPM (Tylenol PM) last night and they finally knocked me out around 4 a.m. I also had some hot milk. Woke up at 7:30. The Breath thing is still on the edges but it did not trouble me this a.m. so far. Just writing or talking about it seems to bring it on. The twitch comes and goes, never entirely disappearing. I thought of going to yoga but...no way! I am tired of feeling sick! I am actually reluctant to go to bed at night because I am so fearful of the Breath thing. During this whole ordeal I have become aware of death being close by. Philosophically good but unpleasant to live with. Called X for a little verbal sympathy. AB called and we went shopping and to tea and then on to her house for dinner. The unpleasant symptoms faded and I felt nearly normal. I think this is a lot psychological. Later had a phone conversation with X which boosted morale a lot.

12-13-99

Good night’s sleep even w/cat on the bed! This a.m. I have the usual twitch and to a certain extent, the breath thing, but it is cut down to size. I am no longer panic-stricken by it. Zoe called. She is having a much worse time than I have had so far. Zoe is now up to 20 L-dopa pills a day. Don’t know what to tell her. 2:30 p.m. breath thing is trying to seize control (and) Twitch is active. I am bored just doing odds and ends. Not one of the better days. A cup of chamomile tea seems in order. That, and the heating pad helped.

Note that, at this point, nine weeks after stopping her drugs, she is having a pretty good day, with no pacing or violent breathing problems, and the twitch is coming and going. She is even settling down for a cheering cup of tea. Yet, in her discussions with me at this time, she cannot remember that it was much worse just a few weeks before.

¹ These journal entries appear as Becky wrote them, except for occasional additions (in parentheses) for the sake of clarity. Names, as in all the case studies, have been changed.

She has no sense of improvement, no idea that anything has changed: she is morose. This is typical. An absolute loss of perspective occurred during her withdrawal, and when I would read her notes back to her from the previous week or even the previous day, she was always amazed that her condition had been changing. After the ten-week period passed, she experienced a clearing of the mental mists and she began to have some perspective.

12-14-99

Woke up around 5, got up at 6. Dare I say it? I seem to have gotten a handle on the Breath Monster. My diaphragm muscles don't seem so flaccid. Now I must work on the twitch! It makes my hands uncontrollable, my legs quiver and my teeth chatter. Yesterday at dinnertime I got really hungry. I went to the store and got a salmon steak, broccoli, red potatoes, carrots and ice cream. I dined in luxury! I am sick to death of frozen dinners. Today is Pilates¹ day. Forgot to go last week.² Talked to Zoe on the phone again. She is having a very difficult time. She is unable to do without the meds, yet they don't help. This is a hideous disease! The Breath monster is back. I am trying to ignore it, hoping that the brisk walk to Pilates will defeat it. I think I ate too much lunch.³

12-15-99

The Pilates and the walk made me very hungry and I kept snacking even after dinner. Bed at 11 and slept until 2:15 without TPM.⁴ Twitch kicked in vigorously and only after 2 TPM and a cup of warm milk did I manage to go to sleep again, comforted by the cat. Woke up at 7:30. The breath thing was happening. Ignored it as much as I could and had breakfast. It is still prowling around the edges. But I have things to do. Yesterday was a fairly good day. Today has not started as well. The twitch is active. I still weight [sic] the same in spite of eating more. However, I am feeling much more normal nearing the end of the 10 week torture of withdrawal from Sinemet. Where do we go from here? (later, 4:50 p.m.) It turned out to be a bad day. The Breath Monster took over completely. All I could do was sedentary things. But at dinner things improved briefly. Now it is back.

And so, as if a cloud of terror was lifting, she started to feel better. December 15 was nine weeks and five days after stopping her L-dopa, and her weekly report was starting to show that she was living again, getting out, eating, and talking about the Breath Monster as a not unconquerable adversary.

¹ Pilates is a form of exercise that works on developing muscle symmetry. She regularly went to yoga or Pilates or various programs if she felt good enough to get out.

² She had been in no condition to go.

³ This report excited me: she was eating well, she was going to exercise, and most importantly, she was thinking in terms of defeating the Breath Monster, whereas in the past she lived in dread of it. This signified a major attitude and perspective change.

⁴ This was the first time since she started using sleeping aids that she had fallen asleep at bedtime without some pill. She still needed a sleeping aid after waking at 2:15 a.m..

Over the years, I have learned that ten days to ten weeks isn't a strict boundary of the bad symptoms; it appears to be more the beginning and end of the period of bleakest despair. It is the time when a person will say, "What the hell! What does it matter if I die a junkie, what does it matter if I take just one pill?" This is the time when the brain is arguing with itself, whispering words of hopelessness into the ear. The end of ten weeks doesn't mean that the problems are gone; it appears to be the time frame in which the positive voice of reason starts being able to stand up now and then to the voice of despair. The battle is still difficult, but after ten weeks, he may be able to remember with a bit of clarity why it was he started the fight. He starts to get his brain back.

Around this time, we started tracking the ratio of good days to bad. Slowly, over weeks, Becky went from two good and three bad days to two good and two bad. And then, she went from two good and two bad days to three good and four bad, and then two good and one bad. We shook hands and exchanged hugs when the ratio of good to bad finally became reversed so that the good days were outnumbering the bad. She had daily struggles with her new outspoken negativity, something that she had never experienced in her life prior to her recovery from Parkinson's disease. She could never shake the feeling, on her good days, that she was going to be punished for them sooner or later with a bad day. And the bad days were pretty bad. On a good day she would visit her shut-in friends, take in a play, a community event, walk along the beach, go out to lunch with some friends, or dinner and a movie. On bad days she would have difficulty figuring out how to eat breakfast; she would pace and gasp, twitching and grabbing at her waist; she would have no appetite and no interest in the outside world, feeling too scattered to read and hating the television; and she was afraid to go out for fear of a vague something that she could not identify. The insomnia continued. She usually took two Tylenol PM at night and two again at 2:00 in the morning, for a total of four a night. The package of TPM says to not take it for more than two weeks. She had been taking it for nearly two months. I was concerned about the Tylenol PM, but she was at least getting some sleep.

January, 2000

1-7-00

Nothing unusual...(The) twitch is annoyingly active but got chores done. Left message with neurologist telling him that I have not taken the Sinemet and a follow up app't is not necessary. He will probably be mad.

1-8-00

Last night I went to a play. It was opening night and a wine buffet was served. Was very hungry and ate a lot. I got a teeny bit tight and felt very mellow (did not make a fool of myself to my knowledge). Twitch was noticeable but subdued. Breath monster was completely dormant. I did not try to hide or excuse my twitch. Relied on friends to fetch and carry for me (very uncharacteristic!) Had a great time! Home to bed w/o pills. Woke up late with violent twitch. Took 2 TPM and slept thru the night. Woke up at 7:30. Noticed times when there WAS NO TWITCH. As soon as I realized it the twitch came back violently. Very slow and clumsy this a.m. Checked bank statement and realized that I don't do this

sort of thing well. No patience for figure work. Said to hell with it. Uncharacteristic! It is noon and I had lunch. Eating helps. Good days seem to alternate with bad ones. I am very tired but lying down is no good either. Too much twitch. Will take a walk later. Can't concentrate. Brain has turned to mush! Feel depressed. Not a good day.¹

In late January her son called and pressured her to move in with him. Becky suspected that his motive was less than altruistic: he had figured out that it would benefit him financially, somehow, to have her as a dependent. This sent her into a spin of horrible days, with twitching and restless legs at night, plus insomnia that didn't respond to anything. She had terrible muscle spasms in her arms and legs, shaking her "like a terrier shakes a rat." She walked for miles that next day, to wear herself out and calm herself down, but it didn't help. She had two terrible days, but then she wrote the following entry.

1-27-00

(I) feel fairly OK. Re-read my journal for the week, JW-H has nailed the symptoms right on (I had read to her some material on drug withdrawal.): breath monster, spasms and all. Yesterday and the day before were very bad. Today should be OK if the pattern holds. Must get as much done as possible while I feel fairly good.

Halleluiah! This was a new attitude! It was the first time that she had been able to review her previous days and realize that there was a pattern, and that she could expect a perfectly good day during which she would be functional. It was an exciting time because it meant that the brain haze from L-dopa and from withdrawal was lifting. Once she was able to see the big picture again, we hoped she would be more emotionally stable. She was working with a hypnotist to help her with her insomnia, and she was practicing visualizing herself being calm and relaxed.

February, 2000

In February she started to realize that she could not sleep without Tylenol PM. She was taking up to 5 per night. On 2-3-00, she wrote:

I have changed pills. TPM taken in frequent doses is hard on the liver I hear.²

She stopped taking the Tylenol PM. On her own initiative, after consulting with someone at a nutrition store, she switched to an herbal product, Calm-R-rest. Four days

¹ Two months earlier, she would have been grateful for such an uneventful, ordinary day.

² Acetaminophen, the active ingredient in Tylenol, can cause liver damage and death if taken outside prescribed guidelines. In an FDA study of 300 cases of acute liver failure, 38% of these failures were associated with excessive acetaminophen use. Most over-the-counter guidelines suggest a limit of two weeks of Tylenol. I.K. Smith, MD, "The Tylenol Scare," *Time*, April 9, 2001. (The page number for this citation is not on my photocopy. Sorry. The article is in the "Personal Time: Your Health" section of the journal.)

after stopping the TPM, she began suffering terribly, possibly from the abrupt change in her sleeping aid. This was her first experience with drug withdrawal shock from a non-prescription, over-the-counter drug, and one that was not, in theory, a dopamine-enhancing drug. Note that her symptoms of drug withdrawal are the same as the symptoms for dopamine abuse. One possible explanation is that, because these drugs ease pain, a role normally played by dopamine, her extended use of this drug was allowing dopamine to be redistributed in the limbic area. Then, when she abruptly stopped this drug, the limbic system was overexposed, leading to those drug withdrawal symptoms that are normally associated with dopamine-enhancing drugs. In her case, the withdrawal from Tylenol PM most closely resembled the withdrawal symptoms from heroin, another pain sedative. With heroin withdrawal, insomnia and hypersensitivity are the dominant problems.

Again, please note that during this time her voice was vibrant, and her speed of movement was normal, maybe even exaggerated. Her posture was fine, except when she was attacked by the diaphragmatic spasms of the Breath Monster. Her symptoms did not resemble those of Parkinson's in any way except for the violent ticcing, which bears a superficial resemblance to the tremor of PD. Based solely on this twitch, her neurologist was always certain that Becky's Parkinson's was worsening.

2-1-00

It is 2:55 a.m. and the twitch is so bad I cannot sleep since I woke at 1:30. I have taken hot milk, aspirin, and herbal relaxant to no avail. I have prayed, I have paced. The Breath Monster has taken hold after a day's respite. I can't go on like this. I can't visualize. I am afraid to take sleeping pills. HELP!

(9:05 a.m.)

Oh well, I took the sleeping pills and they worked eventually. I got about 1.5 hours more sleep. I dread bedtime. Why do the shakes torment me at night worse than in daytime?

And so it went. During withdrawal from Tylenol PM, the insomnia was the biggest problem. She started experimenting with sleeping aids, NADH, L-phenylalanine, L-glutamine, vitamin C, progreens, vitamin E, multiple vitamins, and Octacosanol. The rigidity and bradykinesia of PD were not an issue, and she had a strong voice and good muscle control when the shaking stopped. She was clearly not a vibrantly healthy person – she was exhausted and twitching. But she did not fit the picture of unmedicated Parkinson's disease. And at last, the ratio of good days to bad days was slowly, over weeks and months, beginning to improve.

At the end of February, she noted that she was beginning to feel a bit more normal and she was panicking less. Her shaking and twitching were milder on 2-24-00 than they had been since September of 1999, just before she had realized that the L-dopa was causing the twitch and she decided to quit the drugs. It had been five months. The five months number struck a chord with me: one of the patients in Oliver Sacks' study on L-dopa had developed hallucinations and was therefore taken off the drugs. Though this patient's hallucinations decreased in intensity after stopping the L-dopa, they had continued for five months. I wondered if the five-month number was significant. Since

then we have seen a few instances when a person appears to go through a sea change after five months, in addition to the ten-week changes.

March, 2000

In March, Becky had some nights that she recorded as “almost normal.” One night she slept until 5:30 in the morning. She noticed that while watching movies on television, she twitched during the high emotion moments, and she also noticed that she was becoming better at controlling the twitch for short periods of time via relaxation techniques. But there were still many bad days, especially if it was rainy and cold. She kept daily notes, but I am selecting bits and snatches that capture the tone. (Writing up all her notes would create a 300-page book.)

3-15-00

Foggy (weather-wise and mentally!). Slept fairly well (10:00 to 4:45 when the twitch became active). Got a supply of Walgreen’s sleeping pills (generic Benedryl)¹ and will try using them as a tranquilizer. It seemed to work on Mon. No I won’t depend on them. I got my lesson through Sinemet!² Since last week I really think something changed for the better. After the last acupuncture treatment it was like a curtain going up.

3-23-00

A good week!

April, 2000

4-3-00

The good news is that for about 3-4 days I have had no breath problem. Also, I am not so tired. My appetite is better. What remains to be dealt with is the shakes, weakness of the muscles, and energy level.

4-5-00

The shaking now sometimes retreats to just my right hand or left foot.³

4-6-00

During visit to acupuncture office 50% of the time the right foot and left hand were NOT moving, only the R hand L foot was going.

4-11-00

I take back that earlier observation that I have turned a corner to recovery. This last week has been discouraging. But I can only continue

¹ The active ingredient in Benedryl is Diphenhydramine Hydrochloride. In this book I will refer to this drug as Benedryl, a patented name, but one that, through usage, is nearly synonymous in the US with Diphenhydramine.

² These are prophetic words. She did in fact become addicted to the Walgreen’s sleeping pills.

³ It had been whole body shakes most of the time, ever since the second week of withdrawal.

on this path because any other is a dead end. (Ha, ha, we are all indeed dead in the end!)¹

4-12-00

Slept soundly from 10 to 6:30 with only 1 trip to the toilet. Shakes were much improved. WHAT DID WE DO RIGHT?

Now she was able to predict the specific times or events when the twitching would be bad: when talking on the phone, waiting for the bus, or upon first awaking at night. The breath monster was long gone. Two times during this week, the twitch just stopped, but when she realized it and marveled at it, it resumed.

By late April the twitch was stopping more often. If she used her arms or hands, the twitch would stop, and she could pick up a teacup without spilling. It had almost become a resting tremor. This tremor was slightly larger than her tremor of a year ago, as should be expected: dopamine-enhancing drugs can cause or worsen tremor, permanently. A few times a day, most notably upon waking, adrenaline tremor was very strong, nearly violent. It took over her whole body. It seemed to last about half an hour, but by watching the clock, she learned that the strong shaking only lasted a few minutes. The twitch stopped completely now and then during the day. If the breath thing ever did appear, it would last for one breath or two, a moment of slight tension in the diaphragm, and then disappear.

In late April she also started noticing an increased fuzziness in her head. We were to learn that this was coming from the Benedryl, but we didn't figure it out for some time. She was feeling more depressed. Also, when she felt agitated from insomnia or because the mental fuzziness was bad, a twitch would start up. The ticcing twitch seemed to have become her body's answer to any problem.

4-25-00

Tired, cranky, and unwell. I want energy and optimism! I had a horrible night. I felt like Galvani's frog and still do. Muscles ache from spasms. None of the usual remedies work. Don't know how I will get through the day. It feels like the Bad Old Detox days

May, 2000

5-3-00

More of same! How long, O Lord...? I have gotten to a point during this week where I cannot function and it seems to be getting worse. I can't read write or move comfortably. Help! I dread tonight!

On 5-4-00 she read the insert on the Walgreen's sleeping pills (a generic type of Benedryl) and realized that they were probably causing her increasing drowsiness and fuzziness. By the way, neither drowsiness nor fuzziness of the head are symptoms of PD. PDers tend to be restless more than drowsy, and intelligent rather than dull. She decided

¹ Reading the preceding days of the week, she had actually been doing very well and had only started feeling depressed the evening before, following getting chilled at water aerobics. Getting chilled is very hard on the dopamine balance. The next day she was doing well again.

to stop taking the sleeping pills. Because they were sold over-the-counter, she assumed that there would be no problem with reducing them all at once. She was wrong. It was pure hell.

Without Benedryl she was unable to sleep for more than a few minutes. The sleep deprivation led to panicked, nearly delirious exhaustion. For five days she slid towards withdrawal symptoms, worsening every day. She went from groggy to hyper-alert, and all of her Pavlovian (learned) symptoms for drug withdrawal reappeared.

5-9-00

I don't know what to do next! I even considered going back to Sinemet. There would be moments of "normalcy" at least. But "I have set my life upon a cast, and I will stand the hazard of the die!" (*Richard III*). Pilates this afternoon. It is a losing battle.

5-10-00

In spite of St. John's Wart tea I feel very depressed (and) I am tempted to go back on pills in spite of the horrors. I feel that it can't be that long to my end. Why suffer? If I were younger and had long life ahead things might be different. I don't see well either. How can I get relief between treatments? How can I evade the demons? Constipation might be a problem, having just had a bout with it. I have become fearful of mainstream doctors who only adhere to the pharmaceutical companies' party line. So I talk about taking their pills but probably won't. I notice occasional quiet moments before dozing off, but then the demons jolt me awake. Life was so great before this rotten disease! Yeah, that's what they all say! At night I gravitate among my bed, the floor, the chair, and pacing. During the day I have tasks to distract me.

5-16-00

WHAT CAN I DO? Faint nausea. Sleepless night. Violent twitch. I feel awful. Can't do or think anything. Nothing helps. Is death near?

5-17-00

Went to bathroom several times at night but otherwise slept fairly well. Twitch still violent in arms and legs which exhausts me day and night. Wine and food help. I could become an alcoholic easily! On the whole I do not feel well; what can we do?

5-18-00

Sometimes I can swing arms, but then, suddenly biceps seize up. Have to take a deep breath, relax, then it's OK again for a few minutes. Also, severe dry mouth wakes me up. Mouth is so dry it crackles. It's tight like shrink wrap. A sip of water dissolves it, and then I'm fine.

My own notes for that day say that her eyes were less terrified, and she was making more jokes.

5-20-00

Slept OK in spite of forgetting to take my calcium at bedtime!

She began having alternating bad and good nights of sleep around this time.

5-24-00

Slept erratically, feel very bad today. Violent shakes, breath demon, slowness, faint nausea. No relief in sight. How long will this go on? Will I even be alive next year? I need to sleep but fear bedtime.

She decided that she was suffering more from the withdrawal-induced insomnia and the terror than she had been from the drowsiness and mental confusion of the Benedryl. The sleeping pills were a lesser evil. She gave up the fight after three weeks of withdrawal from Walgreen's sleeping pills.

5-29-00

The last two nights I have gotten a whole night's sleep with the help of the sleeping pills¹ which may or may not be harmful. At this point, I do not care. The message from the medical establishment is "Life's a bitch and then you die." Thanks, doc!

5-31-00

Asked the pharmacist about over-the-counter sleep pills.² [His answer was,] "Highly addictive!" More despair! Massage this afternoon. Maybe that will help. The worst part of all this is that I can't get beyond myself and my illness. Later the miasma lifted after visiting "Blanche Dubois" in the nursing home. At massage I began to feel better. In fact, after TS finished my head, the twitch was GONE for at least 5 minutes. It is subdued even now, and I am actually hungry. I am having a glass of Merlot. If I'm going to be an addict, I will be a wino! It is now 7:15 p.m. and I still feel OK. See if it lasts.

After talking to the pharmacist, she decided to stop taking the Benedryl again. Her five days of resumed pills had succeeded in tempering the withdrawal symptoms, but within two days of quitting the pills yet again, she had slid into withdrawal once more. She continued to decline into the familiar, and yet ever-new, abyss. This next journal entry was written on her first optimistic day of no pills before the withdrawal boom lowered.

¹ This was the first time since October 8, 1999, that she had slept through the night - red-letter days!

² When she asked the pharmacist, she accepted his word as gospel. She had not credited the written warning on the package. She did not believe any written warnings about the medication, or my expressed concerns. Although she had long since written off her neurologist as uninformed and unreliable, she still did not believe negative information about her pills until it came from a man in a white coat. Although she could laugh about this foible, it was still very real to her.

June, 2000

6-1-00

Thank God for yesterday afternoon and evening and sleeping through the nite without pills! I felt nearly normal. But today I was shaken awake by violent vengeful constant shaking. I expect to pay for the peace of yesterday.

Her sense that she would pay for her peace was correct. For the next two nights and days, she had no sleep, and when she stretched out on the floor, she felt that she was losing consciousness. She panicked and thought she was going to die. The next night, she slept through the night again. She had a few more bad nights and started taking the sleeping pills again.

Her son called and told her that she must come to Hawaii, and that he was coming to California to see her condition in July. If she was feeling bad, he said she must sell her condo and move to Hawaii to live with him. He hadn't seen her in a year. He announced that, since she had Parkinson's, he would be able to get a court order to force her to live with him in Hawaii where he could keep an eye on her. She was in a panic, and decided that sleep was more important than mental clarity. She would accept the mental fogginess and the confusion as a permanent condition. Even with the sleeping pills, however, her anxiety about her son's intentions catapulted her twitching into high gear. She was able to sleep again with the pills, but her sleep was anxious and restless. She also felt that she was not looking good, and she needed a quick fix.

On June 16, 2000, she went to the doctor to get some drugs for her anxiety in anticipation of her son's impending visit. She was prescribed Alprazolam, which she promptly named Ali-Kazaam. It is most commonly known as Xanax. Her doctor also demanded that she start taking the Sinemet again. Faced with certain removal from her home by her son if she failed to obey the doctor, she complied.

6-20-00

Slept well after an "Ali-Kazaam" and the usual sleeping pills. Feel as near to normal as I have felt in months after 2 Sinemet CR (25-100) taken at 7:45. I AM NOT TWITCHING. That settles it. I cannot do without medication however faulty it may be. I can think more clearly. I have to force myself to eat, but that may be my boredom with food. Sinemet may be a sinister drug but it is all we have and so must bear with it. Cold turkey didn't work. It is noon and I just took 2 more Sinemets. The basic dose of 2/day is not strong enough¹... The maximum written on the label is 2 pills 4 times/day. I suppose that then we go to a stronger pill.

I am lucky that this strength pill works at all in any quantity. It has been over a year of no meds and you can't say I did not try. I am too old to be a hero. I am at a crossroad now. I am resuming meds and considering

¹ Note this carefully, where she says, "...the dose isn't strong enough." Probably Becky's neurologist fully expected all of her symptoms of anxiety and twitching to be completely gone within 24 hours. Anything less than complete cessation of symptoms was an indication to increase the dose. Even though Becky knew from my regular readings of the drug inserts that these drugs often took months to be effective, she was once again swayed by the power of the white coat and the promise of immediate health.

letting my son be my caretaker, which can be dangerous to my self-esteem and independence... The twitch resumed but it is not all-consuming.¹

Here she is incorrect; it had been only 8 months, not a year, since quitting her drugs. She had completely forgotten that there was once a time when she was taking no medications and had apparently recovered from Parkinson's. She had forgotten, following her terrible first bout with drug reduction, that she had been doing pretty well until she decided to abruptly stop taking the Tylenol. In general, she was very confused about her own history on the drugs and her withdrawal experiences. She was determined to keep looking forward. She pointed out that it was my job to keep track of the past; she was going to keep looking towards the future.

Also, she was feeling great after just one day of pills, which should have been a matter of concern. The drug instructions for physicians say that L-dopa should be started at very low levels; the effect from the medication might not be visible for several months. But following her doctor's orders, her symptoms were obliterated and her cares were gone, all within 24 hours! She was obviously surfeited with L-dopa. According to the drug company's instruction, this was gross overmedication.

Becky – a review of seven months

After restarting L-dopa in October of 1998 to “impress” her son, and becoming addicted within several days, she had developed a permanent tic in her arm and was beginning to suffer respiratory distress after eleven months. At that time she was taking two pills (400 mg levodopa) per day. Panicked by the breathing problem, she had stopped abruptly in October of 1999. By February of 2000, she was doing well; her withdrawal symptoms were gone, her tic was minimal, and she was exhibiting no symptoms of Parkinson's disease. She had started taking Tylenol PM to help with insomnia during the drug withdrawal months. She was pleased and confident. When she learned that Tylenol PM might be a liver toxin, she quit taking it abruptly. The resultant agonies suggest that she had gotten addicted to her over-the-counter sleeping pills. To help her deal with the insomnia portion of the withdrawal, she started taking nightly double doses of Benedryl (or the generic form of Benedryl). Because of cloudy thinking and feeling groggy all day, she had stopped taking the high doses of Benedryl. This abrupt change had triggered all her brain's repertoire of withdrawal symptoms: twitching, nausea, free-floating terror, and utter insomnia.

We were to learn over the next few years that all patients develop a personal set of drug withdrawal patterns, and usually, when faced with withdrawal or any form of stress, the brain will fall back on these familiar patterns as a way of expressing its trauma. Now, at this stage in her journal, she was starting a new regimen of prescription drugs. Due to the impending visit of her son and his resolution to determine whether or not she was fit to live alone, her anxiety levels soared. She had never been prone to anxiety in the past, but the last seven months of insomnia and drug withdrawal had sapped her mental and physical stamina to the point of decimating her previously iron will. She was willing to

¹ Note that the twitch disappeared for a day or two. In chapter 12, in the section on super-dosing, you will see why this massive hit of the drug stopped the twitch for two days. Of course, as her body readjusted to the new dopamine supply, the twitch resumed, a semipermanent part of her repertoire ever since her first addiction event.

do anything, even taking the drugs again, so that she could continue her independence. As you will learn in later chapters, her relationship with her son was a difficult one. Every time she resumed taking drugs, it was due to a threat from the son, her only heir, a man who, she feared, was primarily concerned with his own personal financial perspective.¹

Now she was taking Sinemet again, at higher doses than she had ever taken before. Also, she was taking Xanax. A new, even more bizarre nightmare was about to begin.

After starting the Xanax plus L-dopa, life was good for a while. Becky reverted to her old ways, which included catching up on her reading. El Twitcho resumed, but in the glow of L-dopa and Xanax it didn't bother her a bit. Then one day at the library, her favorite haunt, she decided to do some studying up on Xanax. A book reviewer had suggested a new book, *Prozac Backlash*, by Dr. Glenmullen, a Harvard MD, that was a sort of exposé of side effects of the antidepressant and anti-anxiety drugs, plus the industry cover-up and use of misleading research used to get many of these drugs approved. Xanax was one of the drugs included in the book's scope. The book was extensively supported with published research and technical work.² It is an excellent book from a researcher's standpoint. In *Prozac Backlash* Dr. Glenmullen makes the point that the real damage from the tricyclics and SSRIs may not be their short-term effect on serotonin and/or norepinephrine,³ but their inadvertent effect on dopamine, that neurotransmitter that does seem to keep coming up in *this* book.⁴ He described in detail how research proved that use of anti-anxiety or antidepressant drugs will, over time, cause a (possibly permanent) reduction in dopamine, the same as any of the illegal addictive drugs.⁵ They were especially likely to set in motion tardive dyskinesias, also known as hand twitching: the Xanax that Becky was using could probably cause damage to her brain and, ironically, reinforce the hand twitching that she already had from the L-dopa. Her Xanax, according to the most recent research, was going to *reduce*, within a few months, her dopamine levels, and cause unpredictable physical symptoms, which would most likely include hand twitching. It was also addictive and it caused parkinsonism: in

¹ She finally got out from under her son's threats. In 2002, at the suggestion of a friend, she told her son that she had altered her will: if she was moved out of her home against her expressed wishes, all of her estate would go to the local chapter of the Animal Protection Society. Her son immediately ceased his demands that she come and live with him.

² Unlike this one!

³ *Physician's Drug Handbook*, 9th edition, Springhouse, Springhouse, Pennsylvania, p. 23.

⁴ Chapter nine has further information about the relationship between dopamine and serotonin.

⁵ In the short term, these drugs cause an increase in dopamine levels. But as you know, any drug that sets in motion a dopamine increase will soon lead to a dopamine decrease. The brain will reduce native dopamine levels to compensate for the incoming dopamine. Thus, these dopamine-enhancing serotonin and norepinephrine stimulators eventually cause a drop in dopamine levels.

In the 1980s, it was guessed that serotonin works in "the opposite way" as dopamine (whatever that means). I suspect that this idea grew out of the old 1950's theory that all neurotransmitters acted in pairs. In the 1950's, acetylcholine and dopamine (DA) were deemed "opposites." In the '80's it was changed to serotonin and dopamine. The Opposites Theory is now falling apart, but old ideas die hard. I suspect that increased serotonin, far from being an opposite, may enhance DA levels. If such is the case, serotonin-increasing drugs will elevate dopamine in the short term, and therefore be addictive. The rebound effect from long-term exposure to serotonin-enhancing drops would be that native DA levels *drop*. With long-term exposure to serotonin-enhancing drugs, native DA levels will eventually adjust downward, just as they drop in response to excess dopamine. This is exactly what is seen in the lab in lab animals.

the words of the insert that accompanies the drug, possible adverse reactions for Xanax included “confusion, tremor, insomnia, nervousness, muscle rigidity, (and) weight gain or loss.”

It appeared that Dr. Leslie had demanded that Becky take a drug that could cause, over the long term, tremor, which she supposedly had, insomnia, which she had, nervousness, which she had, plus muscle rigidity, which is a symptom of Parkinson’s but which Becky no longer had at this time. Dr. Glenmullen’s book explained very clearly how the family of drugs which included Xanax could cause brain changes which create drug-induced parkinsonism, a syndrome which resembled Parkinson’s disease but which is brought about by addictive drugs.

Remember, parkinsonism is different from Parkinson’s disease. Although the external symptoms of drug-induced parkinsonism are similar to Parkinson’s disease, the actual mechanism in the brain is different. The two syndromes share the symptoms of tremor, rigidity, slowness of movement, balance problems, and dopamine deficiency. They both respond favorably, in the short term, to L-dopa. But the difference is that parkinsonism is caused by damage to dopamine producing cells. This damage (at this time, 2003) appears to be irreparable. Parkinson’s disease, on the other hand, includes dopamine decrease among its symptoms, but it appears that the dopamine decrease is a correct function of a brain that needs to suppress dopamine production due to other events in the body. Many symptoms of Parkinson’s disease are *not* dopamine related. In Parkinson’s disease, the brain cells that produce dopamine are dormant. Once the injury-based, emergency, red-alert signal in the brain is turned off, the brain can once again produce dopamine. In parkinsonism, the brain cannot reverse itself. Becky’s doctor was now prescribing for her a drug that was known to cause parkinsonism.¹

Now let us draw a temporary, Act II curtain over the Becky saga. As Becky was becoming addicted to yet another drug, we were growing more successful at predicting the pace and symptoms of drug reduction in our other patients.

¹ This chapter raises questions about more than just medication. Why was Dr. Leslie, an intelligent man who had doubtless done well in his school exams, and who had finished med school in the 1980’s, seemingly unaware of the side effects of these drugs? Why were most of the doctors fresh out of school encouraging their patients to stay off the drugs as long as possible? Why was Dr. Rafferty, almost twenty years older than Dr. Leslie, more open to new ideas about the medications than Dr. Leslie, with whom he shared an office? Why, from among more than sixty patients with the same diagnosis, did we have only *two* that were taking the same prescription? We found that the single most important factor in determining how a doctor might prescribe these drugs was the year that he graduated from medical school.

This subject, being only tangentially related to the medication issue, is addressed in appendices 5 and 6.

