

*“What goes up must come down.”*

*Sir Isaac Newton*

## 14. CYCLES OF CHANGE

### AN OFT REPEATING LOOP OF UPS AND DOWNS

#### **No dose stands alone**

Drugs taken up to ten weeks prior influence the daily patterns, single dose patterns, and several-day patterns. Although patients were trying to make daily explanations for their Build Ups, Deficits, Roller Coasters, Crashes, and Slides, the ten-week perspective was always more significant.

#### ***Ten weeks, more or less***

Ten weeks is approximate, of course. It may take six weeks or fifteen for the drugs to come to equilibrium. Severe adverse effects of the drugs might linger for half a year or be semipermanent.<sup>1</sup> However, the most common time frame for the worst of withdrawal or the maximum benefit from increase does seem to be very nearly ten weeks to the day, as if there is a timed mechanism, a reset button deep in the limbic zone that has ten weeks as its refresh rate. However, due to the vagaries of weather, other health issues, relationships, and expectations, there may be other time frames to work with as well. I may use the term “ten-week phase” in this book. You will understand that this is an estimate.

Many of the current manufacturers’ instructions for dopamine-, serotonin-, or norepinephrine-enhancing drugs hint at a two to three month period before the drugs reach full effectiveness. Our patients who were reducing drugs saw a marked shift in reduction symptoms within a similar time frame. Whether or not the ten-week period has to do solely with accumulation or solely with reset buttons, is a combination of both, or is reliant on some process of which we have no idea whatsoever doesn’t really matter for our purpose. What does matter is this: the pill you are putting in your mouth today may be working in conjunction with all the pills you have taken in the last ten weeks.

Knowing that every dose was being affected by doses up to ten weeks earlier made the whole process of drug reduction even more daunting. How could one possibly

---

<sup>1</sup> We had first read the “ten weeks” number in *A Primer of Drug Action, Non-Technical Guide to the Actions, Uses, and Side Effects of Psychoactive Drugs*. It was with regard to one phase of cocaine withdrawal. It stated, “The withdrawal phase, which lasts 1 to 10 weeks, is the period of maximal relapse potential and drug craving which...may be associated with reduced dopamine transporter levels and reduced frontal cortical activity” (p.126). The rest of the text made it clear that the drug craving might be semipermanent, and yet, it had been repeatedly observed that week one to week ten was the time frame when a person was most at risk of relapsing into drug use. My patients often want to use this ten week number as an exact, inviolable number, and are often discouraged when they continue to feel like the underside of a shoe for eleven weeks, or even fourteen. However, even patients who feel miserable beyond the ten weeks do notice that right around ten weeks they can tell that something, however subtle, is improving.

track all the cumulative effects during a drug decrease? Maybe we needed a system to keep track of all these factors. We found, instead, a cyclical pattern that gave us what we needed.

## CYCLES OF DRUG REDUCTION SYMPTOMS

The overmedication phase (adverse effects, dyskinesias, build ups) that bestirs one to initiate a drug reduction in the first place may recur again, after a person has gone through the various phases of drug reduction. The cycle appears thus: Overmedicated; Drug reduction; Vacation/Slide; Withdrawal; Back and Forth and/or quick Turnaround; Feeling Good; and back to Overmedicated again. The timeframe for completion of this cycle was, very often, ten weeks. The patterns repeat themselves over and over, following nearly every drug reduction.

The patterns described in the previous chapter could be used as signposts in the confusing welter of drug reduction symptoms to show where a person was in the cycle. Although symptoms on any given day might not be significant, what were significant were the repeating daily patterns, or subtle *shifts* in the daily patterns or dose-related patterns. Amazingly, if a person could think about his medication in terms of months and not days, and understood the significance of the patterns, he might be able to adjust his drugs to appropriate, maximally beneficial/safe levels without undergoing ferocious drug withdrawal symptoms.

### Details of the cycle

Here, complete with signposts and (estimated) time frames, is a more detailed look at the cycle of drug reduction that might occur following a moderate decrease.

1. Overmedicated – This phase is marked by adverse effects: dyskinesia, overly bright eyes, illogic, unwarranted exuberance, daily Build Ups, Roller Coasters, freezing, or painful dystonias whether On or Off (most pain-causing dystonias are side effects of the medication).<sup>1</sup>

*Time frame* – How long might this phase last? If no changes are made in medication levels, this phase will last indefinitely and will most likely continue to worsen. Even if the medication is reduced, these symptoms may still continue for a few days.

2. Vacation and Slide – The symptoms of overmedication may begin to retreat: a possible decrease in dyskinesia, tension, insomnia; fewer Build Ups, Roller Coasters, or drug failures.

If one begins to feel downright healthy and well balanced, this is referred to as a Vacation, or the calm before the storm. While these overt signs of improvement are occurring, the brain may be invisibly sliding down into a state of limbic insufficiency.

*Time frame* – This phase may last one day to twenty days, ten on average. Usually within ten days there are hints of drug reduction symptoms. If a drug reduction was inadequate, there may be a return to symptoms of overmedication within a day or two of

---

<sup>1</sup> Drug excess symptoms include *any* form of adverse effect, even if an MD says it's "normal."

the Vacation. Such an abrupt return to overmedication does sometimes occur. It may signify that another immediate drug reduction is in order.

3. Limbic Stress – This phase abuts the dreaded agonies of drug withdrawal. During this time drugs may appear to be ineffective, or if they work, they may provide uneven coverage. Possibly only a few of the daily doses will be effective. It is just as likely that none of the doses will work.

Symptoms include: nausea, free-floating anxiety, insomnia, immobility, shaking with terror, or frantic, restless pacing. Any learned symptom of dyskinesia may appear, including ticcing and spasming of all muscles, including lung and heart.<sup>1</sup>

*Time frame* – These symptoms usually worsen over a period of up to ten weeks. After ten weeks these symptoms may abruptly cease or they may begin to ease up ever so slightly. The change after ten weeks may be so subtle that there may be only a sense that a change is pending, even though the symptoms are still raging. Prior to this, there may have been a sense of impending doom and ever-worsening symptoms.

After ten weeks there may be moments during which a person begins to resume brain clarity, even remembering, at times, why he made a drug reduction in the first place. The time when a person is most likely to succumb to resuming the drugs at the previous, overmedicated level is in the span from ten days to ten weeks after decreasing the medication. After ten weeks have passed, a person might begin to see that, just possibly, his body is starting to readjust to the decreased amount of drugs.

4. Back and forth – This sometimes-tortuous phase can feature fewer drug withdrawal symptoms, or the drug withdrawal symptoms become erratic. Just when one starts to be certain that the withdrawal is over, there may be a day, two days, or alternating days of drug withdrawal, even while days of relative peace and normal movement are occurring.

Some doses of drugs might be effective or partially effective. It may be that the afternoon or evening doses are more predictable than they have been (daily Deficit). The effective doses may be less prone to crashing than they were before. The switching phase of the drugs may or may not be much worse, depending on whether or not a person is producing more native dopamine. This phase may precede or take the place of the Turnaround, which is the time of transition from insufficient drugs to excess.

*Time frame* – This phase may last anywhere from a day or two to several months. In general, a person who has never been addicted and who makes prompt reductions at the first flush of feeling good or at the first inkling of dyskinesia or grimacing will spend less time in this phase than a person who has become addicted. If no addiction has ever occurred, a person may be able to get through this phase in a matter of days or even hours. It can be quite abrupt.

---

<sup>1</sup> A complete list of drug reduction/withdrawal symptoms is in Appendix 3.

5. Feeling good – This phase might start small and build or burst forth overnight, fully blown. The medications may suddenly switch from unpredictable to utterly predictable. Symptoms are: “fantastic!” and “feeling human again!” This stage is particularly dangerous. After the long, slow slog through drug withdrawal, the temptation can be to linger as long as possible in this medication-induced glow.

It is far safer to be perpetually undermedicated than to ever, however briefly, be overmedicated. Therefore, if a person who previously had Parkinson’s disease is suddenly, because of his drugs, feeling on top of the world, it should be clear to the meanest intelligence that something is wrong. Although the person may feel that he is finally balanced again, he is in fact on the verge of overt overmedication.

*Time frame* – It may be a matter of hours, or it may be a matter of up to three days, but inevitably, the good feelings of this period will make way for symptoms of overmedication. In fact, it is overmedication that is causing this glee. The turnaround, the abrupt transition from feeling lousy to feeling great, is usually an indicator that a person is overmedicated.

If a person *were* perfectly medicated, neither excessive nor deficient, he would not feel particularly good. He would feel a peaceful pause from the rigors of drug withdrawal but he would also recognize faint but unmistakable signs of those particular Parkinson’s disease symptoms that are dopamine-related: primarily, slowness of movement, thought and speech, and depression.

If the person is also recovering from Parkinson’s, he might be feeling extreme weakness and/or the exhausting but emotionally satisfying symptoms of Parkinson’s recovery (pain in previously numb areas, lack of muscle tone in areas previously rigid, extreme fatigue, unexpected susceptibility to emotions, sadness, and tears, lassitude, etc.). In either case, he should not be “feelin’ good!”

One should be either slightly affected by Parkinson’s symptoms or even experiencing the rigors of recovery, neither of which feel particularly good; feeling good – in a medicated person with Parkinson’s – is a subtle sign of drug excess, so the overt symptoms of overmedication are just lurking around the corner when one once again feels good following a spate of misery-inducing drug reduction symptoms.

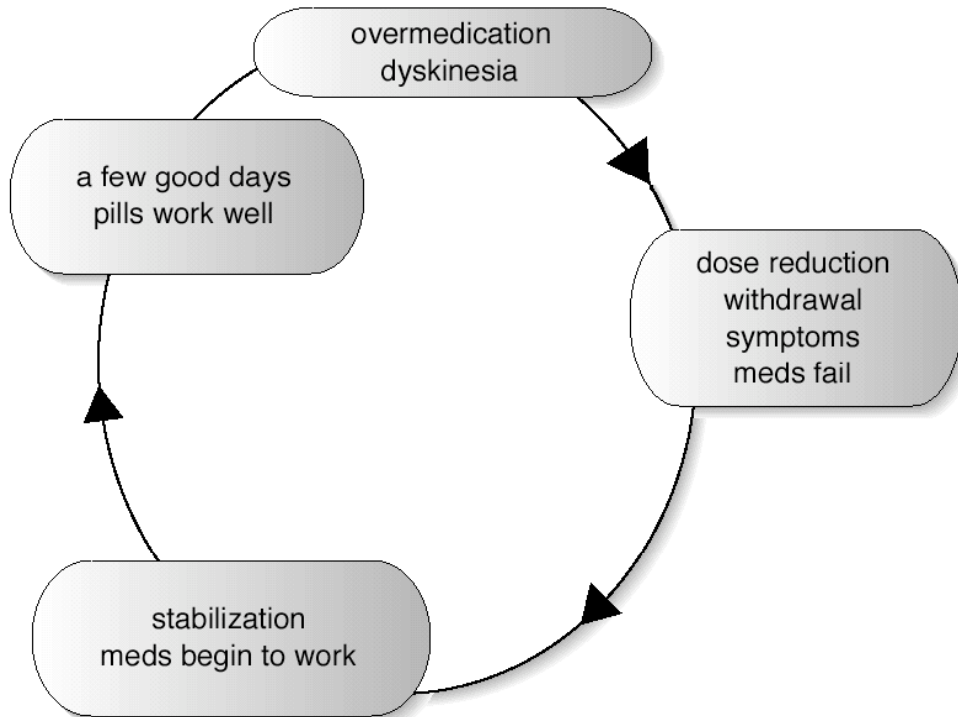
The rule of thumb is this: *if you have Parkinson’s and are taking medications, if you feel good, you are probably overmedicated.*

Only when a person is completely off the drugs can he finally risk feeling truly joyous. Only then can he be certain that his joy is coming from his true nature and not from an overloaded limbic system.

Again, this phase usually lasts one to three days.

6. Overmedicated – This phase is marked by overt adverse effects: dyskinesia, overly bright eyes, illogic, unwarranted exuberance, daily Build Ups, Roller Coasters, freezing, or painful dystonias whether On or Off.

*Time frame* – How long might this phase last? If no changes are made in medication levels, this phase will last indefinitely, and will most likely continue to worsen. If the medication is reduced, these symptoms may continue for a few days.



The drug reduction cycle

This cycle might be repeated after every drug reduction. The most obvious way to know that a person has completed a cycle is the return of inner peace, or worse: symptoms of overmedication. As soon as a person feels good, he might need to make another drug reduction and begin the cycle anew. This disheartening realization – that there could be no pauses during this cruel cycle – was almost the hardest thing for recoverers to bear. The very hardest thing was the fact that, if a person had ever been overmedicated, however briefly, he might never recover completely from the drug-induced brain damage. Instead, after recovery from Parkinson’s and getting completely off the drugs, he might linger forever in the Back and Forth stage of the cycle: on some days he may manifest no Parkinson’s symptoms; on stressful days, PD may appear full-blown.

***A lifetime of permanent back and forth***

A person who has become addicted to the medication may always be in the back and forth stage after he gets down to a small amount (none-to- 150 mg levodopa/day).<sup>1</sup> If a person has ever spent too many hours on the drugs at excessive levels, he may, for the rest of his life, have days when he feels good alternating with days on which he feels miserable, even if he gets off the drugs completely and has no Parkinson’s symptoms, per se.

Although he may eventually get off the medication and be able to live well on a maintenance dose of 25 mg levodopa/day or a minute dose of whichever DED he prefers, for the rest of his life he may always hover at the edge of dopamine sufficiency, on the lip

<sup>1</sup> For comparable amounts with other drugs, please see chapter 17.

of the threshold. Any higher dose will push him over the edge into adverse effects and ever-increasing addiction.

The very small dose of DED may be required to compensate for the addiction-induced brain damage. This person may never be truly at peace if he is not taking the drugs. Without the medication, a person who was addicted may find that he simply cannot bear the tardive dyskinesia, the painful, heightened sensitivity and depression that may ever be his lot, should he stop the medication completely. And yet, even at extremely low doses, the medication may cause dyskinesia, mental imbalance, and gradually worsening parkinsonism. This person may forever have symptoms of overmedication, even at microscopic doses, but without the medication, his discomfort may be too great to support a life worth living. A person in this difficult situation may find that the slightest change in the weather, the onset of flu, or the mood fluctuations of everyday life can send him into a tailspin that can last for days.

In our experience, anyone who takes dopamine-enhancing drugs for a period longer than three days after having manifested even the slightest signs of recovery from Parkinson's is at risk for a lifetime of back and forth even if he gets off the medication or is somewhat stable at an extremely low level such as 25 mg levodopa/day.

### ***Perpetual ticcing or tremor***

If a person's tremor was caused by or increased by medication, he may, for the rest of his life, manifest shaking at the slightest sign of stress, or he may develop constant tardive dyskinesias even if he recovers from PD – just like some people develop years later after having taking antianxiety drugs and antidepressants. A person who had tremor with his Parkinson's who *ever* took the antiparkinson's drugs will probably be especially susceptible to tardive dyskinesia even if he recovers from PD. As for the rest of his Parkinson's symptoms, they may continue – symptoms now of drug-induced parkinsonism.

### **Pleading for mercy**

Strangely, or maybe not so strangely, patients who were starting to feel truly good again after months of withdrawal despair would beg me to “allow” them to postpone the next drug reduction. I always reminded them that I had nothing to do with their drugs. Each person had to make his own decisions about his medications. I was not able to say anything one way or the other, except to point out what people had done that appeared to be effective, and what people had done that appeared to be a formula for disaster. And still, after I explained all this, they would cry and ask if I couldn't make an exception in their case.

No matter how many cycles of drug reduction they had experienced, each cycle seemed new at the time. The limbic area does not seem to have much ability to reason and remember. It cannot remember that the bad days of drug withdrawal have been followed, every time, by an improvement in overall health and drug function. The limbic system lives one breath at a time. It only knows that the drugs made it happy, and that during reduction it is desperately unhappy.

Laurel, as described in the last chapter, made the brave decision to make another reduction straight away. She was atypical. Most patients working without a drug gatekeeper chose to postpone making subsequent drug reductions.

### ***Feeling good was bad, feeling bad was good***

Feeling good was a sign of overmedication? Offs were caused by too much medication? This was painfully counterintuitive.

Nearly all the doctors, except for those most recently out of school, would treat the Offs as if they were symptoms of insufficient medication. The crazy idea that having Offs, Build Ups, and increasing periods of immobility were signs of drug excess was the opposite of common sense. Nearly every patient struggled with the idea.

When patients were Off, they had only one thought: how to get On. When Off, no matter if the Off was due to a Build Up or was occurring in the middle of a Roller Coaster, More Drugs always looked like the answer.

The spouses could understand the premise. The people with the drug addiction really struggled with it. They might be able to understand it while they were in my office, but they could not understand it the moment that the Off began. Remember, anyone who is so far gone that On-Offs are occurring *is* addicted, and therefore somewhat addled.

### ***Blurred signposts***

I found one thing to be fascinating: patients were usually very honest when writing up their journals or filling in their graphs. However, in my office, when confronted with the evidence of their own charts or journals, they were, addict-like, often careless with the truth.

For example, Becky would look me in the eye and tell me that she had reduced her medication. I would point to my copy of her weekly journal and show her that she had increased. She would be baffled every time.

A few addicts were honest if they were Off. Most were not capable of objective, reflective self-analysis whether Off or On.

## ***Hua To***

Hua To Huang had been slowly reducing his medication for over a year. He had been hideously overmedicated when he started working with me. His dyskinesic contortions of face, neck, arms, legs, and torso were pitiful. He was only 40 years old. He had been diagnosed several years earlier. He appeared to be recovering: his facial expression returned, his sense of humor came back, and some of his movements appeared to be more fluid. He had never had tremor and had no signs of hand-tapping tardive dyskinesia. Of course, the drugs were masking much; we had no way of knowing what his underlying PD symptoms actually were.

He was deeply sincere and scrupulously honest in his self-evaluations when Off. At such times he could objectively report to me that he had been overmedicated during the week and tell me about his dyskinesia. However, when he was On, he was unable to tell me whether or not he had been overmedicated. Sometimes, even while his head jerked violently back and forth, he would tell me that he hadn't been overmedicated in the last week, and no longer had dyskinesia. If I pointed out that he was having it right before my eyes, he would try to explain to me, "Basically, what is happening is, I am moving right now but, basically, it is not a problem."

His compassionate wife might plead with him to tell the truth, but he had no idea what she meant. On the other hand, he was able to record faithfully in his charts that he had been over the top during his Ons.

### ***Altered self-awareness***

It almost seemed as if there was a split personality involved in some of the medicated patients. It was as if the medication allowed a person to feel confident in his confrontations with the world. A person under the influence was able to behave with confidence and joy, seemingly unaware of his drugged condition. And yet, it seemed as if there was always another person inside the cheerful (or tormented) shell that was able to recognize the drugged person as a mere puppet.

I suppose that this is not so strange at all. We all know of people who, when drunk, are supremely self-confident and a friend to all, can see no problems with their behavior and may not even consider themselves to be under the influence. And yet, many an imbiber, if you look him in the eye and ask with sincerity whether or not he is drunk, may answer happily in the affirmative. One part of him knows that he is drunk, and yet the part of him that is interacting with the world may feel supremely confident that it is his true, brilliant self that is manifesting.

For this reason, alcohol is considered (in drug study circles) to be a “disinhibitor” as well as a depressant: alcohol makes a person feel as if his inhibitions are gone, as if his drunken behavior is more honest, capable, loving, and intelligent than his everyday, inhibited behavior. Of course, as we all know, a drunk has less clarity of thought, is less capable of physical function, is more susceptible to mood swing, and is less able to assess his own performance than a sober man.

The drunken *illusion* is one of increased openness and affability. The *truth* is, a drunk is addled. And, most significantly, there is usually a second personality, a higher awareness, hidden behind the mask of drink. This inner person knows perfectly well that he is, in fact, a wise man cloaked in the temporary garb of a stupid drunkenness that thinks itself clever.

### ***The inner wise man***

In the case of PDers who were recording their daily symptoms, it appeared that it was usually the wise man, the objective man behind the drugged man, who kept the diary. It did seem that people taking antiparkinson’s medications were able to objectively write down their symptoms of the day. And yet, during an interview with me or their spouse, they might not be able to assess their past week’s symptoms with any degree of objectivity whatsoever. I would be reading their journal, noting that every dose of medication was causing dyskinesia, but when I turned to the patient to say, “Looks like a lot of dyskinesia this week,” the jerking, grimacing patient might respond with, “There was no dyskinesia this week.”

How then, if a person’s objectivity is altered during drug use and during drug withdrawal, will he be able to make use of these signposts? Correctly interpreting these signposts might require a painful degree of honesty and symptom analysis. This brings us to the need for a helping hand.

## NEEDING HELP

Nearly all the successful patients, the ones that stayed in the program and especially those who got off their medications, were the ones who came with a partner. The friends, caregivers, or spouses of the patients provided critical support. Very often, people going through medication adjustments would be confused, argumentative, hostile, and even violent when spouses would tell them that they were having dyskinesia or other symptoms of overmedication. The valiant spouses who kept on in the face of this seeming ingratitude and helped to analyze every hour of their PD partner's life for several years were equal heroes in the experience.

Of all the medicated patients that were trying to reduce their drugs, only two people who lived alone succeeded in getting off their medications.<sup>1</sup> All the others, those who lived alone and those whose spouse/partner felt that the PDer needed autonomy with the drugs, failed to successfully reduce their medication. Worse, those who were living alone or trying to go through drug withdrawal without the support of a friend or spouse were the ones who were most likely to go crazy and use the drugs to create euphoric On! episodes, ultimately ending up in care facilities.

### *Expecting the doctor to be the support person*

Even the relatively objective spouses had trouble at times determining where a person might be on the cycle of drug decrease. So many questions arose: if a person was not showing signs of improvement nine and a half weeks into a drug reduction, did that mean that the reduction had been too severe? What if a person felt great after the evening pill but still had horrible Offs in the morning – was this person in a Deficit, a Turnaround or simply in a moderate stage of drug withdrawal? Their best hope at figuring it out was by having records of every behavioral change over the last ten weeks.

No doctor can be expected to follow the dozens of daily symptoms and guess whether or not a person is sliding up, sliding down, on the cusp of overmedication or nearly done with withdrawal. No one can guess whether or not a particularly difficult withdrawal phase is due to an over-ambitious reduction or the result of having lingered too long in Feeling Good in a previous reduction. There are so many variables! Unless he lives with you, it is not reasonable to expect your doctor to be your support person.

### **An example of medication gatekeeping**

To illustrate how difficult it can be to decide whether a person is undermedicated, overmedicated, in withdrawal, or simply suffering from Parkinson's, and to drive home the idea that a drugged patient cannot go this alone, let me share from Sophia's purple journal.

---

<sup>1</sup> Taylor Paul and Buzz. I am referring in this statement to those people who had been on dopamine-enhancing drugs for more than a few months. A few people such as Elaine and Sammy, who had been recently diagnosed and were only taking very small, starter doses of medications at the time they joined our program, were able to get off the drugs quickly by themselves.

## Hjalmar

Sophia was right beside her husband Hjalmar every step of the way. It was she who decided when and by how much he should reduce. She kept the little purple notebook of his doses and any symptoms that might be significant. Hjalmar had been diagnosed with Parkinson's disease eighteen years earlier, in 1980. His original symptoms were right hand tremor, no right arm swing, and utter lack of facial expression; he was only 47 years old at the time of diagnosis.<sup>1</sup> Dr. Rafferty had been his neurologist from the start, and there was warm, mutual respect between these two men who had been doctor/patient for nearly two decades.

At the time of this journal excerpt, Hjalmar had clearly started recovering from Parkinson's (Dr. R had remarked on his many striking improvements), and had been slowly reducing his medication for over three years. He was down to 300 mg levodopa/day (3 of the 25/100 Sinemet, regular) from a high in 1998 of 1100 mg levodopa/day (combined Sinemet regular and Sinemet CR), Artane (an anticholinergic drug, 5 mg three times a day), and Mirapex (a dopamine agonist, .5 mg three times a day).

After he had been at 300 mg levodopa/day for several weeks (after having decreased three weeks earlier from 350), Sophia noticed some strange new patterns emerging: drooling, shuffling, and inability to feed himself. These symptoms seemed to actually get worse two hours after each dose, but she felt that they were clearly signs of Parkinson's, not symptoms of overmedication. Hjalmar continued to worsen for another two weeks, and so she increased the drugs slightly to an average of 325 mg/day. He got much, much worse, so she decreased for two weeks to 275 mg/day. He got worse still. So she increased again to 300 mg/day. This made him frantic and yet he continued drooling and unable to move. So she decreased again. He got still worse. She went back and forth over several months. Here are some of her notes towards the end of this difficult time. She made notes every day and created a week summary from the daily notes.

As you read through this, try to determine for yourself whether Hjalmar is in drug withdrawal or overmedicated. Remember, adverse effects of Sinemet can include drooling, slowness of movement, incontinence and hallucinations. Symptoms of drug withdrawal can include drooling, slowness of movement, incontinence, and hallucinations. Parkinson's disease can have symptoms of drooling, slowness of movement, and incontinence. I have put the dosage changes in italics.

6-22-01: 300 mg/day all week. Very weak, drooling, leaning forward, peeing in the bed, can't get up from chairs, confused regarding urination in the daytime, peeing on the floor. Squirmy dyskinesia. *Reduced 3 p.m. pill in half due to dyskinesia yesterday.* Last night dry at bedtime.

6-29-01: Couldn't figure out how to put his clothes on. Stuck to the floor all the time and squirmy dyskinesia after just one pill in the morning.

---

<sup>1</sup> Photographs of Hjalmar's return of facial expression were included in the article: J. L. Walton-Hadlock, "The Use of Yin Tui Na and Stomach Channel Acupuncture Points in the Treatment of Facial Immobility in Parkinson's Disease," *The Journal of Chinese Medicine*, No. 69, June, 2002, p. 43-47.

7-6-01: Wakes up fine, but after one pill he is stuck to the floor, anxious, bent over. One day *he forgot his 3:00 p.m. pill* and he was less stuck in the evening.

He seems to be better with fewer pills, but his last reduction was so recent, and he is drooling and bent over so much of the day already, and last time when we reduced he could barely move. Reluctant to reduce again.

7-13-01: Walking slowly, different than the freezing, this is a completely new pattern of slowness. He must be overmedicated. One day *he took only 200 mg* and did so much better, and in the mornings, prior to taking his pill he does better than an hour after taking it. But he can no longer get in and out of bed by himself, he is profoundly weak, and slightly paranoid, I think. Last night he said, "I'm afraid I'll get pregnant." He's confused in general. *Reduced to 200 mg/day.*

7-19-01: Very weak. Needs help throughout the night, falling down even with his walker. Drooling, incontinent, cannot get into bed. He can't even wash his hands or face. He's getting crazier. He was fighting me when I tried to help him, gripping me too hard. He can't feed himself. He is much worse this week; evidently he did not need a reduction in medication after all, he must have needed an increase. *Back up to 300 mg/day.*

7-26-01: He's stuck, drooling, incontinent, singing, laughing, noisy all night. His right hand doesn't work at all. He simply can't use it. Up every hour to pee at night, smiling away. He fights with me when I try to help him to the toilet. May not know who I am. I think it was a mistake to increase the drugs. *I reduced him down to 200 mg/day* and the next night he slept better.

8-3-01: A rotten week! Had helpers over, and he was fighting with them. Found him in bed one morning with only one diaper on, don't know what he did with the other one or his pajamas. Needs help with everything. For the first time in his *life* he was too weak to take communion at church. He needs help with everything. It's as if he's given up trying. He's drooling and weak and incontinent.

8-10-01: He so much worse, *tried giving him Mirapex* – he hasn't taken that in a year, but he's so bad. After two days with Mirapex he was much worse, craziness, hallucinations, thought he had a pink bunny in his hand. Wanted me to get rid of the Coke in his hand. He wasn't holding anything. Thought he was up on the roof. He was sitting in his chair. More stuck. *Stopped the Mirapex.* I forgot his afternoon pill on Tuesday and he made more sense that evening, so ***Wednesday I quit giving him any pills.*** Simply don't know what to do anymore. He's crazy with fewer pills, he's crazier with them. I know this is too fast, it might be dangerous, I can't take it anymore. But he's been dry at night the last three nights. Still getting stuck and drooling.

Now, based on the neat and clean theory of easy to interpret cycles, just what was going on with Hjalmar? He had not had any obvious days of Feeling Good, and yet, based on the laughing and singing all night, together with the hallucinations, Sophia finally decided that the real problem was, in fact, overmedication. You need to bear in mind that Hjalmar had been one of my first patients, and every single dose reduction had been an unpredictable adventure. At the time that Sophia decided to stop the drugs cold,

we had only recently determined the 10% rule to prevent life-threatening withdrawal, and we had also seen a few instances where a person in recovery needed to make reductions faster than 10% in order to avoid hysterical mania. (In these latter cases, a person went from undermedicated to riotously overmedicated, seemingly overnight. In these cases, the problem was not life-threatening withdrawal, but mind-threatening overdose.)

Sophia was trying to guess, from the maze of symptoms, whether Hjalmar was at one extreme or the other, or whether he was simply manifesting the true face of his Parkinson's disease. The "squirmy dyskinesia" and hallucinations decided her: he was over the top.

8-17-01: One night he completely soaked the bed. Don't know how much fluids he had. Four nights later, slept through the night, and dry! Yes! Daughter Mary stayed with him for a couple of hours on Tuesday and says she will never do it again. She thinks she hurt her back trying to pull him up out of his chair. He went for a walk with Dwight this week, but still needing help with almost everything. DROOLING all the time.

8-24-01: Washed himself and got himself partly dressed. Eating better by self but still wants help with everything. Drooling still terrible. Got out of chair by himself but needed help the rest of the day. Did a good job at the NovaCare facility Weight Training for Seniors program, raised to level 4, but slept the rest of the day. On Tues the bed was dry and he walked three times around the (.33 mile) park loop with Dwight, but needed help with everything the rest of the day. Weds, nothing special, but he can't convince himself that he can do anything without being helped. Fri, at NovaCare increased two of his weights to level 5 – still can't do anything but drool at home.

8-31-01: Everything the same. Sure would be nice to see some improvement. Weds, got off toilet by himself. Sat. absolutely grinned at his new haircut. (At the time Hjalmar had started our program he'd had no facial expression for over twenty years even when medicated.) We had company for an hour or so and I only had to wipe his drool once! Rest of the day needed help with everything. Fixed his own lunch one day!

9-7-01: Drooling might be slightly less. 3 times around the park (no walker, as usual).

9-15-01: Went to Community Theater last night, didn't drool too much. Friday he took himself to the bathroom. Needs help with everything, still drooling. Last night couldn't even eat pizza, the easiest thing to eat. Wanted us to feed it to him. Arms increasingly rigid. Did I do wrong to stop the medication?

9-28-01: Less drooling the first half of the week. Walking a mile in the park three times a week. Helper comes in three times a week to give him a shower. He is having trouble feeding himself. *But two times this week I had a real conversation with him, the first real talks we've had in nearly ten years.*

This week, at his weekly acupuncture session, he expressed an opinion for the first time as to what he wanted help with: "Could you do acupuncture on my mouth or lips? Sophia has a hard time with the drooling." This thoughtful remark nearly reduced Sophia to tears. Until now she had never been able to tell if he even knew what she was

going through. The “two conversations” that they had had were about his concerns for her, wondering what would happen to either of them should the other one die first. He wanted to know if she had made any plans in that direction. After nearly twenty years of mind-altering drugs he was sincerely curious and concerned about the future and aware of the needs and feelings of people around him, for the first time in a decade. He was also self-conscious about his drooling for the first time.

10-4-01: Terrible drooling, needs help with everything, but sometimes could feed himself. Walked a mile in the park two times, did his weight program. His sleep is fantastic, and his voice is reasonable.

His voice had been inaudible prior to starting our program, and although his voice had returned, it had disappeared again around the time that the drooling, hunched posture, and unpredictability of the medications started, back at the beginning of summer.

10-18-01: A good week. He got dressed by himself two times this week, one time he had a great big booming voice. Better able to feed himself. Got up and down from chair by himself once this week. I think he can't see real well – he sits around with his eyes closed. Did fine at the six month MD visit, though he didn't swing his arms when he walked. Dr. Rafferty was not real curious as to why we'd quit the drugs, didn't ask us any questions.

10-26-01: Ten weeks with no medication! On Saturday morning Hjalmar noticed that he was cold, and then later that afternoon that he was hot. Even with his ice cold feet he has never noticed temperature in his whole life! Slight improvement in dressing and eating, balance is lousy but no falls, still difficulties with chairs, toilet, drooling, and initiating movement. Sleeping a lot. Overall, much more calm and manageable than those last few months on the drugs.

11-2-01: Same this week, lots of drooling, sleeping. Better bladder control. Lots of talking in his sleep. His mental clarity is fine. In Sunday school he made two contributions to the discussion, and they were good, cogent points. He hasn't contributed in years. People in church were commenting, “He's in there again.” Or, “His mind is back!” He's using his hands better this week. He got his underwear and T-shirt on by himself. He's extremely weak. He has trouble initiating movement, although he walked 1.25 miles one day. He simply cannot get up from the toilet or chairs. Much of the time his voice is OK.

Hjalmar got his flu shot, a process that stimulates the immune system and which can induce mild symptoms of illness. Whether it was the flu shot, the onset of cold weather, or the Thanksgiving dinner, he had a wild week. This was also the fourteenth week after Hjalmar had stopped taking any drugs. Here is the report of the week's symptoms:

11-30-01: Yelling in the night that his shoes were on. Hallucinated holding a coffee cup in his hand, didn't know what to do with it. Didn't remember our 30-years neighbor, eating imaginary cookies, going through the motions. Sitting on the stairs, didn't know how to get down. Pooped on bathroom floor and didn't

know it. Says he doesn't know how to play the radio or get out of bed. No incontinence, though, and less drooling. Walked about a mile, three times. One crazy day!

12-7-01: Several times reached out and turned on lamp by himself. Dressed himself several times, got into chair by himself. The week is getting better. His chronic shoulder pain is less frequent. Urination good all week. Feeding himself is slightly improved. No hallucinations.

Hjalmar told me with wry pride at the weekly visit, "Today I made my own toast and poured my own juice!"

12-21-01: Getting himself dressed. Washes up self in the morning. Only needed help with food one time. Needs help to get out of the chair but can get off stool and the high bed by himself. Also, can get out of lift chair by himself. He gets stuck in doorways or in the bathroom, but just needs a shove to get going again. One hallucination: laying in bed, thought he was stuck in a vacuum cleaner. I think that he may have been only half awake, dreaming. Dreaming is allowed! Drooling bad some days, less on other days.

I included some bits from Sophia's journal that extended beyond the ten-week period because it demonstrates just how extremely slow recovery can be. Also, it makes the point that at ten weeks (Oct. 26) there was not an abrupt return to perfect health. However, at ten weeks there was the beginning of recovery from the drug withdrawal. The most significant change was that he started to make sense; he was capable of meaningful conversation and was concerned for the welfare of those around him.

In retrospect, he probably would have done better had he reduced his medications more quickly – after first noticing recovery symptoms – instead of taking three leisurely years. Sophia, nearly 70 years old, had been understandably reluctant to make reductions, despite his increasing dyskinesia, if Hjalmar was at any time slow or having difficulty moving. This meant that she only decreased the drugs when adverse effects of the drugs became harder to bear than the weakness and other recovery symptoms. By the time he took the last of his medications, he was clearly suffering from overmedication. This overmedication and prior decades of overmedication have doubtless contributed to a serious level of brain damage. Hjalmar may never recover the degree of movement that we are hoping for. However, he does continue to improve.<sup>1</sup>

---

<sup>1</sup> As for the rest of Sophia's journal, which records Hjalmar's very slow recovery of physical function, it is too long to include here. It must be read with the awareness that he had lived with Parkinson's for over twenty years by this point, and he had been taking mind-altering, powerful stimulants day in and day out for most of that time. It was to be a long, hard haul for Hjalmar before he could engage in much physical activity. However, he still feels strongly that Sophia had made the right choices for him, and that joining our project was a good decision. As Sophia regularly points out, "All the other people who were in the support group when we joined are long dead. We must have done something right."

When Hjalmar most recently saw Dr. Rafferty, he used his walker. Although he had used a walker for years, even before starting our program, he had made it a point of pride to never let Dr. Rafferty see him using it. Dr. Rafferty said that he was sorry to see Hjalmar reduced to using a walker, after he had done so well for so long. (Footnote continued on next page.)

I included the above notes from Hjalmar and Sophia's journal to show just how difficult it can be to know whether or not a person is struggling with withdrawal, overmedication, Parkinson's, or all three. Had Hjalmar been going through this alone, he could never have made the difficult decisions regarding drug reduction. In fact, many times during the preceding years, when Sophia had made a small reduction in his drugs, she would find Hjalmar in the kitchen between meals, looking through the drawers.

"What are you looking for?"

"I'm looking for my pills."

"You already had your morning pill. You'll get another one in two hours, at 11 o'clock."

"Oh. OK. I want another pill."

Half an hour later Sophia would hear footsteps in the kitchen. There would be a replay of the above dialogue. Half an hour later, they would perform the scene again. Sophia quickly learned that she had to hide the medication and never let Hjalmar see where she kept it. During many drug withdrawal phases, Hjalmar didn't even know that she had made a small reduction, sometimes just chipping away at a part of a pill. And yet, within a few days of starting a reduction he would start looking through the kitchen drawers, feeling as if he had forgotten to take his pills.

Hopefully, this vignette conveys the difficulty in evaluating drug symptoms that may be influenced by drugs that have been taken up to ten weeks earlier, combined with symptoms of Parkinson's disease and symptoms of recovery. If the above sketch helps even one person realize that drug reduction is challenging and should only be entered into with a true friend, partner, or spouse, then the preceding pages will have been well spent.<sup>1</sup>

---

Dr. Rafferty, an outspoken opponent of Asian medicine, had attributed Hjalmar's improvements over the last three years to Sophia. "You certainly do take good care of him," he said. "He's doing better every time I see him." So when Dr. Rafferty, a deeply caring, warm-hearted man, saw Hjalmar using a walker and learned that Hjalmar was still not taking his antiparkinson's medications, he was saddened.

He asked, "Are you happier, not taking the pills and having to use a walker?"

Hjalmar replied forcefully, "I have my mind back. That is worth more to me than appearing to move well. Besides, I've made a lot of progress. My first symptom was my loss of facial expression and my tremor. I don't shake anymore, and now I can smile again."

Dr Rafferty suggested, "No, you can't."

Hjalmar, who had long awaited this opening, said simply, "Oh, yes I can..." And flashed a radiant smile at Dr. Rafferty.

Dr. Rafferty stared. Hjalmar grinned bigger, and started to chuckle. Dr. Rafferty looked slowly back and forth from Sophia to Hjalmar. He concluded their biannual visit by saying, "I guess you know what's best, and I'll see you in six months."

<sup>1</sup> What is not mentioned in the journal notes about Hjalmar is this: like most people with Parkinson's he had been tremendously driven, with powerful intensity of purpose, boundless strength, and stamina. That was not the reason he did so well in our program. I suspect that what enabled Hjalmar to survive the drug reduction and the recovery from Parkinson's were qualities more rarely seen in PDers: humility and acceptance that a plan of great beauty and love lies hidden behind the unfathomable will of God. Throughout his years with me, he never veered from his conviction that God was with him, and that every lesson he learned from Parkinson's was a blessing. Though he strove for health and battled his Parkinson's, on a deeper level he accepted his illness and embraced his battle with the same humility with which he had accepted his great physical strength and power of his earlier, pre-Parkinson's days. Those qualities of strength and purpose, so often treasured by PDers, were deemed by Hjalmar to have been only temporal gifts from God, to be used in manifesting God's love. (Footnote continued on next page.)

## Mark

Mark and Margaret are another example of how a partner can be of help during these difficult times. I will have more details on Mark's very impressive, slow and steady recovery, thanks to Margaret, in a later chapter. But for now, I will point out that one time, when Mark made a joke after weeks of staring at the walls, Margaret made an immediate, slight reduction in his drugs. Her suspicion that Mark was on an upslide was exactly right: four days later, he was having dyskinesia after his first dose of the morning. Another very small dose adjustment was all that was needed to plunge Mark back down almost to the edge of drug withdrawal, where he hovered for another ten weeks. Had Margaret not already initiated one reduction based on the simple observation that Mark had made a joke, Mark would probably have been subjected to a more violent up and down than he subsequently experienced.

Margaret was extremely tuned in to tiny alterations in Mark's behavior. Hjalmar's wife was also. Sonny's young, second wife was also very aware of any change, but her extreme resentment of the extra work required of her while Sonny was in withdrawal made her want to delay every drug reductions until a "more convenient time" or until he was in agonies of dystonia and dyskinesia. She frequently pointed out to me that she had not planned on spending retirement taking care of Sonny, and she was bitter that life was "passing her by." Sonny's reductions, when she got around to making them, were usually painful, long, drawn out agonies of withdrawal.

## Hjalmar again

For another example of a spouse detecting a positive change amidst the darkened clouds and adjusting drugs accordingly, let me insert this quickie about Hjalmar that occurred when he first got down to 300 mg/day, just before he sank into the confusing welter of symptoms described earlier.

### *Sneering at sports*

Sophia, like Margaret, was getting good at seeing patterns in Hjalmar's drug decrease cycle. She was especially excited when the following, new benefit/symptom of drug decrease occurred:

"Last week," recounted Sophia, "a friend got tickets to the Giants game up in San Francisco. Hjalmar didn't come. He's always thought spectator sports were a waste of time, but I am a complete baseball nut. So after the game – it was a great game – when I got home, Hjalmar was just sitting there in his chair, smiling, with this wry sort of smile on his face, like he used to get years and years ago before he ever had the Parkinson's. So I asked him what he was smiling about, and he said, 'I'm just picturing fifteen thousand adults sitting around getting excited watching a few grown-up men in funny clothes throw a ball back and forth.' That's my old Hjalmar! That's just how he used to talk twenty years ago! It's his real self! I don't care if he can't move very well, I've got my husband back!"

---

When God took away his strength, Hjalmar, like a shorn Sampson, grew closer, not further, from God. Despite Parkinson's disease, Hjalmar still loved Him.

By following these quick glimpses of her husband acting like his old self after decades of contented illogic, Sophia was able to summon up enough confidence that things were going the right way that she could override hers and Hjalmar's fear of further drug reductions. This little event was just one of the changes in Hjalmar that helped her make her subsequent bold decision to stop the drugs when they became so unpredictable at what Dr. Rafferty called "very low levels."

## *Summary*

There is a pattern to drug withdrawal. The drugs are not the utterly unstable and unpredictable monsters that they seemed to be when they were first discovered. However, the pattern is an extended one, a several month cycle, not a several hour cycle.

After a drug reduction, while a person is going through this long, ten-week cycle, there are signposts – daily and hourly symptoms – that indicate just where a person might be in the cycle. These signposts may be obvious, but they are more likely to be subtle.

A person who is about to step onto the path of drug reduction should be willing to seek daily help and support from someone who is willing to travel alongside. If there is no such person available, one is probably better off never to attempt reducing the medication, as the subsequent ups and downs and backs and forths invariably lead to extreme excesses of the medication. And finally, while I am shooting off warnings, no medicated person should attempt to go through the recovery process: the potential risks of recovering while still medicated are worse than Parkinson's disease.

## *Statement of purpose: review*

In case you are wondering why I am writing this book, considering that I am stating that no medicated person should enter into the recovery program in the first place, let me again state here that I never said that this book would provide a safe method of drug reduction for any and all people who want to recover from Parkinson's. This book is an adjunct to our strongly worded warnings that we will not accept medicated patients into our treatment program.

But hopefully, this book has become much more than that: the *preceding* chapters may serve as a warning for those patients, recently diagnosed, who are considering taking medication for their Parkinson's symptoms and whose doctors may be uninformed as to the nature of the drugs and the correct dosing. The details on drug reduction in the *following* chapters may be helpful for those who need to decrease their medication slowly and safely because they are suffering adverse effects from excessive levels of medication.

All of these chapters, fore and aft, are not intended as guides for people taking antiparkinson's medications who now want to stop taking medication and try to recover. For most of them, because they are already taking drugs, it may already be too late for them to stop the drugs and to try to recover.

However, for those people taking drugs, and for those whose drugs are becoming problematic, they or their doctors might wish to extrapolate from the experiences in this book to come up with drug programs that will help to best manage the drugs, minimizing adverse effects and optimizing/extending the years during which the medication might be helpful. Of course, even if the drugs are taken correctly, the symptoms of a person with Parkinson's disease will continue to worsen. But by using the drugs correctly one might avoid or postpone adding painful and unnecessary dyskinesias, dystonias, and parkinsonism to the steady decline of idiopathic Parkinson's disease.

I also hope, although I am not overly sanguine about this last, that this book may possibly open a door for MDs who are questioning the current thinking about Parkinson's disease medications. I am especially excited about the possibility that the final hypotheses in the last chapters of this book, in which I propose a relationship between the parasympathetic nervous system and addiction, might some day lead to a better understanding of addiction in general. If this study of Parkinson's medications can eventually help those who struggle with addiction of any kind, then the grassroots researchers and myself will have been rewarded beyond our highest expectations.

I repeat, if a person is taking medication, he should not enter into a Parkinson's recovery program.