

“When the Hare awoke from his nap, he saw the Tortoise just near the winning post.”

“The Hare and the Tortoise,” Aesop

23. BUZZ AND VIKTOR

A PAIR OF STUDIES: TORTOISE AND THE HARE

In August of 2001 I got an email from a total stranger named Buzz. He had recently recovered from Parkinson’s disease, and he wanted to know how he could contribute to our program. I was thrilled to hear from him. The local television station had scheduled a one-hour broadcast about our program and I wanted to feature people who had not been my own patients.

A growing misconception held that my personality, and not our techniques, was responsible for people recovering from Parkinson’s disease. To squelch this idea, we chose people for the TV interview who had not been my own patients.¹ None of us had ever heard of Buzz until he contacted me. Perfect! Three weeks after initial contact, he motored down from Oregon for the broadcast.

The evening before the TV interviews, I met Buzz and learned details of his recovery. It turned out that his acupuncturist, Eileen, had visited our clinic and attended a weekend workshop on treating PD two years earlier. She was now working with eight Parkinson's patients at her private practice up in Oregon. Buzz told us about her technique and about himself. The most amazing thing about Buzz’s story was his all-at-once decrease in his drugs. He is the “hare” of our chapter. His crazy method of drug reduction was harrowing, but he survived it. His relative youth and his otherwise good health may have helped. His spiritual convictions certainly played a part. He was very lucky to survive; historically, case studies exist for patients who have died from abrupt stoppage of this drug.

We do NOT recommend Buzz’s method of drug reduction. However, here is his story.

Buzz

Buzz was 53 years old when he was diagnosed with PD, a diagnosis confirmed by two neurologists. He began recovery therapy when he was 57 years old. At that time his symptoms were already severe. His second doctor considered his case advanced Parkinson's. He was no longer able to work when he started getting treatments from Eileen. He had severe tremor. His balance was poor: he had to hold on to the shower safety bar with one hand while washing his hair with the other hand – there was no way that he could keep his balance without holding on. Several times he had lost his balance

¹ Dr. Fred Jones, a retired professor of medical research, advised our project in its infancy. He said I had two choices: I could be recognized for establishing a scientific protocol that was effective no matter who did the work or I could clamor about my own patients’ recovery. If I chose the latter, fifty years down the road, people would say “there used to be a woman who could treat Parkinson's disease, but she’s dead now.” The choice was obvious: the emphasis must be on the treatment, not the one who wrote about it.

and fallen while walking. His small motor skills were almost gone: picking up a coin was difficult, doing buttons and making meals nearly impossible. He walked with little “baby steps.” Neither arm swung, and his face had no expression on the left side. He had tremendous difficulty in getting out of bed – had fallen to the floor trying to get out of bed, in fact – so he had moved his mattress to the floor for safety. He wrapped a towel around his neck to catch the drooling. His posture was hunched forward. His voice was weak.

At the time he started receiving treatments from Eileen, his medications were:

1) Sinemet (carbidopa/levodopa), 25/250 six pills a day. (The dosage is not a typographical error. Although the more common ratio of carbidopa to levodopa is 1/4, the drug is also available in the 1/10 ratio.)

2) Klonopin. (Buzz does not remember the dosage.) This powerful anticonvulsant suppresses limbic system response. It is used to suppress seizures, mania, some symptoms of schizophrenia, and recently, it is used for dyskinesias caused by antiparkinson’s medications.

3) He had recently stopped taking BuSpar for anxiety. BuSpar affects serotonin, norepinephrine, and dopamine activities.

After the TV interview, I asked him to jot down details on his drugs. He sent this to me in email format:

Buzz’s own story

“I was taking Buspar, don't remember the dose (not in my journal either), but I started taking it for 'anxiety' about six months before I started your program. Took it for two months, but the anxiety was escalating faster than the medication could handle, even when I cheated and took extra tablets (yeah, I know, stupid...but fostered by desperation!!). Stopped taking it when I was switched to Klonopin by my neurologist.

“Klonopin, don't remember the dose (maybe 0.5 something – not in my journal either), but was switched to it four months before starting your program to counter the growing anxiety. At the time I started your program, I was taking 2 pills twice a day by prescription. But I was cheating again...and would sneak more as needed, usually six pills a day. Yeah, cheating on myself! I began reducing the use of Klonopin about 4 weeks into your program...simply because my anxiety was lessening pretty dramatically. I kept taking less and less (only as needed) until New Year's Day...when I flushed 'all of it' down the toilet too.

“Here are my best recollections (plus reviewing my journal)...in response to your questions. It's so interesting – how quickly we “forget” the things that we don't want to remember anymore...

“When I started your program at age 57, I was taking:

“L-dopa, 25/250, two pills three times a day: morning, noon, and early evening. I had been on this higher dose for about a year. Prior, for three years, I was using lower dosage pills, 25/100, two pills three times a day, same times. When my dosage was increased to 25/250, I started to try to periodically skip a dose once in a while, or even for a couple of days, if possible, just to see how long I could endure. I felt like the increased meds were making me deteriorate faster...something was sure screwing me up.

“I was having On/Offs from the L-dopa (it never lasts long enough), but since I was 'almost' living a shut-in existence...I just toughed it out because of my fear that the meds were taking me down faster. I was just 'very careful' and timed my trips outside the house with excruciating care, so that driving, shopping and seeing people were always done while I was "On"...even when I was almost Off. Yeah, my driving was getting kind of scary too!

“I never took extra meds at night, although the temptation was starting to "haunt me" along about the middle of the night. There were lots of nights I just "sweat it out"...until 7:00 a.m. and the first daily fix to get me "On" again.

“Gosh, that first fix of the day was even better than sex...or at least what I remembered about it!

Buzz's drug reduction program

“After I was in your program for two months, I made my first decrease in meds (against the advice of my neurologist) to two in the morning, one at noon, and one in the early evening.¹ That went well² (somewhat!), and a couple of months later, on New Year's Day 2001, I decided (against "everyone's" advice...Eileen's too!) to quit all meds totally. It worked for me, but the first 8 weeks was, simply put, a real total absolute bitch!! I made it through luckily...and have never looked back.

“For a year+ now, I have taken zero meds. Even when I get a headache (only on occasion), I practice Qi Gong for 15 minutes or so, until it goes away.”

Crazy dangerous

As Buzz recounted his story, I was horrified. He had, against the recommendation of his therapist and his doctors, gone off his medications in two reductions – a rate that approached cold turkey. I asked for details. The verbal account did not match the daily journal entries. He remembered only that it was hard, and that it lasted at least eight weeks. He had forgotten most of the details. The journal was more revealing. He had endured fourteen weeks³ of incomprehensible motor and mental collapse. As he told me after the TV interview (and I paraphrase),

“I am so glad I live alone. If I hadn't lived alone, I couldn't have done it. I had whole days where I couldn't move and just lay there in my own confusion. Couldn't eat, think, nothing. If anyone had seen me, he would have been scared to death. I would have been put in the hospital and put on drugs against my will. There is no way, absolutely no way, I could have done it if anyone had been trying to help me.

¹ If you are following the math, that is a change from six to four, a decrease of 33%. However, he was not addicted, because he still had Parkinson's. Therefore, this reduction, though difficult, was not full-blown withdrawal. It's probably significant that he was taking the 1:10 Carbidopa: Sinemet variant. (See: Sinemet in Appendix 2.)

² This is a glossing over of the facts. As recorded in his journal, this was a very difficult time.

³ In his email, recorded here, he states that it was a period of eight weeks that was so difficult. However, this number is incorrect. His own journal, which he has graciously shared with me, indicates that it was fourteen weeks, not eight, before he began coming out from under the agonies of drug reduction. This is an example of selective memory, no doubt. I have seen this faulty memory very often in other drug-using patients; their after-the-fact summarized memory of their experience does not tally with their daily records. It was fourteen weeks before he *began* to even think that he was beginning to see an improvement, not eight weeks.

“I had arranged to have friends and family bring food and leave it on my doorstep. If they had come in, they would have called an ambulance.”

His formidable attitude is reflected in his daily entries. For example, he had a day when his entry read “not too bad today.” The next day his only entry was again, “not too bad today.” But the following day, it reads, “I was able to move my arms a little bit today and drag myself along the floor for the first time in days, thank God.”

In case you’ve missed the point here, on the days when he was “not too bad,” what he evidently meant was, he was still alive and not insane. “Not too bad,” does not mean that he had mobility. “Not too bad” meant, “I am still alive and conscious.”

I cannot recommend what he did. He is lucky he didn’t die. I do not recommend this method. I include it here only because he had the fewest total problems with his drug withdrawal of any of our patients who had been taking such a large amount when starting the program. Also, he never developed a subsequent yearning for the drugs, which has occurred in our patients who took longer to get off their medication. Therefore, in the name of science, his case must be included, but I cannot stress strongly enough, this does not appear to be an ideal method, and it may entail many risks, including death.

The other reason that I am including Buzz in this book is that many people have seen the television broadcast or a video of our subsequent interview with him, and I fear they might admire his methods without appreciating his suffering. Therefore, to buffer his televised insistence that “stopping the drugs quickly was the best thing I could have done,” I have included his case study here as an opportunity to point out that he is lucky he didn’t die.

Buzz’s current condition

He currently takes no medication and no one would ever guess that he had ever had advanced Parkinson's disease. All of his obvious symptoms are gone except for a small tremor in his left hand that occurs when he is nervous – such as when he is being interviewed.

His small motor capabilities are excellent. As a small aside, when I showed the video of him for the local Parkinson’s support group, I was surprised that no one seemed particularly moved by his “testimonial” type words. There was a stronger response, surprised shaking of heads and tutting, when he said that he was cleaning rain gutters again. I did not anticipate the gasps of amazement from the group when, in the video, he deftly picked up a penny from the table to demonstrate his new manual dexterity. It was clear, after running the video, that it was not his words of gratitude nor his reflections on “being given a second chance,” but the conquering of little motor function problems that most deeply affected the audience. Curious.

As for balance, he is once again getting up on his dad’s roof and cleaning the gutters. His energy level is good. He is actually in excellent health. When he came to our town for his interview, I taught him how to dance the leg-kicking bit of the can-can; he picked up the left-right coordination quickly, and within a few measures of singing along with me, kicking his feet in the air, he had all the moves down.¹ He has a radiant smile.² He is continuing to improve. He still has a faint degree of rigidity in his left arm and

¹ It is rumored that I have promised to dance the can-can with anyone who recovers from Parkinson's disease...

² The immobility of the left side of his face is completely gone.

wrist, and the tremor is continuing to change. The tremor is becoming more delicate, smaller, and more fluttery. He is confident that the shaking hand will go away. I am waiting to see – even the relatively mild antianxiety drugs taken by the general population can produce delayed onset (sometimes years later) permanent tardive dyskinesia.

Attitude

I am going to include a bit from Buzz's continuing journal to show his attitude and incorrigible sense of humor. He was having a particularly virulent shaking in his hand one day, although his other symptoms were long gone. He is certain that the rapid changes in the tremor are due to the changing muscle tone in his arm – as the rigidity left his left arm, the left hand began to tremble uncontrollably. I am uncertain whether it is tardive dyskinesia or residual weakness, but it is the only remaining indication that he ever had advanced PD.

Buzz's journal

"49 weeks now meds free, and believe me, the best thing I ever did for myself...was getting completely off those PD meds as quickly as possible. My recovery process really started rolling from that point on...and has only accelerated since that was achieved!! This has been a good two-week period. Some of the stiffness is working itself out – I really started loosening up a little about four days ago. The shaking of my left hand, however, continues to increase in intensity (which is good!!), as the last of the PD works itself downward toward the end of my left side limbs.¹ It is such a slow process, but probably only because I am in a hurry to rid my body of the last vestige of this nasty disease. My left hand now vibrates so frantically and unceasingly that it is really getting to be funny!! If my hand is out of my pocket everyone thinks I'm waving at them...if it's in my pocket, they think I'm some kind of pervert!! One lady was staring so hard at me at the grocery store (my hand was in my pocket) that I felt compelled to say, "Sorry, it's just Parkinson's disease." Her response was, "Yeah, sure!!" Who would have ever thought that there could be humor in recovering from Parkinson's. But there is...and each and every day I continue to move a little tiny bit closer toward a complete recovery – it's practically within my grasp now!

Buzz's faith

I have had the honor of reading his whole journal. It is evident that he was helped tremendously by his deep and unwavering faith, not in our program, nor the possibility of recovery from Parkinson's, but in the presence of God and the infallible wisdom of God's mysteries, even the mysteries of illness and suffering. His journal is deeply moving. He has donated it to our project, in the hopes that it will someday be made available for

¹ His symptoms in his torso, including balance problems, had improved first, and then the facial expression, and then manual dexterity. The stiffness in his left neck and arm was the most recent to go. As his arm became more limp, his ability to restrain his tremor decreased. Even though the internal shaking and restlessness were gone, the long-time brain habit of shaking continued. Tremor is usually the last symptom to ebb.

others who are recovering. We have a long list of things that we hope to publish, and Buzz's journal is on that list.

Eileen's thoughts

Eileen, Buzz's acupuncturist, confided that Buzz was her most bold adventurer with the medication. He had also recovered the fastest of all her patients. Eileen felt that Buzz's distinguishing characteristic was gratitude. Eileen said that the patients in her PD program who were having the least benefit were those who were bitter about their illness and resentful that she wasn't doing a better job at healing them faster. The ones who were making the most progress were those who realized that it was their job, not Eileen's, to return to health.

The ones who were making slow progress, if any, would discount their recovery symptoms or express doubt that the improvement would last. If they couldn't deny their obvious improvements, they might insist that they were just caused by the power of suggestion.

She had one patient whom she had been treating every week for free for nearly two years, and he had never yet thanked her for her time. Buzz, in contrast, always managed to bring her a few flowers or some small gift when he came. He was always thanking her and expressing gratitude for this program. He accepted every symptom of improvement as a good thing and was grateful for it.

Buzz could see the logic of the illness. It made sense to him that he had had Parkinson's disease. He also accepted the possibility that, by overcoming the cause of the illness, he could change the course of his life. Buzz, more than any of her other PD patients, was willing to look deeply at himself, his attitudes, and his actions, and see how they might have been contributing to an illness marked by rigidity and disconnection from both his body and from his fellow man. After embarking on the recovery program, he resumed his long-ignored meditation practice. He was grateful for having Parkinson's and for having recovered from it. He often averred that he never wanted to go back to being the person that he used to be before recovering from Parkinson's. He also opined that people who just want to get treatment so they can go back to being the heroic, unbending person that they were before were missing the opportunity of a lifetime. He felt that he had lived two lives – one in which Parkinson's was the obvious conclusion and the other in which humility, hope, and love were the driving forces – conclusion unknown.

Eileen felt that there was a strong correlation between his attitude of humility, acceptance, and faith in an unseen logic behind the mystery and his relatively rapid rate of recovery. Most of all, she kept coming back to Buzz's gratitude and love for others.

VIKTOR

To contrast with Buzz, who stopped his medications precipitously, I would like to share the case of Viktor, who waited a few days too many to reduce his drugs. He planned on reducing his drugs for more than a year before his hand was forced. He is the chapter's tortoise. I will include quotes from his journal. As you read his journal, imagine that you are a researcher, looking for clues about the medication as he recounts his hourly changes. It may seem slow going at first, packed with details and repetitions, but by the end of the chapter an excellent picture of dopamine change will emerge.

At the time he began reducing his drugs, Viktor was 51 years old, had been diagnosed three years earlier, and was taking 500 mg/day L-dopa and 3 mg/day Dostinex (a European dopamine agonist, approximately equivalent to 9 mg Requip). He had been using our PD treatment protocol for just over a year when he first came to our clinic.

Viktor had been mildly overmedicated when I first met him, one year before he became our patient. His symptoms of overmedication were a little ticcing pattern that tilted his head several times a minute, as if he was bringing his ear towards his elbow. When the twitch was at its height, he also had a grin that was a bit forced, as the facial muscles pulled up too hard on the corners of his mouth. His main symptoms of PD were loss of voice, bradykinesia, and shortening of stride, all of which had responded well to the medication.

Years of psychotherapy

Prior to using Tui Na, Viktor had spent years working with philosophies and psychotherapists to get to the root of his lifelong inability to cry or emotionally unbend. He felt that his emotional rigidity was related to the physical rigidity of Parkinson's disease. While he could understand logically that his inner and outer rigidity were related, he found he could not change himself through mere mental exercises or talk treatments. He discovered during his FSR treatment sessions that Yin Tui Na could get through to him in a way that talk and thought could not.

Reluctant to reduce meds

He admitted at our first meeting that he was overmedicated but was reluctant to reduce his medication until convinced his recovery had started in earnest. Since starting our protocol with a practitioner from his hometown, he was sleeping better and had more feeling in his feet, but he doubted the significance of these changes. After starting at our clinic, he became buoyant in mood, almost to the point of effervescence. I warned him at our first meeting, and again a year later when he started attending our clinic, of the symptoms and dangers of overmedication. He thoughtfully considered the warnings and appeared to understand the risks. Viktor was very intelligent and objective. He felt well prepared for the eventuality of drug reduction.

At this time, we had not yet started our present policy of not working with medicated patients. Viktor's disastrous aftermath, which occurred despite our sharing with him in advance everything we knew about the 10% plan, the Slide, the Crashes, the ten weeks, and our experiences with Euclid, Angus, Birdie and all the rest, settled our wavering indecision about patients on drugs. After Viktor, we no longer admitted medicated patients to the program.

Recovering and not reducing

I was especially concerned when I saw Viktor after a one-year hiatus: he appeared more overmedicated even though he had not increased his med levels. In addition to his

previous dyskinesias, his shoulders were making a little upward twitch. And then, after two weeks of working with us, something switched in his brain.¹

Two days after a treatment session in which he felt that some last, resistant knot had come untied in his leg, he went from a dignified and controlled investment banker to a maniac. He was uncontrollably happy, he could hardly sleep, and he had to run, jump and laugh all day. His eyes glowed with a rare effulgence.

Explosion of motion

Viktor was a rarity in that he had the ability to realize that even if in the best of health, he should not need to run on the beach to keep from bursting. Most medicated patients who burst into ecstasy want to attribute their unnatural buoyancy to recovery and their innate eternal youth, rather than giving credit to their drugs. Viktor, who had never been an athlete, recognized that dancing half the night in his flat and running on the beach for an hour simply to rein in his new exuberance was most likely a drug problem.

He decided to reduce his medication to the point where he could keep both feet on the ground. During this explosive time, I saw him more frequently than once a week, and even spent a night at his home once when he was scared.

Terrible tensions

His biggest problems during drug reduction were his “terrible tensions” that started in conjunction with his euphoria, just after he became wildly addicted, on the fourth day of his cautious drug reductions. At first, these tensions only enveloped him during the highest point of his Ons. Soon they began to occur during his Switching, and then in Roller Coastering high points. Within two weeks, the excess drugs transferred their attentions from his mental area to his motor area. Incoming pills were directed to expend themselves in “terrible tensions,” and his euphoric feelings came to an end.

The chest tension was especially frightening. While Becky’s spasming centered around her diaphragm and Coach’s in his heart, Viktor’s left leg and entire torso were gripped in a death hug of muscle spasm.

The tensions drove him to make more rapid reductions than he had planned, with the resultant paranoid and withdrawal symptoms that he had been so keen to avoid.

The tension stopped for a few days during a Vacation phase. Sliding from excess to insufficient limbic stimulation, his drug intake was very low and the tensions disappeared altogether. However, once the drug withdrawal symptoms began, even his brief spurts of On time would often be accompanied by episodes of the returned tensions. This led to accelerated drug decreases and worse withdrawal symptoms, which frightened him into resuming the drugs at an even higher level.

Prior to his sudden, glorious burst of drug-joy, he had never experienced Ons or Offs. The introduction to On-Offs was simultaneous with his explosion into addiction.

¹ Viktor was participating in the visitor’s program and not the free clinic. To accommodate PDers and their practitioners who travel from long distances to observe and receive treatment or free training, respectively, a group of licensed acupuncturists in Santa Cruz operates a clinical program, the PD TEAM of Santa Cruz, in which visiting PDers may receive an intensified program – up to three Tui Na treatments a day – for a period of up to two weeks.

Viktor was one of these visiting patients. He had received several treatments a day for two weeks just before his severe overmedication erupted.

The On-Off pattern continued ever after that day, regardless of whether he increased or decreased his drugs in his search for a “balanced” dose. The deathly tension also became a permanent part of his repertoire and eventually started appearing during his paranoia attacks, as well as during his Ons.

Not all patients’ drugs convert to mental dynamite when they begin to recover. For instance, in the case of Olli from chapter two, his adverse effects began to steadily increase, and, though determined to reduce his drugs, he found himself increasing them. These increases created ticcing and blood pressure trauma, but they did not create anything that compared to Viktor. However, we had seen two cases similar to Viktor’s, where the drugs transformed into pharmaceutical grade explosives. Viktor was the third, and we vowed he would be our last.

As you read from his journal, excerpted below, try to pick out the small patterns occurring each day – but do not be blinded by them and miss the larger patterns that occur over the weeks. Bear in mind that a one-time appearance of Deficit- or Build Up-like patterns does not necessarily signify a limbic transition; the Deficits or Build Ups are most meaningful when they are daily, repeating patterns, occurring over several days. If those patterns seem to appear on one day or another at random, they may be merely the result of drugs taken in the previous day or two, and therefore *not* indicative of a place on the larger cycle. As you read about his drug responses over the course of any one day, keep in mind his drug levels from the previous day, the previous ten days, and the previous ten weeks.

As noted earlier, he was taking 500 mg/day of carbidopa/levodopa, and 3 mg Dostinex (a European drug, similar to 9 mg/Requip). The following is transcribed from his notes. In a few places I have corrected or modified his English. (His clear and precise prose in the following journal is all the more proof of his very high level of intelligence and analytic ability when you consider that English is not even his primary language. I point this out for those would-be drug reducers who imagine that their intellect or analytical ability will somehow allow them to oversee drug reduction without being traumatized by it.) Some days he sent long reports; other days the reports were brief or were transcribed from phone calls. My comments are in brackets. I have inserted daily totals for his levodopa next to the date. This is the best example in this book of the time frames needed to understand the drugs. After wading through days of seemingly unimportant events in the notes below you will behold the full power of the delayed limbic response.

Viktor’s journal: Look at Me – I’m Dancing!

Day 1 – Reduced L-dopa to 450 mg (down from 500 mg).

[From my notes: still grinning with forced, tight facial muscles, twitching in neck and face, no apparent change in motor function after today’s 50 mg drug decrease. He felt such unrestrainable exuberance that he had to go running on the beach for over an hour again. He’s finally decided to reduce his medication. He plans to reduce slowly and carefully until he stops having any episodes of spontaneous giddiness and wild energy.]

Day 2 (450 mg)

[Even more exuberant, laughing and jumping around his living room. After his noon dose, he felt euphoria and muscle tension that were only relieved by again running on the beach for an hour in the afternoon.]

Day 3 (450 mg) I got up at 8, a little stiffness all over, feeling a little bit strange but OK. 50 mg L-dopa at 9 a.m. and sleeping till 10:30, then little stabbing pain along the sternum, light nausea, tension all over, strange feeling, tension in hips (pelvis) but no impression of motor weakness, but rather a little bit “braked.” By noon I feel almost normal, take 150 mg. A little tension all over, which suddenly at 12:30 disappears completely. I am feeling fine in every way at 2:00 p.m.

[Euphoric in afternoon.]

Top of the Slide

Day 4 (400 mg) [Another decrease: a 20% decrease in four days.]

I was a little bit more clumsy this afternoon and slower in motion but OK. I feel my own legs; that’s a very new sensation.¹ There are very light cramps in the right leg around 9 p.m. but very short only. Only my fingers are slow on the computer. I feel very good; I do not feel much change in motor capacities. There is a bit more difficulty to move in bed, but that’s all. But in the morning after the first dosage, I feel overwhelmed; there is pressure on the chest, tension in arms, pelvis and legs and a kind of tiny nausea. That starts about 20 minutes after taking the meds at 9 a.m. and lasts for about 30-40 minutes. The second and third dosage is without major side effects, but more tension in the legs for an hour or so.

Day 5 (400 mg) I might have less back pain. I sleep between 2 and 4 hours, then I am awake for 1 or 2 hours, then I sleep for the rest of the night. I have had this pattern for over six months. In the morning before standing up, before any medication, I have strong recovery dyskinesia.² Today even before taking the first dose I had nausea, tension in the legs, pressure in head and stomach, but not in the chest. In the morning my motor function was weak. After the second dose light cramps in the right leg after 30 minutes and stronger after 1.5 hours. Moving very well in the afternoon. Same pattern after third dose: after 1.5 hours light cramps in right leg. Motor capacities slightly slowed down but acceptable. In the evening a bit slower but still OK.

¹ In most cases, return of proprioception and increased sensitivity to temperature and pressure in the extremities and limbs after decades of PD-driven, subtly increasing numbness can be guideposts in the journey through recovery.

² Recovery dyskinesia is not the same as tremor. It can occur in body parts that are beginning to experience restoration of nerve function. Viktor never had obvious tremor as one of his PD symptoms until his drug decrease plunged him into withdrawal symptoms: if there had been any tremor, it must have been extremely slight and completely masked by the good feelings brought on by the drugs. In the case of this journal entry, I suspect this morning’s movement might have been drug based, and was not recovery spasms – but I might easily be wrong; I was not there to observe. For more about recovery dyskinesia, please see *Recovery from Parkinson’s Disease: A Patient’s Handbook*.

Day 6 (400 mg) Sometimes I feel weak in motor function, but sometimes I have almost full motor function and at the same time a kind of brake which slows me down. Also, there is in addition this phenomenon: I may almost not be able to turn in bed, but when I have enough of that and stand up, I have full motor function. I am holding more again with my right hip and leg. I feel overmedicated. After the last dose this afternoon at 4 p.m. I had some tension and pain in the legs, which rather increased during the evening. It's now 11 p.m. and the tension has gone. I am still moving fine.

[At this point he still needed to go running on the beach every day to work out the buildup of tension in his legs. He also still had moments of euphoria every day after the tension went away. His tension increased throughout the afternoon and evening. His first dose of the day worked best, and the last dose caused the most problems: the medication was building up over the course of the day. However, this does not mean that his limbic system is raising his baseline dopamine levels already in a healthy rebound due to his dosage decreases; in fact, his limbic system is still in decline and doesn't even suspect yet that its dopamine levels are still in a free fall. The apparent Build Up is more likely due to the motor area's increased sensitivity to the drug. (This could be because of recovery, and switching to an addictive, parasympathetic state, as well as being flush with dopamine – for a short while following each dose – in the motor area.)

[His threshold is rising (his brain is building barriers against the drugs, a process also known as addiction), while his baseline of stored dopamine is slowly dropping (due to both the abrupt drug decrease and to the addiction-based brain changes that are suddenly occurring because of using drugs during recovery). However, due to the apparent Build Up, a person who was not watching the larger picture might think that it was already time to make another drug reduction.

[If he had not become addicted, so that adverse effects had not yet become a part of his repertoire, he would be noticing, at this early stage, only the effects of the drug decrease and not those of increasing adverse effects. However, he has been in the addicted stage for nine days, and he is actually still increasing in addiction symptoms even though he has made a 20% decrease in his medication. Now that he is in recovery, any amount of the drug will be dangerously addictive, and cause adverse effects.

The “show”

[He is still having bouts of euphoria, which he named “the show.” His brain is still trying to find ways to get rid of the excess dopamine. It is even excessive in the morning before taking his first pill. As you will discover later, his brain is already starting to make glimmering amounts, which stockpile in the night and are released in the morning. Upon his awakening in the mornings, the glimmer of morning dopamine release into the motor area appears to combine with the excess amounts of medication that are still in his brain, causing his adverse effects even before taking his first pill of the day. He notes that, on most days, he still is “fine” after 2 in the afternoon. This “fine” corresponds to the time when he melts into a euphoria unmarred by excess tension. This latter time is a condition so high above the Safety Level that his brain cannot resist – he is in mindless bliss. See: Superdosing.]

Day 7 (350 mg) [Another decrease: a 30% decrease in seven days]

Morning took 100 mg, after half an hour felt tension in the legs, lasted 5 or 10 minutes. In general, motor function and emotions are fine. At 11:00 I had slowness, difficulty writing, pain in right hip and tension in right ankle. Took a nap until 12:00. At noon took 100 mg, 15 minutes later “the show” began; I almost jumped, I had strong electrical sensation all over the body. It won’t let me sit quietly, work, or watch TV. I try to lie down, but immediately get up again because the tension is so strong and unpleasant that I cannot relax. Then a brief cramp in the lower left leg and light pressure on the chest. Then heat along the right leg and light, non-muscular tension. The whole thing lasts for 20 to 30 minutes, and then it’s over, I could relax again and move normally. By 2:00 I am fully OK.

Day 8 (350 mg) Morning took 50 mg. Light tension after half an hour, motor function weak. At noon took 150 mg. Strong tension after 1.5 hours, motor function good. Evening took 150 mg. Strong tension after 1.5 hours, motor function variable.

Day 9 (350 mg) Morning took 100 mg. Light tension after 1.5 hours, motor function good for 2 hours. Noon took 100 mg. “Nightmare” (tension and feeling strange) after 20 minutes and strong tension after 1.5 hours, motor function OK (bad between 2 and 3). Evening took 150 mg. Strong tension after 45 min and after 3 hours, motor function OK until tensions began after 3 hours.

Day 10 (300 mg) Morning took 100 mg and noon took 50 mg. Both fine, and without cramps. Evening took 150 mg. Made strong tension in the legs after 2 hours; it lasted half an hour, then fine. A bit slow, but not too much, and I am not afraid at all. I may take only 200 tomorrow.

[On day ten has was taking 300 mg, a 40% decrease from his original 500 mg. Adding up all his drugs over the last ten days, he had *averaged* 390 mg/day. This is an average decrease of 22% for the ten day period.]

Vacation

Day 11 - No Sinemet today! The morning was marvelous. I went walking along the beach, slowly and carefully. Then I went to the bank and after (12 a.m.) I was done with motion. I went home and had to lie down. I could not zip my pants. At 2 p.m. I could move again enough to get up. Motor function resumed in the afternoon and I am (6 p.m.) quite well again although a little slow. I increased the Dostinex by 50% to 3 mg. I don’t plan to take Sinemet any more and I put it away. I feel fine.

[This was the first day with no moments of euphoria or tension. He went abruptly from 300 mg levodopa to none because the powerful tension in the chest and legs that followed the medication and which often preceded or followed the periods of euphoria

had become too frightening. He is just starting a little Vacation. How confidently he declares that he no longer needs the medication!]

Day 12 – No funny feelings, but the little bit of rigidity this morning, a little bit of pressure in the head and chest, a lot of recovery dyskinesia, and a bit of tremor. Good sleep, but woke every hour. Motor function good. Today is Tuesday – the last Sinemet was Sunday 4 p.m.

(Later the same day) This morning is very different from yesterday. I am slow and feel (over-) excited in the same time. I would like to lie down but cannot stay in bed because I am too nervous. There is some tension in the whole body. And the body is a little heavy. The agonist: Dostinex, 3mg (equivalent to 9 mg Requip) in the morning, that's all. It's a long lasting substance.

[Viktor was starting to feel nervous though motor function was still good. He was just beginning to feel the effects of decreasing his medication, twelve days earlier. The vacation was winding to a close, the Slide was becoming apparent. The tension that he felt in his whole body now seemed to be anxiety related and different from the powerful muscle clenching of the torso. Also, as he will discover later, the Dostinex creates yet another type of all-body tension which is distinct from the dopa-induced clenching and which will start to be apparent soon after he doubles his dose of Dostinex. Unfortunately, in his journal he uses the word “tension” for all these conditions, though his explanations to me indicated that they are distinct. Note that he is experiencing tremor for the first time. Watch how it quickly increases in intensity.]

Day 13 – During night extended periods of intense shaking. Very slow this morning, difficulty in writing and moving. Quite strong tremor, body feels heavy.

[He was no longer having periods of ups and downs. He was starting to feel heavy throughout the day. The vacation was nearly over...]

Day 14 – I went for a walk and had lunch. I am very slow. The difficulty is that I cannot sit and do something because I am too excited despite immobility. But I cannot lie down as well because I start to get more nervous (panicked?). There is also a lot of tremor.

[As he nears the end of the slide, anxiety and discomfort have begun to appear.]

Day 15 – no entry

Day 16 – Today is worse than yesterday. Difficulty moving. I'll survive. It feels as if the limbs were disconnected from the brain. That's new.

End of the Slide

Day 17 (200 mg) Though yesterday was difficult, last night was quite good: I walked around for an hour or so and then slept for nearly one hour and so on until 6 a.m. this morning. It was then I started to feel weak and could not move. After taking the agonist I was fine and moving well for the whole morning. After 1 p.m. I had a kind of breakdown and did not recover for the whole afternoon. I could

nap but did not move better after. I had an immobility crisis, almost like I was frozen. I almost cannot move, sit or lay down without “jumping” up again. I just move very slowly from one end of the room to the other and then back again without end. There is tremor, too. I slept an hour but it’s not better – after I lay down again and almost can’t get up at 3:45. I felt close to withdrawal shock. At 5:15 I took 100 mg Sinemet. This afternoon was so different than all before that I am convinced that it is the right thing. I felt normal after 5:45. I changed from almost no motion to normal. That lasted until 8 p.m. and then I had the same experience as in the afternoon.

[He took another 100 mg at 8 p.m.]

Back on the drugs

Day 18 (550 mg) I took **50 mg Sinemet at 1:15 a.m.** with little effect by 2:15 in the morning. It’s 4:30 in the morning now and I feel heavy and immobile. Then began almost two hours game of lying down and standing up again shortly after. ‘Standing up’ means fall out of the bed with a special rolling technique. It was easier with the Sinemet, but still slow and difficult. I finally managed to sleep for half an hour until 4 a.m., but did not move better after. It’s 4:30 a.m. now and I feel heavy and immobile, but am still better than without dopa. I took 4 mg Dostinex, [double his usual amount] and the restless down-and-up again game continues until after 6 a.m. There is one position I can stay in bed, on the back, but only briefly. On the sides it is impossible to lay, or on the chest – which I always did before. I finally fell asleep around 6:30 and slept until 8:30. When I woke, I immediately began to shake. I had an impression that came from another world, I was kind of glued with the back to the bed and managed only with difficulty to roll and fall out of bed. Standing up was almost impossible, and moving also. I felt like having the feet glued to the ground, turning around was a big job and I was shaking like hell. Between immobility and shaking I couldn’t do almost anything. It was not possible to eat or drink something and I hardly could manage to make a phone call. I managed to take **100 mg Sinemet at 8:45** and felt better at 9:15. It’s 9:45 a.m. now and after having written this I feel again a little bit weaker. I have to organize something, maybe a nursing home. I am afraid, and I cannot stay longer alone. The Sinemet is fading already. I have some pressure in the head and the impression that my fingers are a little bit slower.

At 10:45 I am back to freezing again. At **11:00 I take another 100 mg Sinemet**. It takes an hour to get me moving again. But the result is not as good as with the first dose. I have strong tension in the right leg. I keep moving, as apparently the fear stays or even increases. For a moment I have the impression that the effect wore off already (12:15). [Roller coaster.] There is an overall tension which is so strong that I almost cannot write or do anything else than move around. I lay down without sleeping and feel better after 1:00 p.m. I take a shower and shave. It is almost normal, but afterwards I have difficulties again in writing.

At 2:15 I start to tremble and immobilize again. It comes suddenly and is much more violent than before. [Crash.] I have the impression that it is triggered

by only thinking of something that should be normal, but which is difficult for me, such as thinking of asking someone for a favor.

Viktor's theory

This is where my theory comes in: The trauma which underlies the uniquely Parkinsonian vigorous mental resistance to acknowledgement – and therefore healing – of the particular injury that causes the pattern of incorrect energy flow is probably different with each patient. In my case it must have something to do with closeness. Therefore, even thinking of contact is triggering a freezing reaction with me. I am of the opinion that this trauma plays its own role besides Parkinson's disease and therefore, even if there is no Parkinson's anymore, it produces immobility when the system is weakened and a trigger is around. And such are plenty in recovery. That's the way I experience my immobility now: I talk to someone on the phone or think of something and my problems increase – I lose my voice, and I move more slowly. I really cannot move anymore.

I take **100 mg Sinemet at 2:15**. It takes a terrible hour until I feel better. In addition to immobility there is almost unbearable tension in the right leg. Finally I can lay down a moment (3:15) and I feel better. I hope to find someone to stay with me tonight, otherwise I'll call an ambulance.

Later in the same day at **4:30 p.m. I take 100 mg Sinemet** (4th one today) and my friend Clay comes. I don't feel better, I feel even worse. At **7 p.m. I take the fifth 100 mg Sinemet** of the day. Clay has left and Maddy, a friend of Clay, has come. I show her photos and we talk. At 8 p.m. I feel suddenly fine again. I think that the safe company and the feeling good with her help. It is the absence of fear. At 9 p.m. I still feel fine. 9:45 it begins to become difficult. At 10 p.m. I take a nap and sleep till 11 p.m. I move fluidly for 15 minutes then I slow down again. At 11:30 p.m. I go to bed and sleep for half an hour again. I am slow, but still move fine. I lie down and nap for another hour. At 12:45 a.m. I am up again and now it gets more difficult. Maddy went to bed and I am alone.

I notice that my body starts slightly to panic. I slowly move around and finally I succeed to sleep again. This pattern of sleep and unrest continues until 5:30 a.m. when I finally start to sleep for almost two hours until 7.30. I am slow but can move. Maddy has gone and will be back in the evening.

Increased dose

[*Viktor took 550 mg of levodopa on the above day.* This is more than he was taking before he ever started reducing, just 18 days earlier. In fact, because he increased his agonist medication by 50%, he is actually taking more medication now than he ever took in his life. He started the decreases seventeen days earlier because of the euphoria and accelerated them because of the terrifying feelings of constriction and tightness over his body, especially in the legs and chest, that came on during the highest point of each dose. These tightening feelings in his chest that came within an hour after taking a dose were worsening even though he had quickly reduced his medications down to 200 mg/day. That was why he stopped taking levodopa altogether – it was starting to produce a feeling of impending doom within an hour after taking each dose.

[Finally, after an eleven-day slide and a few pleasant vacation days for his quick-responding motor area and frontal lobe, his slowing changing limbic area *started* to react negatively to the decrease: “an impression that came from another world,” “panic,” and “shaking like hell” although he had never tremored previous to this time.

[Until these strangely terrifying events began, his drug *reduction* symptoms had merely been the bothersome symptoms of motor function decline. His *overmedication* symptoms, tensions, freezings, crashes and tightenings, were symptoms of inability to tolerate the medication at previously acceptable levels (recovery). However, as his limbic area dopamine slowly and invisibly dropped into the insufficient range, seventeen days after making his first decrease, he started having the life-threatening, mind-altering effects of lowered dopamine in the *limbic zone*. His lowered limbic levels and drug withdrawal symptoms on day 17 were probably due to his first, mild (10 to 20%) increases. The full effect of having stopped drugs altogether (100%) might not show up for another few weeks yet, if he was still alive!

[These withdrawal symptoms caused him to start taking the drugs again. However, because of the slow rate of change of the limbic area, slow *whether decreasing or increasing*, he did not notice any immediate improvement in his nearly lethal level of fear and anxiety, even though he had resumed taking levodopa at his highest level.

[His first dose this day, at 1 in the morning, had only a slight effect. His second dose started working in half an hour. His second dose worked better than his first; this meant he was starting the day with a deficiency. His third dose took over an hour to start working, and the effect was not very good – he had Switching and a mid-dose Off (Roller Coaster). When he finally went completely Off from the third dose, he crashed badly, the first time he had ever done so. He had started the day with what seemed like a deficiency, but it later appeared as if he had experienced a Build Up day, complete with a Roller Coaster and Crash in his third dose of the day.

[Amazing. Over the course of this one day, he went from a deficit to a Build Up, complete with Crash. He had adverse effects from the medication: muscle tension and On-Offs, both indicative of *overmedication*. Overmedication? Yes. Because he was recovering – his Parkinson’s brain pattern had been turned off – he could not tolerate L-dopa at any level in his quick responding motor area or frontal lobe without suffering almost immediate adverse effects.

[However, he also felt a new restlessness and terror, and he was shaking like “hell.” His limbic area had insufficient dopamine. This was due to the rapid (seventeen days) drug *reduction*.

[He is in a combination hell: he can no longer tolerate the drugs in any amount without being overmedicated, and he is experiencing drug withdrawal; he is simultaneously overmedicated and undermedicated at the same time.

[It is seven days since he wrote that he no longer needed L-dopa. He took 550 mg on the above day, plus doubling his Dostinex. This frantic increase is a normal behavior. We have seen it again and again. Most people who are trying to reduce who decrease by more than 10% end up taking more medication than they started with. They usually resume the drugs at the new, higher-than-ever-before level just about the time that the Slide ends and the drug reduction begins to reveal itself.]

Drug withdrawal plus overmedication

Day 19 (500) I go back to bed and sleep again from 8 to 8:30 a.m. I cannot move really, take **100 mg Sinemet at 9:00** and the horrible waiting [Switching] starts until the good effect sets in after approximately 50 or 60 minutes. I cannot sit, I cannot lie down, and I hardly can walk because my body is panicked (a feeling like tension, close to explosion, without being able to move properly). It's 10:15 now and I move well but feel a little bit strange like yesterday: I have some pressure in the head and the impression that my fingers are a little bit slower.

[The “horrible waiting” is the Switching – during this time the tension and surging power are so terrible that he cannot be still, and yet the tension holds him nearly immovable. Despite his taking 550 mg the day before, by figuring his average dosage from the first day of his reduction cycle until this day, he was averaging 135 mg/day.¹ He was averaging a stupendous 70% reduction from his original 500 mg/day over the last 19 days: he was in shock.

[Even so, he got motor function – complete with switching and tension – from a single pill. In other words, though his dopamine levels were close to the threshold of the fast-acting motor area, his limbic area, which cannot respond as quickly to the drugs, was still acting out in terror. The limbic center essentially had been stripped naked, and even with incoming doses of levodopa bringing his brain above the motor threshold, the limbic area had been, and continued to be, traumatized.

[Also, even though his limbic area was very low, he was now recovering and therefore susceptible to addiction. Although, on average, his limbic area was low, the incoming doses were going over the Safety Limit and being perceived as trouble, hence the rapid appearance of Switching, Build Ups, and Roller Coasters. When he took a pill, his brain levels of the drug soared in the short term, initiating addiction processes. When the brain levels ebbed somewhat, being used up by the motor area, the still-deficient limbic area would scream in panic. This had never happened before; in the past, he had had Parkinson's disease.

[You can see how an observer who expects this drug to be out of the body within six hours and imagines that the effects from one day are separate from the effects of the preceding day might accuse the drug of being unpredictable: prior to his first reduction, Viktor had been wildly overmedicated all day long at 500 mg, and then, just over a week later, moving nicely at none. Yet only six days after that, he was panicked and barely functional when he took 500 mg again. Without the long-term outlook, the effects of the drug would appear practically random.]

At 11:10 a.m. I am back to immobility. It is so violent. It goes from moving to freezing in one shot. [Crash.] I manage to take 100 mg Sinemet and go to bed. Ten minutes later the telephone rings. I can't move. I somehow panic and manage finally to get off the bed. And then something strange happens: I start to move in the frozen way, but suddenly, twenty minutes after having taken the Sinemet, I start to move completely normally. I keep going for 15 minutes in a

¹ To figure the daily average for the last two and a half weeks, add up the total number of mg's he's had during the last 19 days, and divide the total by 19.

firm gait. It is a new feeling. The brain seems to be more connected to the body. It is 11:50 now and I am writing this without any difficulty. Either the dopa came in faster, or my brain produces it, or both, or simply a wonder. Thanks to God.

[He is wavering near the motor and frontal lobe threshold. Therefore, he will sometimes feel perfectly normal, as far as movement goes, and when he does, the motor function will ease some of his anxiety (relatively quick, frontal lobe, reasoned emotions), which in turn can temporarily override an underlying deeper, unreasoned unease. This is an interesting feedback loop with which we are all familiar: if we are depressed we can't move well nor do we feel like enjoying ourselves. Yet, if we can start moving or singing for some reason, we will feel better, and this movement will ease the depression. There is a chicken and the egg circularity to the mind, the emotions, and movement. Woe to those who would try to make it into a simple, additive, predictable program!

[For the person who cannot understand this quick change in motor area and anxiety function while there is an underlying terror, consider a person who has just been through some terrifying ordeal. He may be temporarily relieved and his shaking eased by a comforting bowl of soup, a warm blanket, and a stroll around the grounds with a good friend. However, when the friend leaves and the victim is alone, he will soon succumb to shaking and terror, and his ordeal may replay itself over and over in his brain throughout the long days and nights that follow. He will not be himself for weeks, but he will be able to temporarily rise above his trauma now and then. Activities such as mild exercise will help him calm down in the short term. However, time alone will soften the underlying shock.

[Viktor teeters on the razor's edge between motor function and unreasoned fear. When the frontal lobe (anxiety center) is satiated, he will feel good. As soon as it is emptied, the screams from his limbic area will be apparent again. Because of the slow rate of limbic readjustment, the 500 mg/day amount will not return Viktor immediately to a condition of constant On in the few days that follow.]

At 1:00 in the afternoon I am back to immobility. I take a nap and wake up at 2.30 p.m. I can move but only very slowly and I become more and more immobile. At 3 p.m. I take 100 mg Sinemet and sleep for 45 minutes. I feel good and mobile. I work till 5:00, take a shower and become slow shortly after. Freezing sets in. I take 100 mg Sinemet at 5:30 p.m. and go to bed.

Shortly after Maddy arrives. I can't open the door. I am blocked in the bed. Fortunately I have unlocked the door before going to bed and Maddy can help me getting out. We start to talk. I'm getting slowly better. For a nice period of time I am fine. We have dinner and around 7 p.m. I get slow again. But this evening is so different. I keep a basic mobility which is very different from the previous day. Only when I lock into a position (sitting and standing) I get blocked, glued to the chair or the ground. Maddy needs to help me more often out of such situations (e.g. sitting on the sofa) but the overall mobility is better, as Maddy notes too. I try to get asleep around 11 p.m. but cannot. We are watching TV and talking.

At 1 a.m. I try again and finally I sleep for an hour. It continues that way until 6 a.m., walking around (quite easily), sleeping for an hour and the same

again. There is much less fear. Until I wake up the first time at 2:30 a.m. there is none. After 2:30 there is a slight feeling of such and little tremor. (There is little tremor the whole night.) It only sets in when I take the agonist at 6 a.m. and the body gets excited. Then I have this overall tension, a kind of explosive feeling and tremor. But it's still less than the previous days.

Maddy leaves at seven. I move nicely but slowly. I go to bed at 8 a.m., wake up at 9 a.m. again and stand up. I move nicely for a moment, but then it slows down. I decide to take the first 100 mg Sinemet and then the desperate waiting for its effect begins. [Switching] It's like always, restless shuffling up and down the flat, sitting down and standing up immediately, no way to stay or sit quietly. It's exactly 10 a.m. when it flows in. The face muscles ease, the knees become flexible, the hanging arms movable and within seconds the whole body is back, back to motion, emotion, life. I sit down and write this report. It's 10:30 a.m. now and I feel a little bit heavier again. I have the impression of impending immobility.

At 11:45 a.m. I am getting slow and at 12:00 I take another 100 mg Sinemet. I lie down and try to sleep, but the ringing of the telephone wakes me up at 12:20. I don't get up fast enough to take it, but five minutes later I am well moving again. At 2:15 p.m. freezing starts again. I take the third 100 mg Sinemet at 2.30 and lay down for a nap. I am up again at 3:15 but I am very slow and that does not change. I pretty soon start to run up and down the apartment as I cannot stand or sit still. I have terrible tension on the right side. I even cannot handle the TV remote control. But suddenly at 5:15 p.m. tension eases and I can move normally again and write on the computer. I feel pretty good for at least an hour. Then I slow down again and am very slow (immobile) for the whole evening.

[His first pill of the day worked in one hour. His third pill requires nearly three hours. His rising threshold prevents the third pill from working as well; most of the receptors are turned off for the day, sending his threshold so high that his On, when it finally occurs, is too strong – he must run up and down the apartment and he suffers the “terrible tension” of an overmedication attack – and only during the hour when his meds are receding from their maximum high, during which he had extreme tension and hyperactivity, is he able to feel a good On for the first time all day.]

Day 20 (350 mg) I had a pretty good night. I am moving slowly this morning but I am moving a little bit better. I'll take 100 mg at 9 a.m. I am slow but I am really moving. Despite slowness I feel fine. I take 100 mg Sinemet at 9 a.m. and lie down because I have a kind of drowsy feeling and 40 minutes later the medication works. The drowsy feeling remains. I am getting slow at 11:10 a.m. Shortly after, freezing sets in. I take the second 100 mg Sinemet at 11:30 a.m. and move again normally at 12:00. I take a shower and dress to go out. I walk five minutes to the local stores and buy food for lunch. Entering in the shop and talking to people triggers loss of voice, slight dissociation but does not directly affect motor functions. I think that I am more afraid that I am affected in motor capacities than I really am. But it made me at least insecure. At 1 p.m. I am at home at lunch. At 1:30 I notice that movements

start to be slower and my right hand starts with tension. I'll take another 50 mg Sinemet.

(Later) The afternoon is slow but not unpleasant. In the evening I freeze a little bit more. After 6 p.m. I am moving around because I cannot stay still. But it is less unpleasant as it was on other days. But immobility increases somehow and around 11 p.m. Episodes of freezing start to happen in which I cannot move, turn, start, or stand up from sitting anymore. And there is something returned which I had not had since I got rid of the pills: back pain.

[This is his fourth day after resuming levodopa and increasing the Dostinex. After being at 500 mg/day for just a few days, he is already sleeping well and he is moving in the morning prior to taking his medication. At this point, his limbic area is starting to feel appeased. However, due to the scare that he had, Viktor is considering staying with his old, familiar 500 mg, or maybe vacillating between 500 mg and 350 mg per day, as needed.

[He is having his back pain again, which he has figured out was coming from the pills, not the Parkinson's. He'd had back pain for the last few years. The back pain stopped when he was completely off the pills, and, now that he is taking the medication again, the back spasms and pain have returned. Also, he now has freezing when the pills wear off at night. Is this a form of Crashing? It may be, because 11 at night is when he used to feel relaxed, as the effects of the medication started to ease. They no longer ease, they Crash. As his addiction increases, his Ons and Offs will become more abrupt.]

Day 21 – (350 mg) I walked a lot this night but I slept also a good part. I get up at 6 a.m. and am pretty slow with these freezing episodes in which I am glued to the ground. I sleep again from 6:30 to 7 a.m. and from 7:30 to 8. I move a little bit better now but still very very slow. I have the impression that I am feeling bad most of the day and being able to just do what I need to do to survive. I am not able to read or to watch TV because I cannot sit down quietly and I cannot concentrate. At 9 a.m. I take 100 mg Sinemet. The waiting starts and at 10 a.m. the effect comes in. At 11 a.m. I freeze again. No way to go somewhere for lunch. I almost cannot write. I do it by one finger. I take a nap at noon and wake up at 12:30 again. I feel a little bit better, but there is still this terrible sticking to the ground. I take another 100 mg Sinemet at 1 p.m. and in the same time another nap. I go up again at 1:30 p.m. and move better now. But I don't feel like going for lunch as I did yesterday. I'll see now what happens this afternoon and shall take another 100 mg at 5 p.m.

I don't understand that I was overmedicated at 250 mg ten days ago and that I have difficulties now to move at the same level.

Memory loss

[Viktor cannot understand why the drugs are not working the same today as they were two weeks ago. Just before beginning his med reduction, he attended a workshop on the medication and assured us that he understood completely the ten-day slide, the withdrawal, and all the rest. However, now that he is in actual withdrawal, he remembers almost none of what he learned at the workshop. There are two reasons: 1) during

withdrawal, the logic portions of the brain are not particularly accessible and 2) a person who is stoned (overmedicated) is barely capable of actually learning anything that he can use later when he is no longer medicated. Our patients consistently tell us that they have no recall whatsoever of things we told them while they were still under the influence of the medication. He took 300 mg this day and not 250 as he thinks.

[His movement did not become smooth until nearly morning. It took all night for the crash to wear off. Note: the cause of his improved walking in the morning is not pill-related – his last pill was the evening before and this was followed by almost immediate freezing. His nine o'clock at night pill was working by 10 and he was frozen by 11. This is a build up – the medication working less and less correctly as the day goes by and the drugs build up in the body. You will notice that he starts only moving somewhat normally after six in the morning, nine hours *after* taking his last pill, and *before* taking his morning pill. This glimmer of normal movement is coming from the perfectly regulated, native dopamine which, when unobstructed by drugs, works most elegantly. This good movement is of course obliterated by the pills that follow – pills that he needs, because without them, he will descend again into panic and immobility.]

(Later) I take a shower, write some emails and am back to freezing at 3 p.m. But it's somehow better. In any case I survive till 5 p.m. and take the third 100 mg Sinemet. Half an hour later I move fine again and feel good. At 7 p.m. I feel some weakness and take 50 mg Sinemet. I get strong tension in the legs 30 min. later. They are over at 8:15 p.m., but I am much slower too. Immobility is back at 8:30 p.m. including this unbearable gluing to the ground. That stays for the whole evening. I can sleep some time and when I wake up at 4 a.m. I can move a little bit better. It's 7:30 a.m. now, I move slowly but I move.

[Now he is entering a challenging stage: when his medication begins to work, he has distinct unpleasantness such as tension in the legs. When the medication wears off he has a crash, during which he moves less well than he would even before the medication began to work. Note that during the night, as the final medication Crash of the day wears off, he is able to move again, slowly. His drug-induced On times are short, not much more than an hour. By 7:30 the next morning, he has completely gotten over the Crash, and has a nice glimmer of dopamine before beginning his day's cycles of Ons and crashing Offs. During the glimmer, he is moving slowly, with none of the tension that he gets during the On and none of the freezing and sticking to the ground that he gets during the Off.]

Day 21 (350) mg L-dopa and a Benedryl – It's hard waiting till 9 a.m. again. I take 100 mg Sinemet and go to bed for a nap until 9.30 a.m. I move easily but with some uneasy feeling. At 10:15 a.m. slowness sets in again and at 11 a.m. I am pretty immobile. It's a long waiting until I take another 100 mg Sinemet at 12 and mobility resumes at 1 p.m. I shave (that's a good sign), take a shower and go for buying lunch. As most shops are closed (it is Thanksgiving Day) I almost don't get home before slowness sets in again at 2 p.m. The waiting is not so unpleasant as it was and at 3 p.m. I take the third 100 mg Sinemet. After a nap I stand up at 3:30 p.m. and move normally again. I start freezing again at 5:30 and

take 50 mg at 6 p.m. It does not move much and the evening is pretty immobile, but restless however. At 10 p.m. I suddenly have the impression to have more sensation in the body and to move easier. But that does not last long and there is again freezing. I take a Benadryl and sleep for 1 hour. It is midnight when I get up again. I am pretty immobile. I sleep and am up in intervals of an hour or so, but night is long and restless. I take the agonist at 6 a.m. and sleep between 7 and 8 a.m. But I don't move better after. I'll take the first 100 mg Sinemet at 9 a.m.

[He decreased his evening dose to 50 mg because he was hoping that with less medication in the evening his nighttime Crashing would not last as long. He was correct – he was able to move well four hours after his evening dose instead of having the horrible freezing. However, after the above night, he could no longer move as well in the morning. The faint glimmers of native dopamine will diminish as his brain, now addicted, aggressively takes steps to diminish dopamine. Meanwhile, he has grown increasingly sensitized to L-dopa. In the next day, even taking the smaller dose in the evening will not be enough to prevent the dreaded evening Crash. The adverse effects of the drugs – effects caused by the brain's attempts to stifle excess dopamine – will continue to mount.]

Day 22 – (350 mg today.) I take the first 100 mg Sinemet at 9 a.m. I start to move better shortly after 9:30 a.m. At 10:45 I get slow again. At 11 a.m. immobility sets in and I almost cannot stand up from the computer. I keep walking for 15 minutes and get a nap until 11:45 a.m. I'm slow but 10 minutes later freezing sets in and I take 100 mg Sinemet at 12. The effect takes place at 12:30 and for a short moment I have strong tension in the right leg. I take a shower and go shopping for lunch. I almost don't make it home as slowness sets in at 1:30, immobility at 1:45 and freezing at 2 p.m., which is pretty strong. As I hardly can move I take a nap at 2:30 and miss the pill at 3. I wake up at 3:45 p.m. and take another 100 mg Sinemet. 15 minutes later there is some effect, but tension in the right leg in the same time. The effect fades after 5 minutes and it lasts another 15 minutes until there is steady moving again (4:15 p.m.). It lasts until 5:30 when I became slower. I take 50 mg at 6 p.m. and remain slow but restless. At 7 p.m. I get tension in the right side and start to move around. At 8 p.m. tension eases and I have the same feeling of being able to move like yesterday.

For the rest of the evening I am less tense, less restless, but I have got another problem: a stabbing pain in the right hip, which does not let me stay quiet. I take a tablet (Vioxx) and get a nap at 10:30 p.m. At 11 p.m. I am up again and pretty immobile. 11:30 p.m. I go to bed again and am up at 1 a.m. That's the way the night goes on but it's less painful (because of the Vioxx) than the other nights. At 3 a.m. however violent freezing sets in and lasts till 5 a.m. Then it eases but I am still very very slow. At 6 a.m. I get some more sleep. I wake up at 7 a.m. and move freely and normally for ten minutes. Then I slow down again. I take the agonist at 7:15 a.m. and at 9 a.m. I'll take the first 100 mg Sinemet.

Day 23 – (400 mg L-dopa) I take the agonist at 7:15 a.m. Freezing sets in shortly after and remains. I take at 9 a.m. the first 100 mg Sinemet. 40 minutes later I move again and take a shower. But at 10:15 a.m. I am becoming slower already. I lock into immobility at 10:30 and take the second 100 mg Sinemet erroneously at 11 a.m. instead of 12. After 30 minutes I move again and go for shopping. I am back at 12:30 and start to be a little bit slower. I take a nap at 1:45 p.m. and sleep till 2:30. I am pretty frozen and take 100 mg Sinemet. It takes over an hour until the effect gets in. At 4 p.m. it starts to normalize. I slow down again at 5:15 p.m. but am pretty restless. In addition at 5:30 freezing sets in. At 6 p.m. I take another 100 mg Sinemet. I am still pretty immobile and frozen but restless. I am wondering about the agonist. I took 2 mg Dostinex (6 mg Requip) when I came to the US and I am at 3 mg (9 mg Requip) now. Should I change to Requip (short effect instead of the long one?)

[He is taking just as much medication as when he started, when he was uncontrollably bouncing and irrepressibly radiant – he is back to 400 mg of L-dopa, and he has increased his agonist (since a few weeks ago) from 2 mg/day to 3 mg/day, and his MD has told him that 1 mg of the agonist is equivalent to 100 mg of the L-dopa. While I have no idea where this doctor got the idea of an L-dopa equivalency, still, if he is correct, Viktor's equivalence for the combined drugs would be that he started at 700 mg (500 Sinemet + 2 mg agonist) and he is now at 700 mg (400 Sinemet and 3 mg agonist). He is also having very strong freezing states that follow close on the heels of restlessness. He is barely three weeks into withdrawal. If other patients' experiences with withdrawal are any indication, this will only get worse in the next few weeks. Remember, he is still dealing with the shock of the reduction that reached its climax on Day 11, just twelve days earlier. The pills that he is taking today are causing powerful effects – the frightening, dyskinetic tension and the restless shuffling – because they are too strong for him now (recovery), even though he is hardly getting any On time (adverse effects of drug excess plus withdrawal from insufficiency).]

Feeling Good plus Build Up

Day 24 – (400 mg) At 8 p.m. last night I got better and felt finally pretty good until 9 p.m. Then I was getting slower and later immobility and freezing set in again. The night gets long with some sleep and much moving around until 2 a.m. Then I have the feeling that motor function gets better and for more than two hours laying down is pleasant, sleep is longer and the moving less desperate or even ok. But then sometime between 5 and 6 a.m. freezing sets in again. And it is much more violent than I experienced it before. Lying down is a problem, sitting still is impossible, moving around is heavy and the feeling is horrible. Tremor is also much stronger. Sleeping is not simple. Usually I lie down and get up again several times until I finally am exhausted enough to sleep.

I take the agonist at 7 a.m. But it continues as before, horribly immobile, frozen and restless. Little sleep. I take 100 mg Sinemet at 9 a.m. Problems continue but I can sleep at least for a moment. At 10 a.m. exactly motor function sets in again. I can use the computer again and write this update.

[Notice now that his best time was at 2 in the morning, which is six hours after taking his last Sinemet. In other words, he feels best when his dose has worn off. Following the good feeling is a very bad freezing (crash), worse than he has had yet. He had never had violent freezing in the night following sleep, and this was more than six hours after taking a pill. Now, 23 days after his first drug reduction, he is beginning to have his first real periods of “feeling good,” and it is accompanied almost immediately with a Build Up and Crash.

[While the reader may not understand how I can characterize the above as a “good day,” it was in fact the first day that he had with no feelings of impending doom or overriding fear. He was not afraid of being alone. Although he was still suffering from Ons, Offs, crashes and Freezing, these are all the normal symptoms of overmedicated Parkinson’s disease, and they are not particularly indicative of drug withdrawal. However, Viktor cannot recognize this. He considers these drug symptoms to be signs of brain trauma, which they are, and withdrawal, which they are not. As far as I could tell, all his drug doses were working and he no longer felt that he was caught in a “different world.” Therefore, as an outside observer, I marked this down as a good day, a turning point, and I was inwardly concerned that he was not making another reduction. The sudden worsening of all his drug-related adverse effects over the next few days confirmed this guess.

[He soon started having episodes of bad freezing following good feeling even if he hasn’t taken a pill recently. Soon it will be difficult for him to have any period of good feeling that is not followed by a violent crash, and this pattern will now continue until he is once again completely off the medication. Looking ahead, he will be able to get off the medication again – briefly – just as he has already done once before. During that time, this effect of Crashing after any good feeling will cease.

[Tomorrow he will start to experience the violent, horrible freezing that is caused by overmedication – whether or not a person happens to be On or Off at the time – and which most doctors imagine to be part of Parkinson's disease. Remember, once the brain learns to react with a certain response during times of drug excess, it can do the same thing during times of drug insufficiency.]

Day 24 – (400 mg) At 11:20 a.m. slowness sets in. It starts with a kind of pressure in the head, tension in the right hand (arm) and leg, fingers slow down, I cannot write with the right hand anymore and I have difficulties to stand up, although I am getting restless. Freezing sets in at 11:40 a.m. I am getting quite stiff. Waiting is again very unpleasant, but fortunately short. I take 100 mg Sinemet at 12 and take a nap until 12:30 when motion comes in again. I take a shower and go for my daily shopping. I am back at 1:30 p.m. and am already getting slow. I still write with ten fingers, but it’s not easy. At 2:30 freezing sets in. At 3 p.m. I take 100 mg Sinemet and a nap. I stand up at 4 p.m. and freezing persists as if the 3 o’clock pill had no effect. Freezing was never before this violent. I cannot stand still because I immediately lock into the position and don’t get out anymore. At 5 p.m. there is for a moment strong tension in the right side and then after I am a little slow but steady and fine. At 6 p.m. there is slight immobility and I take 100 mg Sinemet. There is tremor but I am still relatively quiet. It’s 7 p.m.

[For the first time ever, he experienced a pill failure: his afternoon pill did not work at all. He is now experiencing evening Build Ups. This is the first time that he has experienced switching together with a complete failure of the medication. He is building up to very uncomfortable levels now; he is highly overmedicated at 400 mg/day and therefore not getting much On time.]

Day 25 (no total available) – In answer to your question what do I mean the day before when I said, “Freezing was never before this violent,” I mean that freezing was the worst ever. The night was quite fine, in any case the best since many days and there was a strong feeling of very slight, but solid motor capacity. Here’s the update: At 7:30 p.m. motion is back. I feel almost normal again. I do really fine till 9 p.m., then I slow down a little bit, but still doing fine: no restlessness, watching TV quietly. At 10 p.m. I am getting slower but still ok. There is little restlessness, much more sleep, more calm. There is still a lot of walking around in the night, but the night is not unpleasant. And in any case, there is dopamine. I feel it as a ground sensation of more strength, when standing up or laying down. That lasts till 6 a.m. Then it gets quite restless until 7 a.m. when I take the agonist. I take a nap and wake up again at 8 a.m. There is extreme immobility, some freezing, tremor, sweating, stronger heartbeat, extreme restlessness. It's a terrible hour until 9 a.m. when I take 100 mg Sinemet and a nap again. I wake up at 9:40 a.m. and move fine.

[As I suspected, he is beginning to feel good. He feels the best in the nighttime, up until 6:00 a.m. After 25 days, his first drug reduction cycle, from 500 mg/day to 400 mg/day, has come to a close, and he is now able to feel good at 400 mg/day. The confusion and emotional horror of drug withdrawal is past. However, judging by his adverse effects, he is much more addicted and sensitized to the drugs than he was when he started to recover.

[By the way, there was an interesting change in symptoms this day. Did you notice the sweating and the elevated heart rate? These will eventually start occurring each day about half an hour after he takes the agonist – which he increased just a few weeks ago. It has taken this long for his body to develop this response to the increase in the agonist.

[So if you are counting how many days he has been Sliding back up and starting to feel good from the L-dopa, and noting his seeming improvement even though he made no change in dosage from Day 24 to Day 25, don’t forget to add in that he did alter his amount of agonist over ten days ago, and the effect of that is also just beginning to show.

[Hopefully, as you are keeping track of his ten days of increased Dostinex, the three weeks of levodopa decrease, the sudden absence of fear, the increase of Crashing and Switching, and all the other changes that have occurred, you are also remembering that his susceptibility to addiction has evidently changed as well.]

Day 26 – (no total available) At 10:15 a.m. there is some tension around, specially in the face, legs. At 11 a.m. the tension is increasing and I am slowing down. Freezing sets in. I have the impression that there are proper motor function and

immobility overlapping; there is almost proper motor function in the legs and immobility in the arms. In addition there is freezing. I take 100 mg Sinemet at 12. After 25 minutes there is return to “normal” movement and for a moment (five minutes or so) strong tension in the right leg. At 12:30 I feel and move fine again. I take a shower and go for a walk. On my way home at 1:20 p.m. slowness starts to set in. At 2:15 p.m. slight immobility sets in. At 3 p.m. I take a 100 mg Sinemet and a nap. I move better when I get up at 3:30 p.m. At 4:30 p.m. there is strong tension in the right leg, which lasts almost till 5:15 p.m. Then it relaxes and I feel fine. But at 5:30 p.m. slowness sets in again. At 5:45 there is some tension in the right leg again. Half an hour later it fades and at 6:30 p.m. things are back to “normal” again. At 8 p.m. slowness sets in. It’s 9 now. I’m slow but quite fine.

Day 27 (no total available – probably 400 mg) There is a lot of tension in the hips. I finally manage to lay on the side instead of the back and sleep deeply between 1 and 3 a.m. but am totally frozen when I get up at 3:00. At 4 a.m. the motor feeling starts to get better and at 4.30 a.m. I actually feel better. At 5 I take a nap and wake up at 5:40 a.m. There is immobility again. I go to bed again at 6 and wake up at 6:40 a.m. I am almost frozen. Moving is difficult. I take 2 mg Agonist at 7 a.m.

[Note: after three days with the increased heart rate and sweating, he has reduced the agonist back down to 2 mg and those symptoms appeared to have stopped. As you will learn in the Appendix sections on agonist drugs, some of the adverse effects of the agonist drugs appear to be coming from the blood-borne agonist molecules interacting with organs in the body rather than with the receptors in the brain.]

Day 28 (400 mg) In intervals I move around and sleep but the sleep phases become longer and I succeed to sleep on the sides. At six there is strong immobility and I take another nap at 6:30 a.m. which lasts until 7:45 a.m. I wake up and am totally frozen. I take the agonist and remain frozen until 8:45 a.m. when freezing eases. In the meantime Janice took care of me. At 9 a.m. I take 100 mg Sinemet and at 9:30 a.m. motion sets in. At ten Maddy comes and stays for an hour. That's apparently too much social interaction and I start to immobilize at 11:30 a.m. I take another 100 mg Sinemet at 12 and start to move better half an hour later. I go for a walk and return at 1:30. At 2 p.m. slowness sets in and at 2:30 I am a little bit immobile. There is also freezing. I take 100 mg Sinemet at 3 p.m. and lay down.

Laying on the side I feel suddenly for a moment the pricks of dozens of needles in the pelvis floor. At 4 p.m. there is strong tension in the right leg, which does not end. In the same time there is some slowness. It lasts till 6 p.m. when I take 100 mg Sinemet. At 6:30 motion comes back. Clay picks me up for dinner at his house at 7 p.m. But at 8:30 p.m. shortly before dinner immobility sets in and freezing. I almost cannot eat. At 10:30 I am home again and feel better but a certain immobility remains.

[He is sleeping more soundly. This can be an indication that the drug withdrawal phase of the reduction cycle is finished, and a person is firmly ensconced again in a stable limbic condition.

[Now that his comfortable limbic zone has been reached, despite the various Ons and Offs of the day, his motor area may react even more violently to the dopamine excess. On this day he experienced for the first time “pricks of dozens of needles in the pelvic floor.” It is impossible to guess at this point whether this is the pins and needles of Parkinson’s recovery that often shows up in a previously numb body part, or an ominous sign of a new addiction pattern.

[He was so much better now than ten days earlier that he has a new concern: he fears that if he continues to improve, he may harm his brain via overmedication. He compared how he is feeling today in general, getting out and visiting with friends even though his mobility comes and goes, to his panic when he was ready to call an ambulance two weeks earlier. Also, he noted that on this day, he took his pill at 6:00 and although he got some motion briefly from 6:30 to 8:30, he then went Off quite badly, only to come On again at 10:30. This is the classic Roller Coaster. His mid-dose Off was so severe that he could not even eat.

[Based on his improved emotional stability and the Roller Coaster, he decided that he might possibly decrease his medication within a few days. His ambivalence was due to two things: it had only been four weeks since he started reducing, not ten; and he was reluctant to enter once again into that dark night of drug withdrawal. He had been utterly unprepared for the ferocity of his panic when the withdrawal first appeared. However, he understood, during this brief window of clarity, that if he stayed at this level of “good feeling” for very long, he would soon have less benefit from his medication: one characteristic of addiction is that ever-increasing doses are needed to attain the same benefit.

[He decided several days later that, in the long term, the greater risk was from overmedication, not withdrawal. He planned to reduce again soon. This was told to me over the phone, and is not in his journal.]

Day 29 – (400 mg) It's sad: I have my first social event with my friends (Clay, Audrey, and Oliviér Hardin) and I freeze completely. No sooner than I was alone at home again, I returned to normal. Well, here’s the follow up: The night is pretty nice. There is slowness but a good motor ground feeling. There is also good sleep in intervals of moving around. The only moment of immobility was when I got up at 6.30 a.m. I take the agonist at 7 a.m. and I move a little bit better at 8 a.m. I take 100 mg Sinemet at 8:30 a.m. in order to advance the schedule for the upcoming traveling day. At 8:50 a.m. the effect sets in and I move almost normal. It's 10 a.m. now and I am fine. I have some tension in the right hip and the feeling that this has something to do with the fact that I have to come out of the shell and into real life again....

[He had been on vacation in the US and was returning to Europe soon.]

Day 30 (400 mg) The night is pretty nice. There is slowness but good motor, grounded feeling. There is also good sleep in intervals of moving around.

The only moment of immobility was when I got up at 6:30 a.m. I take the agonist at 7 a.m. and I move a little bit better at 8 a.m. I take 100 mg Sinemet at 8:30 a.m. At 8:50 a.m. the effect sets in and I move almost normal. At 10:30 slowness comes up. There is some pressure in the head and the arms get heavy. At 11 a.m. I am slow. The 100 mg Sinemet at 11:30 a.m. does not change much. Effect only sets in at 1:00 p.m. I try to go by car for shopping, return however quickly to home. I feel that it is not safe. Then comes some immobility. At 2:30 p.m. I take 100 mg Sinemet and a nap. At 3:30 p.m. I get up and move again fine. At 3:50 p.m. suddenly freezing sets in. I almost cannot move anymore. In addition there is strong tension in the right leg. And it lasts until 5:30 p.m. when I take 100 mg Sinemet and a nap again. At 6:30 p.m. I am ok again, feel and move normally. The evening and the night have a similar pattern as the night before: more slowness around 8 p.m., sleeping in intervals. But there is more restlessness.

Day 31 (400 mg) I sleep less than last night and move (shuffle) more. At 7 a.m. I wake up and am frozen. I take the agonist but that does not change anything. At 8 a.m. I take 100 mg Sinemet and take a nap. At 8:30 a.m. I am up again but still immobile. It takes until 9:20 a.m. and then there is still restlessness and strong tension in the right leg. At only 9:45 a.m. I am back to slow but ok. That does not last long and I am back to immobility. At 11 a.m. I take 100 mg Sinemet and I feel normal at 11:20 a.m. I take a shower and bring the car back to the airport. I am back home when at 1 p.m. immobility sets in. I take 100 mg Sinemet at 2 p.m. and it takes almost an hour until the effect sets in. At 3 p.m. I am better again but still very slow. I take a nap at 4 p.m. and move a little bit better at 4:30. But immobility is soon back. At 5 p.m. I take 100 mg Sinemet. At 6:10 p.m. tension eases and a feeling of normal motility sets in. But I am slow the whole evening.

[He was already noticing less effectiveness from his medication. He was now in the “increasing addiction” phase of the cycle. Due to addiction, his medication will soon be less effective.]

Thus ended his first month with drug withdrawal and one full cycle of drug reduction.

The next month

His subsequent reductions were much more agonizing. By the end of another month he needed full-time nursing care. He was terrified of being alone, and was immobile throughout most of the next reduction/withdrawal phase.

He did not begin his next reduction until day 42. Leading up to this reduction he reported he was “hyper-excited with overall tension (similar to the old euphoria), a restless feeling in the piriformus muscle (day 35).” “Sleep is no longer so good, freezing more violent (day 36).” “A change in overall feeling; nothing left of any safe feeling of motion. Heaviness in the whole body. Freezing...has never been so violent as it is now. I feel helpless (day 39).” “Cramps in the right leg (at 4 a.m.)... After the effect sets in (9

a.m. dose) I move with ease but have a strange body sensation. It's a kind of tension all over the body, especially in the face, and a kind of pressure in the head (day 40)."

He also was becoming aware that he was recovering from Parkinson's: "My physician, the people in the pharmacy, my girlfriend – everyone keeps saying that my facial expression has dramatically changed, that I am looking much better, much more positive, etc. Well, no surprise. I do feel different. Thanks for all...I move normally but have a feeling of being in a kind of mild fog. There is some tension and pressure in the head (day 41)."

On the next day, day 42, he reduced his medication to 350 mg/day to put a stop to the increasing tension. This was evidently too late, however; on day 44, he was "overrun by cramps in the legs. I have the impression that there are somehow counteracting forces, motility and immobility."

By day 46, he reported "an overwhelming feeling of energy or something in the whole body which does not let me quiet in any position. I am close to panic and have difficulty calming down." He did not take his 50 mg evening pill on this day, and in the days that followed he accelerated his drug reduction to 300 mg/day, instead of staying at 350.

The next day, he had no tension and cramps in the evening and so decided to stay at 300 mg/day, even though it was a decrease of 25% from 400 mg/day.

His slide was more abrupt this time: within seven days of the decrease from 400 mg to 300, he wrote, "Last night was the most horrible. I was almost paralyzed. I cannot open my pants anymore and go to the toilet. Heavy immobility and violent freezing." He had a five minute glimmer of normal movement when he woke at 7 in the morning, but, "When I took the 9:00 a.m. Sinemet I experienced instantly total freezing. That must be psychological, as the chemistry has no such immediate effect...at noon strong immobility is back together with freezing and tension all the same time. The tension prevents me from lying or sitting down or resting. It's hell. I am afraid of what comes after today."

I wrote him a list of specific actions that might ease some of his withdrawal fears: food, warmth, and music. I suggested that he might have a mild alcoholic drink or two, and to report back.

He wrote, "I had actually started to reduce food in the evening because I thought it would be better for sleeping and I did not touch alcohol because I was afraid of too much stimulation. And what did I do after your recommendation? I had a wonderful dinner with chicken/vegetable soup and a lamb/potato stew, and I had a can of beer. I put an extra jacket on and piano music of Bach, and finally I had quite a good evening. I could still move fine at midnight."

On day 54, he had a good night and some On time during the day, but dyskinesia in the neck started together with cramps in the stomach, and so he reduced again to 250 mg. This may have been a bit too soon. His next round of reduction was very severe, lasting for months. On the other hand, there is no way of knowing if he might have been even worse with a lesser reduction.

A complication began on Day 50. He started feeling the weakness and supreme need for sleep that can occur during recovery from Parkinson's disease. As he put it, "I am sleeping a lot and am so drunken (from sleep, not alcohol) when I wake up that I go to sleep immediately again." He needed help to perform the simplest task. He could no longer take care of himself. His brother-in-law hired nurses to care for him and he moved

into his brother-in-law's house. Viktor's constant sleeping and weakness were more terrifying to his doctor and his family than the immobility of the Offs. (This is often the case. Doctors sometimes change the diagnosis at this point to Multiple System Atrophy or Lewy-body Syndrome, since there is extreme weakness but no longer the rigidity or expressionless face of Parkinson's.) Several intercontinental phone calls between me and the brother or doctor ensued.

I could only explain that the weakness appeared to be a necessary part of the recovery, and was part and parcel with the benefits that they themselves had noticed: increased facial expression, more graceful movement than before (when On), and more emotional openness to others. As for the latest drug withdrawal, he was doing that because of the increasing collection of spasms and tensions, and the increasing fog in his head when his medication started working. They demanded to know how long every step of the process would take. I told them that I had no idea. They wanted to know if I could slow down the process, or speed it up, or modify it somehow. I said, "No." They wanted to know what to do about the drugs. I spent hours on the phone trying to explain all the principles in this book. His brother had the usual disbelief.

His neurologist was more curious: "We don't really know what Parkinson's actually looks like anymore. We MDs no longer treat actual Parkinson's disease; what we treat now are people who are taking PD medications. We really don't know what we are doing. But what should I do now to help Viktor?" I said that I didn't know.

One other interesting "benefit" of recovery occurred during the third cycle of drug reduction. When he had first started working with us, he confessed that he had never been able to feel emotions and had not cried in his entire life. I suggested that if he recovered from Parkinson's, he might be able to shed a tear or two. He scoffed.

While he was wildly scared and afraid to be alone during the third month, his sister tried to cheer him up by pointing out the silver lining: "You should be grateful you have such a devoted family; you can live in our house, and we are all loving you so much." He told me on the phone that when she said this, the full force of his good fortune hit him; when he thought how good everyone was being to him, and realized how much he had to be grateful for, he burst into tears. He cried on and off for days.

At another point during this month he developed a new symptom: "I am afraid that I can't breathe anymore. There is also this electric burning feeling in the left chest." This was probably due to dyskinesia in the chest, around the heart muscle. This symptom is an adverse effect of the medication. It is not a symptom of Parkinson's, nor is it a common symptom of drug withdrawal. The spasms in the left chest around the heart were being caused by the drugs; he was overmedicated again.

A week later, he cried the hardest yet because his caregiver showed up on time. In his increasing paranoia and terror of being left alone, he was certain that she would be late, that he would be abandoned, that he would die, untended and uncared for. When she showed up promptly, as scheduled, his wrenching sobs of gratitude lasted nearly an hour.

He felt confused and overmedicated, and he reduced his medication further, from 200 mg/day to alternating between 200 mg and 150 mg/day. At first, it went very well. In the middle of this month, he reported "good mobility" on his first day with only 150 mg. Two days later, on his second time with only 150, he wrote, "full motor function for half an hour." A week later, he wrote, "I have hell Crash since last night following a 200 mg

day. Sleepless, heavy, panicked. What's more hell: to reduce to 150 every day or get off Sinemet totally? What are the risks and consequences of going to zero Sinemet?"

The next day, he wrote, "I have only taken 150 today but I'm feeling already overmedicated." The following day, he wrote, "I am completely lost. I hardly can read and understand the emails. I don't know what dose I have to take."

For most of the fourth month, he only took 150 mg/day or less of levodopa. His new problem this month was not withdrawal but the limpness that accompanies recovery.

Four and a half months after he started reducing his drugs, he emailed me from the hospital. His family and caregiver could no longer make sense of his symptoms, and he was hospitalized so that he could be under observation while completely stopping levodopa.

His neurologist in Switzerland was very open to unconventional treatments and readily admitted that Viktor could no longer tolerate levodopa.

After six days in the hospital with no levodopa and with sleeping pills at night, Viktor wrote, "I'm still in hospital. I am without dopa for six days. I move quite slowly but normally and I am independent from help. I have a few moments of good mobility in the morning and during the day. I often have tremor, sometimes heaviness, and bit of tension in the legs and pelvis. Sleep is OK. Tomorrow they may start me on an agonist."

He wrote again, "I am the 13th day off dopa without serious consequences and move fairly well. It appears that the withdrawal effect was stopped by the increase of the agonist. That means that the agonist compensates the effect of dopa but in another way. That does not resolve addiction but shifts the problem on another level. But that seems to be the only way traditional medicine can handle the subject. Let's see if it works. In any case we should be able to learn how withdrawal from a high dose of the agonist (Cabergoline/Dostinex) works."

He wrote two days later, in answer to my greedy questions about his response to the dopamine agonist, "With the agonist I still have some "twitching" – contraction – around the eyes similar to the one I had in Santa Cruz, but not in the neck. Am I lightheaded, you ask? Yes, but not especially. I have no nausea and no insomnia – but I take sleeping pills and I wake up quite early. I shall try to sleep without pills this or next week. I move almost normally. My health is still fine."

In the month that followed, Viktor and I exchanged many emails about his experience in the program. He wondered why he needed the agonist medication if he was in fact getting better. He wrote, "I am convinced that if I no longer have Parkinson's, I should not need any medication." He did not accept the possibility that the drugs themselves can inflict permanent damage and cause drug-induced parkinsonism, after which increasing amounts of medication are needed to treat the damage.

He also felt strongly about our program's lack of sufficient warning about the dangers of medication: "You knew the risks of these drugs from experience, and, as I see it, you waited too long to post the warnings." He disliked the tone of our newly posted (at that time) warning that doctors might give bad advice; he thought that our warning wrongly implied that doctors were acting maliciously. He felt that our program was to blame because we should have known better than to have worked with medicated patients.

I replied, "I think you overestimate how much time I have had since I realized what was going on. The first deaths from overmedication just occurred in this last year. It

was only two months ago – after we posted the warning – that research was published that proved addictability of drugs can change as circumstances change. Prior to that, even though we warned patients that they might suddenly become addicted to the drugs if they recovered, they laughed at the idea. We posted the warning that “your doctor’s advice may be harmful” on the website just a few months ago – when the third patient was “stabilized” by a doctor who doubled her drugs over a period of three days and sent her home just before her violent spasms began.

“In the year 2000 we were still adhering to the conventional thinking, which was that a medicated patient should work with his doctor, and that it would not be hard for a person to quit taking medication if he started feeling better. Now, less than two years later, we have reluctantly rejected all the conventional wisdom, reversed our position and posted warnings on the Internet.

“When I first met you, in January 2001, I was not yet aware of the real power and dangers of these drugs. I suspected by then that they were bad, but I didn’t realize

- 1) Just how dangerous and addictive they were.
- 2) A recovered person was more at risk than a PDer.
- 3) MDs’ training was based on incorrect information about the drugs....

“...But you are right. We have an obligation to ‘first, do no harm.’”

We took Viktor’s criticisms to heart. Two weeks later, the PD team of Santa Cruz decided by consensus that we would no longer work with medicated patients. We changed the warning on the website to state that medicated patients should not follow the protocols that we offered.

One of Viktor’s last emails to me said, “Set up a pilot study with newly diagnosed and unmedicated patients. Show the effectiveness of the program in a controlled way. Dream it. Do it. And you will succeed. (I found the last eight words in a book. Nice.)

Take care,
Viktor.”

Summary

In summary of this chapter, Buzz and Viktor were both in their fifties, in good health other than their Parkinson's disease, and both had been diagnosed about four years earlier. Both went through approximately three and a half months of drug reductions from 400 mg and 500 mg, respectively.¹ They both suffered from periods of crushing immobility.

In addition to the immobility, Viktor suffered from adverse effects of his pills after nearly every dose after he became addicted: terrible tensions of impending doom in his chest, freezings, Ons, Offs, Switching, Build Ups, Roller Coasters, and, very possibly, long-term addiction-related damage such that he will always need some amount of antiparkinson's medication. Given what we know about drug addiction, we have to suspect that Viktor's suffering during his increasingly excruciating drug decreases was exacerbated due to his week of pre-reduction euphoria and gross overmedication. Buzz had never experienced euphoria or symptoms of overmedication and, because he stopped his drugs abruptly, no dopamine excess-related traumas.

Viktor is still dependent on a dopamine-enhancing drug, albeit a somewhat more moderate one (in terms of side effects) than he was taking originally, and at a much lower dose. He may always need medication now; his brain was certainly affected by the addiction as well as by the genuine traumas that he underwent. Whether or not this brain damage is short term or long term remains to be seen.

The question arises: had Viktor decreased his drugs before he became over sensitized and addicted, might he have avoided the tensions and cramps, the mental fog, the euphorias, and the violent On and Off swings, with their Roller Coasters, freezings, and Crashings? Might his drug decreases instead have produced a simple decrease in drug effectiveness, an unveiling of his underlying PD symptoms? In such a case, his symptoms of drug decrease might have been an increase in slowness, rigidity, poor balance, or tremor – the four characteristic symptoms of Parkinson's disease. These symptoms, though frustrating, humiliating, and often very painful, are nevertheless a far cry from the excruciating physical agonies, panic attacks and night terrors of drug withdrawal. And do not forget, despite Viktor surviving these assaults, at the time of this writing he is still needing a powerful antiparkinson's medication, Cabergoline.

On the other hand, Buzz, with his drastic approach to medication reduction, might easily have gone into limbic shock and died from heart or diaphragm spasms or arrhythmias. He certainly ran the very real risk of being hospitalized against his wishes and having high amounts of medication forced on him. (It is likely, based on our past experiences, that the doctor in charge of such a case would have increased his dosage

¹ Actually, although Buzz was taking 600 mg of levodopa a day, he was *absorbing* probably around 400 mg/day. Here's why: for some unknown reason, his doctor had prescribed the Sinemet with the lower percent of carbidopa. Usually, the lower carbidopa amount also causes a decrease in available levodopa. This means that a person who takes a 10/100 pill will have less available levodopa than a person who takes the more common 25/100 pill. (The first of the two numbers is the amount of carbidopa.) It is impossible to guess how much less levodopa was available to Buzz than to Viktor – no two people process the medication in exactly the same way.

daily until he was moving well. In Buzz's traumatized, limbic-depleted condition, this could have taken 10 days, by which point he might have been up to 1000 mg/day.

Questions

While Viktor's route was more painful and possibly more damaging in the long run, was it possibly the safer and saner route to traverse? What lies ahead for Viktor as he continues to work on reducing the agonist? After all, we have seen with Becky, Rudyard, and Sammy that the agonists, while less traumatic than L-dopa and Eldepryl during the short-term (ten weeks) phase of reduction, may possibly do more long-lasting damage in terms of creating long-term depression that will never again be satisfied by anything less than a return to the drug. On the other hand, if Viktor had started reducing his drugs slowly, in advance of recovery, who can say what might have transpired? It would be pure conjecture to offer an opinion.

It is pointless to ponder "what ifs," or to extrapolate from these two cases the ideal style of drug decrease for any other individual. In this particular pair of cases, the rapid hare unexpectedly fared better than the steady tortoise – defying tradition, but not necessarily proving that one method is safer than another. However, though I do not advocate either one of their extremely intense methods of drug decrease, their cases may suggest promising directions for further research, and so I have included them in this book.

Although their cases proceeded differently and had different conclusions, Buzz and Viktor had one factor in common: they were both looking for something more than a return to their "old, healthy" self; they were both looking for the deeper reason behind their illness. They were looking for answers, not just a fix. Buzz and Victor had never met each other, but they had this in common: their greatest hope was that others might learn from their experiences.