

“Doctors prescribe medicine of which they know little, to cure diseases of which they know less, in human beings of which they know nothing.”

Voltaire (1694-1778)

12. LEADING UP TO A SOLUTION

ANOTHER DEATH; THE NATIONAL REPORT

What was happening in the meantime for the rest of the people in the project? By June of 2000 we'd had nearly fifty patients sign up. We'd had two patients who had been recently diagnosed with PD and who had been on very low levels of medication. These two had experienced what we were beginning to recognize were symptoms of recovery. They quickly had gotten off their medication and had some moderate, passing difficulties, just as Becky had had during her very first experience in getting off the drugs. They had never used the drugs again. A few others had gotten off their drugs more slowly and then followed a course similar to Becky's when she chose to give herself a “little boost:” increasing need for the drug and rapidly worsening adverse effects.

We had some patients taking high levels of medication who were still in the early stages of gradually reducing their medication but appeared to be making progress and avoiding Beckyesque pitfalls.

Those who had joined the program and were not taking any PD medication found that their recovery moved along pretty much as is described in the recovery handbook: recovery was painful, slow, and fatiguing but lacked the terrors and paranoias that some medicated patients were having.

The undrugged stories were somewhat predictable. Every medicated case was unique. Most were dreadful, but a few were astonishing; Buzz's story simply floored us, for example. He quit his high level of medication abruptly as soon as he detected recovery-like changes and, against all odds, survived the nightmare.¹ He subsequently made a straightforward and unusually fast recovery from Parkinson's almost as if he had never been drugged. The only indication that he had ever taken the drugs was the telltale (and probably permanent) tardive dyskinesia, the rapid hand shaking that appears to be the long-term Kilroy Was Here of all dopamine-enhancing drugs.

We were beginning to learn from working with the patient researchers that there were good ways to attempt med reduction as well as bad ways. This chapter chronicles this period and introduces some of the early findings as we stumbled on them in our regular visits with the pioneers. We hope the tragic loss of some of our pioneers, described here, will illustrate the dangers involved in using medications for Parkinson's disease once the PD has begun to recede via the recovery process.

¹ We do not advocate this method. Abrupt cessation of these medications can cause death. This person's case will be described later in great detail as an example of what *not* to do, and why.

Failure, for the most part

Most of the medicated patients were struggling, unable to tell if they were getting better or worse. Their attempts at reducing their drugs were futile; they could not tolerate the powerful symptoms of drug withdrawal. They kept waiting for a sign from their symptoms or leadership from their doctors, but they got neither, and their overmedication got worse and worse. A tragic few, like Zoe, were lost forever in a nightmare world of pills, confusion, and relentless, writhing torments. Two people, sweet Rose and one other, had died from the effects of overmedication.

There seemed at this time to be no way to guess who would be successful in reducing their meds and who wouldn't be. It appeared to be one big crapshoot, one with potentially lethal consequences. And if a few were successfully getting off their meds, the majority was not.

Drugs, not attitude, were the problem

Some patients entered into the project brimming with optimism. Others were shoved, sulking and skeptical, into our clinic by an adamant spouse. But curiously, attitude was *not* the strongest predictor of recovery; whether or not a person was using anti-PD drugs seemed to be the single most critical factor; their attitude was a distant second in importance. Most people simply couldn't reduce their drugs, not even by a slight reduction of one or two pills a day. (Back then, we didn't know what the word "slightly" meant.)

After two years, we began to recognize that the all-at-once and the pill-a-day decreases were formulas for failures. The 10%, two-to-ten weeks reduction program, hit upon by chance, seemed the most successful. The 10% rule that we came up with will be described later in this chapter.

There were exceptions to the 10% rule. If a person was already manifesting a significant number of recovery symptoms, they might already be too far addicted to make any reductions. Zoe, for example, could not tolerate a decrease as small as 2.5%. Also, if a person's symptoms of overmedication were too severe, the 10% rule might be helpful, but every single decrease in what might be a multi-year process could very likely set off a ten-week round of withdrawal agonies similar to Becky's.

Therefore, although we had found what appeared to be a safe way to reduce medications for some people, there were still many qualifiers. It was not a one-size-fits-all proposition.

The most curious item noted above was that those drugged people whose subtle electrical patterns had been restored to health, *whether or not their mobility had yet improved*, were the most at risk. If they were not taking steps to decrease their medication, they might end up deranged, dead, or wishing for death within a year or two. By this time we had seen several examples, in addition to Becky, of the change in addictability that occurred after a person began to recover.

Samantha

Samantha (Sammy to friends) had been recently diagnosed and had only taken Eldepryl, an MAO inhibitor, twice a day for a few months. She was 55 years old at the

time. After a month in our program, she started noticing changes in her feet and decided to cut back on her medication. After two months of steady, very small reductions in her dose, she only needed to take it every Monday morning, to help her face the workweek. None of the reductions had been excessively difficult, although she felt more tired than usual. After two months of taking it only on Mondays, she quit taking it altogether, or so she thought. During this time she started showing increased signs that she was recovering.

One weekend, leaving for a camping trip with friends, she decided to take Eldepryl on Saturday and Sunday to have more energy for hiking. She saw me the next week and said that by Monday she deeply regretted taking it. On Monday she had felt strongly hung-over, confused, and deeply longing for the drug in a way that she had never felt before.

She didn't take any more for two months, when she again took some on a weekend in which she had a difficult personal situation to deal with. After that weekend ended and she had even stronger yearnings for the drug and an even deeper feeling as if hung-over, complete with a reappearance of parkinson-like symptoms, she swore to never take the medication again.

Lingering memories of Eldepryl, or any DED

Sammy's drug was Eldepryl, not L-dopa, but we saw the same pattern with all the PD drugs: it was not too difficult to reduce the medications if a person still had Parkinson's *and* was not yet showing signs of dyskinesia (signifying severe brain damage from the drugs). *But* if the person appeared to be recovering from PD and still took the antiparkinson's medication, the medication behaved like a classic addiction temptress.

Without the reining influence of the Parkinson's (anti-addiction) brain pattern, the drugs imparted brief periods of strength, confidence, and even euphoria. And when the drug wore off, the person was plunged into a state of depression and extreme weakness, and experienced feelings of confusion, grogginess, incompetence, and even paranoia. In addition, using the DEDs (dopamine-enhancing drugs) after the PD was gone seemed to invite a quick return of parkinson-like symptoms: the dreaded drug-induced parkinsonism.

The drugs seemed to call to a person more strongly when the symptoms of Parkinson's disease were gone. For most people with Parkinson's disease, the pills have no particular allure; they are just a necessary part of the day.¹ But *if* a person who seemed to be recovering from Parkinson's disease in the slightest indulged in a little "harmless" pill taking on the weekend, the drugs called with increasing enchantment, even though the after-effects, when the drugs wore off, were more unpleasant each time.

Ongoing Parkinson's disease seemed to protect a person from rapid addiction. Recovery from PD, on the other hand, made a person susceptible to addiction and withdrawal symptoms.

Sadly, many of our ex-PDerS seemed to have a lingering, subconscious memory of the joy of the medication. When times were bad, either from illness, grief, or cold weather, they yearned for their powerful meds, meds that were stronger than any street

¹ The exception is those people who take the drug to create an On! feeling, as noted in chapter three.

drug, and which they could get, legally, because they had had, at some point, a diagnosis of PD. I have gotten so many phone calls asking for “permission” to take the drugs.

“My father died last week, I’m a wreck and I need Sinemet” or “I had a bladder infection and now I think I have Parkinson’s again, can I take the pills?” are examples of the way these phone calls usually begin. I have to remind the patient that I have nothing to do with their drugs, and I’m not their MD. But anyone who thinks he will never want drugs again after getting off should be aware of this long-lasting effect.

The National Institute on Drug Abuse

At about this same time, the National Institute of Drug Abuse had made its major breakthrough in the study of addiction: all addictive drugs increased dopamine; addiction was due to diminished dopamine levels that occurred as a rebound against the drugs. Their work meshed perfectly with what we were seeing.

What we had that they didn’t have was a group of people who had originally needed their drugs due to an organic (occurring naturally, within the brain) lowered dopamine level – a group that also didn’t get addicted. The patient base for the researchers on drug abuse was people whose dopamine levels had been lowered primarily in response to drugs or toxins. These people could not reduce their addictive drugs without suffering. Ours could – as long as they still had Parkinson’s.

We were seeing something that no one had ever seen before – reduction of otherwise addictive medications in people who were not susceptible to addiction AND the rapid change in their addictability if they started using medication again after they recovered their normal dopamine system.

This was actually very significant. Many researchers on drug abuse were, and still are, looking for social, educational, and political reasons for drug abuse/addiction. What we were seeing was that people who were not addictable in one brain condition (Parkinson’s disease) were highly addictable when that brain condition was removed. Their susceptibility to addiction had nothing to do with their social, educational, or political standing.

However, we were in no position to publish this information in drug abuse journals. Our premise was based on the curability of Parkinson’s disease. That premise was still unacceptable: according to neurologists, if our patients got better, it was because they had been misdiagnosed. At the time, the SPECT¹ was just beginning to be used, and even PET scans were expensive and rare. Only one of our patients had ever had one. We applied for various grants so that we could pay for before-and-after scans of our new patients, but our grant applications were never even given consideration. Morale sank.

The 10% plan

We had been doing the math. Several patients who had reduced from 1000 mg a day down to 900 had seemed to have the easiest time with their reductions. Other patients who had started from lower levels and reduced daily intake by the same amount, 100 mg, were in agonies. We postulated that it wasn’t the absolute amount of the decrease, but it was the percent change. We looked at other charts and found that this thinking held up;

¹ SPECT scans are an improvement over the old PET scans. Both are radiological scans that can show density of molecular activity.

patients who had been taking approximately 500 mg/day had handled a decrease of 50 mg/day pretty well; they had felt lousy, but never went into withdrawal hell. After two to ten weeks at the lower level, they were doing as well as they had been before at the higher level. We shared this idea with all the patients. Some of them tried it themselves, and others did not.

It soon developed that most patients who never reduced by more than 10% of their current dose, no matter what their current dosage level was, might have an easy or a miserable time during each drug decrease, but they were able to get through the next few months without entering into a ferocious world of mental chaos. They also felt good enough after each decrease to start another round of decrease.¹

In contrast, most people who decreased by more than 10% had gone through hell and resumed drugs at the previous levels or higher. Sometimes even a decrease of 15% propelled one into the abyss. It had long been recognized that strong narcotic drugs were best reduced on a 10% plan. It now appeared that dopamine-enhancing drugs were also “10%” drugs! We finally had something that might really be helpful. Morale soared.

Birdie

Birdie was 65 years old. She had moderate PD, not advanced, not early. She was taking quite a bit of medication: 500 mg/day levodopa, 4.5 mg/day Mirapex (an agonist), several pain relief drugs, and several “good stiff drinks” every day. She lived alone, her children lived nearby. She was very active, always getting out and about, and considered herself to have a rich and busy life. She did not feel that her quality of life had been affected whatsoever by her Parkinson’s; the drugs were working very well for her. She came to us because of her increasing lack of voice.

Beginning of recovery

She responded well to the treatments at our clinic. Sensation returned to her feet after decades of numbness and her movements became more fluid.

She was not at all interested in decreasing her medication over-quickly because she preferred to “live life to the fullest.” She had no qualms or squeamishness about taking whatever drugs were recommended, as long as they would allow her to be independent.

Unfortunately, at the same time that she started having more feeling and motion in her feet, she started having dyskinesia for the first time. Violent cramps appeared in her feet and legs about an hour and a half after taking her pills. As the medicine reached its peak, she would be screaming with pain as her legs tied themselves into knots.

The young doc’s diagnosis: “dyskinesia from overmedication”

We pointed out to her that the spasms corresponded to the effective time of the meds, and asked her to work with her MD. Young Doctor Williams, a neurology/movement disorder specialist fresh out of school, recognized that her symptoms were coming from her drugs. He told her that she was very overmedicated and she should decrease by one pill a week until she felt better.

¹ Full details on the ten percent program are in chapter 17.

At this time we had already seen people nearly die from decreasing at this rapid rate, and we told her so. She told her doctor, and he assured her that one pill a week was very, very slow. Compared to what his older colleagues were recommending, his prescribing was ludicrously overcautious, he felt.

Considering that he was probably thinking of a decrease in terms of 1 to 3 hour half-life, one pill a week was very slow indeed. If he had been thinking in terms of ten-week accumulations, he might have done the math differently.

At any rate, in the first week of her decreasing her meds, her response was not too severe, merely causing some periods of immobility. We warned her that the withdrawal, which resembles a sort of super-Parkinson's, plus having all the features of nausea, paranoia, pacing, violent versions of the side effects, and bouts of fear-stricken whole body rigidity, may not even *start* to appear until about seven to ten days after the meds have been reduced.

But Birdie's leg cramps seemed a little less intense after reducing her medication, and that's what she wanted, so she was determined to decrease by another pill (100 mg) the next week, to further decrease the spasms.

We warned her that, based on what had happened with other patients, the true benefit and possible hell of the drug reduction might not be apparent for possibly ten weeks, so there was no way of knowing if she was now at the right med levels after only one week. But she was still having some mild leg cramps during her On times, so at the end of the first week she reduced another pill. Halfway through the second week, she started to feel short of breath plus having classic signs of drug withdrawal, and her leg cramps were amplified by a new sort of terror – a fear that she was going to die from the leg cramps. Her thinking now was that this was further proof that she was still overmedicated. After all, her doctor said that her leg cramps were definitely caused by her medication. She reduced by yet another pill. This made a reduction of three pills – 300 mg, 60% of her original dosage – in a mere three weeks. She was sliding downhill fast now, and about to enter into actual drug withdrawal.

A 60% reduction

Birdie had decreased by 60% in three weeks. By the middle of the third week we figured that the first reduction of the three was really beginning to show its effect and the second reduction was just barely making itself felt. She hadn't even begun to notice yet the effects of the third reduction. But at this point she was having trouble moving, and she was screaming from the leg cramps. She was both undermedicated, as evidenced by the immobility, and doubled up from leg cramps, a symptom that the doctor said was due to excess medication. (We have not met a doctor yet who knows that during drug withdrawal, the body will mimic, from sheer terror, the same symptoms that it exhibited in the face of excess medication. Both responses are a panic response by the brain to a condition of extreme danger.)

Drug withdrawal

Birdie's children had her admitted to the hospital. By this time she was taking powerful antispasmodics for the leg cramps, cramps that were now so powerful that she thought her leg bones would break. She was imbibing several extra stiff drinks a day plus taking a new prescription, an antianxiety drug to help her with the horrors that were

overwhelming her. She was frozen stiff most of the day, gasping for air, and she had no speaking voice.

Young Dr. Williams reversed his position: based on her agonies, her original problem must have been undermedication rather than overmedication. He ordered her to take six pills a day since her starting dose had been five pills. For the next few days, as the incoming flood of L-dopa combined with the antianxiety pills that were probably just beginning to take hold, she started to calm down.

Gross overmedication

Within two weeks, her levels of dopamine began to rise back to her previous level – where she had been clearly overmedicated to begin with – and then beyond that level to an even higher level. Within three weeks she was having rapid-fire spasming in her fists and face, both common dyskinesias of L-dopa, and the powerful clenching of her feet was literally pulling them into balls. She could not stand and she was deeply confused.

She had several problems going on at once. She was continuing to recover from Parkinson's – once the recovery process begins it cannot be turned off, and it will continue even if you stop having treatments – and she was increasing her medication. Also, because fewer than ten weeks had passed, she was apparently having some remaining symptoms (terror and paranoia) of drug withdrawal when the short-term effect, the flood of each dose wore off. She increased her medication again because the fleeting high seemed to give her precious moments of oblivion during which she didn't notice the pain from the extraordinary foot and leg cramping.

Birdie's doctor ups the drugs

Birdie was entering into a dangerous land – the land of people who are taking L-dopa who do not have a Parkinson's disease electrical pattern in the brain. She was now addictable and had no defenses against L-dopa. She had rejoined the rest of the world, dopamine-wise, and was as susceptible as the people in the *Awakenings* study. Those monstrous situations that Oliver Sacks had described, which were met with jeers of derision from fellow MDs who decried his statements as impossible, started happening to Birdie.

We have seen over and over that if a person decreases dopamine levels for a few weeks and then dumps a high level of dopamine into the system, both withdrawal and overmedication will occur. The limbic area, which, remember, is very slow to change, will still be in a panic, sending out distress signals of terror, which can include shaking, nausea, paranoia, wracking pain and sensory overload. The body may, in these times of stress, also incorporate any patterns that have been learned by the brain to use in times of low-dopamine stress, such as tremoring, hunched posture, drooling, and all the usual symptoms of Parkinson's disease.

The high levels of dopamine flooding the brain will also be picked up in the motor area, which responds quickly to dopamine. The motor area doesn't care that the dopamine levels have been low for several weeks. In the presence of even briefly excess dopamine, the motor area will fire off with dyskinesias, freezings, and hallucinations – all the tricks that it has ever learned to use up the extra dopamine.

In this situation, when a person decreases for several weeks and then increases, the slow-changing limbic area is undermedicated and the motor area is overmedicated. So

this person may alternate between the worst symptoms of drug withdrawal and symptoms of overmedication. Birdie was having all of these problems. This explosion of symptoms is utterly baffling to anyone, including an MD, if he doesn't understand the underlying process.

Birdie's doctor, observing her, decided that, for some unknown reason, Birdie's Parkinson's disease was accelerating at a faster rate than most. Remember, her MD assumed that the half-life of these drugs was measured in hours. He assumed that whatever he was seeing was the result of that day's pills. He had no reason to suspect that she might be reacting one day to drugs that she had increased or decreased weeks ago. He decided she should increase her medication again. She increased again, from 600 mg/day levodopa to 700 mg/day.

After two more weeks, the withdrawal symptoms abated. She was no longer subject to paranoia, nausea, and terror. Within another week, the full effect of seven pills a day was starting to be seen. Suddenly her dyskinetic leg cramping, foot balling, hand clenching and arm spasming was literally mind crushing. She was shrieking in pain. Her body was contorted with spasms. She was screaming and sobbing.

We have seen that people with PD can tolerate a fair amount of overmedication. If the drugs are increased slowly enough, *and the person has PD*, the brain seems able to accommodate somewhat to the drugs. A dose of 700 mg/day does not usually trigger such violent symptoms, so quickly, in a PDer. In general, most PDers with advanced PD don't seem to suffer this level of side effects until they have been above the 800 mg/day of L-dopa level for a sustained period. (Please, do not use this 800 mg number as a guideline. Every person is different; every person has a different tolerance for the medication.)

The point I am trying to drive home as if your life depended on it is not the 800 mg/day number, but the fact that *if a person has recovered, and their electrical circuits are no longer running backwards (in PD fashion), the body has very little tolerance for drug overdose.*

Overdose was now happening with Birdie. Most PDers, if they increase by 200 mg of L-dopa, will not go into screaming torments. But we have seen that if a person has begun to recover, even a 50 mg increase, *even just staying steady or reducing too slowly*, might not be tolerated. Hideous side effects can occur no matter what the drug level, if a person is recovering.

We lose Birdie

At this point the MD decided that she needed drugs to stop the spasms. She started taking anti-epileptic drugs and powerful sedatives. She was taking antispasmodics and combining them with "good stiff drinks."

Her children were certain that our clinic, and not the good doctor, certainly not the FDA approved drugs, had caused her problems. She was sent home to live with her daughter. She wanted to come to the clinic, but her daughter, a registered nurse, would not consider it. Her acupuncturist was allowed to make house visits to give massage treatments on the steely knots in her arms and legs. The spasms and knots persisted despite the powerful anticonvulsants and anti-epileptic drugs. Birdie died just over a year later, in 1999, in a convalescent home.

Another death

Right around this time I heard from health practitioners in both Florida and southern California; they each had had a patient who had appeared to be recovering. Their patients had each been told by their MDs that they were, respectively, overmedicated and misdiagnosed. In both cases, their doctors told them (respectively) to reduce and stop taking the medications immediately. Both patients obeyed and subsequently went into shock.

Failure to stabilize

The Florida patient ended up in a hospital where the medicos ended up deciding that his new unpredictability of response to L-dopa (after 24 hours) proved he did not have Parkinson's. He was put on assorted drugs, one after the other, to determine if his problem was psychological or physiological. They changed his drugs daily. He got worse and worse. He nearly died in the hospital where they were trying to "stabilize" him. He spent his remaining days in a care facility, heavily drugged. He died within the year.

Failure to obey orders

The one from southern California was told to stop taking her medication, as she had evidently been misdiagnosed. The sudden stopping was highly traumatic. She went back on her medication, and her doctor pronounced her a "problem patient," a patient who wouldn't obey orders. Her doctor simply couldn't work with her under these conditions.

Failure to decrease the drugs

Meanwhile, at our own clinic, we had Zoe and one other patient who had been lost to the drugs – they didn't die, but they were illogical, writhing day and night, and in Zoe's case, suffering from a life-threatening respiratory condition that kept sending her back to the hospital.

Every time Zoe's MD or the hospital staff told her to reduce her medication, she increased it. Her doctor's suggestion – that she decrease by 30% – was ludicrous in light of what we knew, even at the time, but of course we could not say anything in opposition to her prescription. I did share information with Zoe and her husband, explaining that a 10% limit had seemed to work for some recovering patients, but her husband was understandably unwilling to risk even a 50 mg/day decrease (2.5%) because even this small decrease seemed to worsen the suffocation. Zoe, due to the life-threatening dyskinesia in her diaphragm, was really too far-gone for help.

Zoe's doctor

You may be thinking, correctly, that we had a moral obligation to contact Zoe's doctor. I did that. This particular doctor was so hostile to our project that he refused even the offer of a business card. He sneered at the business card, which had the word "acupuncture" on it. When I calmly informed him that it was extremely rude to refuse a proffered business card, he gingerly took hold of it, and snarled, "There's a Chinese man in my office; I'll give it to him." No, this doctor was not interested in hearing anything from us about drugs.

We couldn't find local doctors who were interested, and we couldn't give advice to our patients. We were limited to reading to our patients out of the drug textbooks or drug inserts, and sharing case studies with them without making conclusions. Legally, we were not in a position to offer any advice. We kept telling people to work with their MDs, because that is the law, but the MDs were clearly uninformed. I soon received more emails from around the English-speaking world with tragically similar stories. By the end of 1999 we realized that our suggestion to "work with your MD" was possibly a death sentence.

Broken hips

There were variations on the medication problems. Not all the problems were stemming directly from tardy reduction in medication but were coming from the physical weakness that can occur during recovery from Parkinson's. When this weakness appeared in a medicated patient and caused an interface with the traditional medical establishment, it was a formula for tragedy.

It was becoming a common email story: a PDer would have a change in symptoms that corresponded to recovering. Recovery symptoms include extreme weakness; this occurs when previously rigid muscles begin to "melt" into ineffective softness. These patients were unable to move due to their supreme weakness, whether or not they were medicated, unmedicated, or attempting medication reduction.

Due to temporary immobility from weakness, the spouse would frequently take it upon himself to carry the recoverer to the bathroom or bedroom. After the aging spouse accidentally dropped the recoverer, the recovering PDer would be admitted to hospital with a broken hip. In my own private practice, I had three patients with broken hips in two years. My emails indicated that this was happening around the world, in similar circumstances.

Trouble in the hospital

It was during the hospital visits that the real dangers began. Inevitably the MDs would note that the person with a broken hip was a PDer. Concluding that the cause of the fall had been undermedication, the MD would typically prescribe a whopping dose of antiparkinson's drugs. If the patient had previously been taking medication, the doctor would increase the drugs by 50 to 100% (!!!) of the highest level ever prescribed for that particular patient.

Not immediately, but within a few days to a few weeks, that patient would be hallucinating, thrashing about, or doubled over in spasms. This seeming intolerance for the medication would lead to experiments in which one medication would rapidly be exchanged for another. A person might be on three different drugs in one week, and all the while, due to the slow adjustment of the brain to the medications, the brain might still be reacting against something that had been ingested weeks ago. The most common response of the MDs was a desperate attempt to "stabilize" the patient. Again, the stabilization was presumed to be complete in three days.

Off to the nursing home

These disastrous attempts usually ended with the patient being placed in a care facility with mandatory prescriptions for high levels of anticonvulsant and antispasmodic drugs, together with the usual PD drugs.

Also, following the hip replacement surgery, the doctors typically wanted their patients walking as fast as possible. Following my patients' hip replacement surgeries, their surgeon – not their neurologist – demanded that they be given extra-high doses of levodopa. The idea was to get the patient walking again quickly. The doctors in every case prescribed an increase in antiparkinson's drugs – *regardless of whether or not the patient was manifesting any signs of dopamine insufficiency.*

If the word “Parkinson's” appeared anywhere on the patient's chart, the surgeons – a hip doctor usually knows next to nothing about these drugs, by the way – fixated on the diagnosis of Parkinson's and assigned galloping doses of L-dopa to their post-hip replacement patients.

When I went to visit my patients in the hospital, they would be gazing at me out of over-bright eyes, beaming away, arms fluttering, head rolling on its stalk, face jerking and grimacing like the worst excesses of St. Vitus's dance.¹ They were utterly unaware of pain, or the need to walk, or even to think. They were stoned, hopelessly stoned. Their doctors, noticing their disinclination to practice walking, and ignoring their grotesque side effects, usually increased their dosage further. No logic in the world could convince these doctors – and believe me, we tried – that the patient was showing signs of overmedication. Nope. If “Parkinson's disease” was on a patient's chart and that patient wasn't walking, the doctor had carte blanche to prescribe all the antiparkinson's drugs he liked, in an attempt to maximize movement.

In addition to this “the more the merrier” attitude towards the antiparkinson's drugs, all the doctors we have heard of from our Internet patients and practitioners evidently imagined that drug stabilization occurs in three days. Then, after a failed attempt to “stabilize” the patient, they conclude that the patient is either psychotic or misdiagnosed. Several patients were told that they obviously never had PD and were ordered to stop all the medications immediately. They went through the usual trauma and died.

From around the world, I was hearing horror stories from people who were recovering from PD. Their meds were suddenly far too strong, but if they tried to reduce them quickly they went into shock, and their MDs had absolutely no idea what to do.

Morale sank.

Personal responsibility

I paced the floors, I prayed, and I agonized. The nightmare experiences of my patients were ever-present in my thoughts. Rightly or wrongly, I felt a responsibility for every single one of those disasters.

¹ “St. Vitus's dance” (spasms and gyrations of presumed spiritual ecstasy) was the name given in the Middle Ages to the gleaming eyes, frozen smile, and uncontrolled twitching and flailing of limbs that occurred as a side effect of eating moldy rye. Ergot (a rye fungus) causes the excess movement and the delusion of spiritual brilliance. One of the first pharmaceutically produced dopamine agonists was derived from Ergot.

My dilemma

I could not give any advice about the meds. If I did, I would lose my license. If I didn't, patients might die. Even if I did break the law and tell the patients what they were doing wrong and what they should be doing right, 1) they might not be able to follow my suggestions, 2) if my advice conflicted with that of their doctors they would probably follow their doctor's advice, and in either case, 3) the patients would be just as overmedicated as before *and* I would lose the right to practice Asian medicine. I could be throwing away my right to practice medicine and most likely the patients would be making mistakes, even dying, just the same.

Family members

I knew from the attitudes that I had seen from patients' family members that patients' families and friends would override my observations anyway. Very often, the children or brothers and sisters of the PDer in question did not know that their loved one was involved in our program until they ended up in the hospital. When they learned of our program and contacted me for information about the patient, these loved ones were usually raging with frustrated helplessness. When I tried to share information about the known, written drug instructions, and pointed out that the doctor was not complying with the manufacturers' instructions, they were furious – at me.

Coach

Coach nearly died at this time. His PD symptoms had rapidly evaporated in response to treatment. He felt terrific until he suddenly went from being undermedicated to being overmedicated. In Coach's case, the dyskinesia happened to occur in his heart muscle. He started popping nitroglycerin for severe angina.

Coach was actually getting very good medical advice – his wife was a doctor; she was absorbing all of the information that we could give her. She was able to make adjustments to his medication in good time, and he had reduced his drugs, down to 200 mg/day of L-dopa from 400. Then, due to a bout of flu, he felt so punk that he increased his medication to 300 mg/day levodopa. As his flu symptoms waned, he suddenly went beyond a glimmer of native dopamine into a flood of dopamine for three solid days. He felt glorious! And the life-threatening heart arrhythmias began along with a desperate, agonizing fast reduction in order to stop the heart spasms.

There will be more about Coach in another chapter, but the point is, even patients who were trying to stay ahead of their dopamine levels by decreasing their drugs in anticipation of recovery were running into problems if they didn't move fast enough – and there was no way of knowing just how fast was fast enough.

Ups and downs

Ups

The primate research was a big morale booster for us. Even if the MDs were still insisting that our recovering patients had been misdiagnosed, research had shown that brains could change in addictability due to external changes. (Technically, for all you non-biologists, a foot injury is a form of external, or “environmental,” injury.)

We could use our patients' change in addictability as possible proof that something inside their brains was changing, something to do with dopamine receptor activity.

This seemed like a reason to celebrate. Our medicated patients who became suddenly intolerant (addictable) to the medications were the best possible proof that our program was altering people's dopamine levels. We could be nearly certain that we were using an effective treatment to reverse Parkinson's disease. We had possibly found the cure for an incurable illness. Morale went up.

Downs

By June of 2000, the deaths of Rose and Birdie, the virtual loss of Zoe and others, and the reports of deaths coming in from the Internet weighed heavily. We became more somber in our approach to the medications. We no longer paid any mind whatsoever to the prescriptions of the scoffing doctors who had mocked our program and assured their patients, "Just keep taking your medications until you don't need them anymore. If you recover from Parkinson's, you can stop then."

Most pioneers determined to decide their drug dosings for themselves. Others, more cautious, made special appointments with their doctors to ask about safe methods of drug reduction. Some doctors sniffed at the entire idea and refused to give "permission."¹

Well meaning and dangerous

Those well-meaning doctors who wanted to show support for alternative medicine were much more deadly; they invariably advised their patients to reduce their drugs in a way they considered to be slow and careful. Their ideas of slow and careful were usually far wide of the mark. By the time these unfortunate patients went into withdrawal shock, about ten days after beginning the reduction, they were down to no pills at all, and they had no way to get their brains quickly up to the levels needed to prevent the nausea, respiratory distress, heart spasms, violent shaking, and screaming tortures of hypersensitivity to light, sound, and touch.

Doctors, startled by these symptoms, which they considered, every single time, to be symptoms of abruptly worsening Parkinson's disease, invariably gave the patients even higher doses of their drugs than they had been taking before at the maximum. Within ten days at these higher levels, the patients would be having amplified patterns of those very symptoms of overmedication that had driven them, several weeks earlier, to want to decrease their medication.

Typically, at this point, as violent dyskinesia kicked in, the doctors would start pumping anti-epileptic drugs into the patients' bodies, or antispasmodics and muscle relaxants. Following this, as their patients' brains continued to act out against the now

¹ Although well-meaning doctors may tell you the contrary, an adult in the United States is not required by law to follow the suggestions or prescriptions of his doctor. As long as he is not a danger to himself or others, a person is allowed to refuse medical interference. He is not supposed to take prescription medications without a doctor's prescription. But he is legally able to refuse those prescriptions. If a person decides to stop using prescription drugs, that is his option. If, in order to stop safely, he must titrate down slowly and carefully, that is his legal right. But maybe the doctors who outright refused to work with their patients were the smart ones; their patients, in general, working on their own, did better than the patients who got emotional support and incorrect suggestions from their would-be helpful medicos.

extremely excessive DED levels, and their mental responses became fogged by the suppressants, they were hospitalized or put under convalescent care. From there on out, it was just a matter of time, usually less than a year, before the patient died.

Indecision time

We weren't sure how to proceed. We weren't sure if we should even continue the project. And yet, our instructions for the treatment of PD were on the Internet, being shared in chat groups, and articles had been published in several journals. People around the world were treating PD, but they didn't know about the horrible risks from the medications. We'd put information out into the public domain about how to recover from Parkinson's: we could not easily make this information disappear. At the same time, patients had no idea what to do about their medications, and the instructions from the doctors were usually deadly. What should we do about the medicated patients?

Warnings go out

We shared details of these lost pioneers with our surviving patients. We warned everyone about the difficulties, even tragedies, that might lie ahead with drug reduction. I was also regrettably obliged to warn them, based on what I had seen and heard, that their neurologist might be uninformed or misinformed about the medications. Even so, I could not advise in any way, shape, or form, other than sharing public information and past case studies. They were on their own.

No more medicated patients

We made the decision, which still stands, that we would no longer accept medicated patients into the program.

A solution emerges

We agreed to continue working with our current patients, whether medicated or not – they were getting better, and therefore they were most at risk, and we had a responsibility to them.¹ Our small army of grassroots researcher-patients, both in California and abroad, continued diligently recording their experiments in medication reduction, using charts and journals. We were able to fine tune the 10% finding. We discovered the cyclical pattern of overmedication, reduction, fleeting emergence of correct drug levels, and the return to overmedication. We formed hypotheses to make sense of these empirical findings.

The crucial patterns of “drug failure”

We discovered and named the patterns of overmedication that had previously been ascribed to “drug failure,” but which, in light of our new hypotheses, were actually due to drug excess. These patterns were the key to determining any given patient's current location on the slowly moving cycles of medication accommodation. The next chapter will describe and name some of the patterns we saw.

¹ Patients who were overmedicated were met with each week, but they did not receive treatments.

Slow progress

Our project was still creeping forward. Though all of us on the team were acupuncturists, and all of us had neither the desire to be involved with these drugs nor the right to prescribe medication, we decided to keep working with the remaining drugged patients. Without our ever intending it, we were present as witnesses as our patients uncovered a slow, macrocosmic way of looking at dopamine.

Morale went up.

