

*“For many men that stumble at the threshold
Are well foretold that danger lurks within.”*

Shakespeare’s King Henry VI

2. WORRISOME DRUG PROBLEMS

OUR DRUGGED PATIENTS DIFFERED FROM THE REST

This chapter will share examples of how medicated patients veered off from the recovery path demonstrated by *unmedicated* patients. I will include two detailed case studies: one of a patient who slowly became addicted, the other a patient who quickly increased her medication despite life-threatening side effects.³⁹

Something afoot

With uncanny good fortune, the first four Parkinson's disease patients I ever had were unmedicated. In fact, I didn't even have a PD diagnosis for my first three Parkinson's patients. Had I known that what I was treating was Parkinson's disease, I would have probably only used the specified scalp points for PD on this trio. These points were in vogue in China ever since the advent of the western PD theories on brain cell death. But, by great good fortune, or fate, my first three PD patients had never been diagnosed.⁴⁰

When these patients came to me with baffling symptoms and no diagnosis, I spent hours exploring every inch of their bodies looking for some clue as to what had gone awry.⁴¹ I found a curious pattern of energy confusion, similar in each patient, which was traced to the foot. This pattern of Rebellious Qi is one that was mentioned in the ancient literature and referred to briefly in lectures while I was a student, but it was a pattern for which I had learned no practical application.

Shortly after recognizing this energetic pattern in these patients and successfully treating them for their ailments,⁴² I had my first “officially diagnosed” Parkinson's patient. Her

³⁹ The reason for the individual variances in restoration of addictability is discussed in chapter 24.

⁴⁰ All three of these patients, two recently from Russia, one from Korea, had little faith or even interest in western medicine. The first was, in fact, terrified of doctors. This preference for Asian medicine over western allowed me to work with people who, in retrospect, had classic Parkinson's, without the blinders I must necessarily have worn had they been given an official diagnosis of Parkinson's disease.

⁴¹ I had only graduated from Asian medical school a few years earlier and had a slowly-building practice. I was sometimes able to spend long hours, at no extra charge to a patient, just exploring diagnostically, if I was curious about a health problem. I had the time and inclination to devote whole days to a single patient without charging a fee if I so chose.

⁴² This occurred much to my amazement. I was still extremely dubious about Asian medicine, and I had digested my course material by interpreting its precepts through a protective screen of western science and biology.

No one could have been more startled than I to discover that Backwards Running Qi (Rebellious Qi) was actually just that – electrical currents that were running in the reverse direction. Always keenly sensitive to electric charge or static in people's skin (I am blessed with extremely poor eyesight and an overdeveloped sense of touch is my compensation.), I could actually feel with my hands the difference between the direction of electrical current flow in my patients... (Footnote continued on next page.) (Footnote continued from previous page.) with PD-like symptoms compared to the flow patterns of normal

energetic patterns were similar to my previous Rebellious Qi patients. Her symptoms, too, responded to treating the foot injury that appeared to be the source of the irregular energetics in her body. More importantly, her responses and apparent recovery followed the strange course that I had seen in my mystery patients. It was only then that I reviewed the symptoms of Parkinson's disease and began to suspect that my first three patients with shuffling footsteps, tremoring hands, and masked facial expression might all have had Parkinson's disease.

After that, I embarked on a small research project to see whether or not this particular energetic anomaly was present in other people with and without Parkinson's. Something I still can't explain inspired me to visit the local Parkinson's support group. I stammered out my preliminary findings and recruited patients for my small study by offering two months of free acupuncture and foot massage in trade for letting me examine their feet. I got twelve recruits over the next two months. They had all been diagnosed with Parkinson's disease and they all had detectable Rebellious Qi in their legs. It appeared that, in all subjects, the source of the rebellious pattern was a usually unremembered, and most importantly, unhealed, childhood foot injury. This pattern of Rebellious Qi was not present in twelve people picked at random from the rest of my patient base.⁴³

After working with them for several months, most of them began having changes similar to the changes that my first three patients had had. At this time I was also blessed with two officially diagnosed PD patients who were not medicated. Of course, my very first Parkinson's patients, who had never been diagnosed with anything, were not taking antiparkinson's medication.

Based on the recovery symptoms of these unmedicated patients, I had already compiled data that we could use as signposts in determining whether or not a person was recovering and how far along they might be in recovery. This enabled us to recognize that medicated patients were behaving very differently from unmedicated patients. The medicated people in this small project responded favorably to the same treatments I was now using on all the Parkinson's patients, but only to a point. Within a few months of the appearance of apparent recovery symptoms in medicated PDers, an inexplicable divergence became apparent between them and the unmedicated patients, in both their recovery rate and their symptoms of recovery. Worse, a few medicated patients who appeared to be making rapid recovery from Parkinson's abruptly developed ghastly, medication-related symptoms.

Forebodings

It was at about this point that I began to fear that I had stumbled across the cause of Parkinson's disease. I had grown up in the western sciences. I had learned decades

people. It was only when I realized that some people had variant patterns of electricity under their skin that I suspected that this objective (to me, anyway) phenomenon might be related to the Qi that I had spent four years studying in school. Suddenly, Qi went from being a theoretical concept to a tangible, measurable quality. There was no name for this discernable energy flow in western medicine or even in the entire field of biology. However, based on how it moved, changed, and was affected by other electrical patterns, it seemed related to the principles of electricity and magnetism I had learned more than thirty years earlier, in physics class.

⁴³ J. L. Walton-Hadlock, Primary Parkinson's Disease: The Use of Tui Na and Acupuncture in Accord With an Evolving Hypothesis of Its Cause from the Perspective of Chinese Traditional Medicine, *American Journal of Acupuncture*, Vol. 26, no 2/3, 1998, p. 163-177.

earlier, in 1968, that Parkinson's disease was incurable, and the incurability of it had been hammered home in every physiology class, both western and eastern, that I had ever attended. I knew that, just as the sun came up in the east, Parkinson's disease was incurable. I feared the direction that my thoughts were headed. I did not want to be the person to find a possible cause for this illness.

I was, at that time, an extremely private person. Finding the cause of idiopathic Parkinson's disease carried a moral responsibility to publish the information. If the medications posed a special problem, I also had a responsibility to uncover just what that problem was and write it up.

What a monstrous position to be in! Looking ahead, I could see where writing up what I suspected about the drugs and knew about Parkinson's disease would be an invitation to hostility, mockery, and contentious debate from patients, doctors, and possibly even the hugely wealthy and powerful medication industry. I wanted no part of any of it. I was peeved by what fate seemed to be ladling out for me. And yet, and yet...how could I not follow these leads and see where they took me?

THE MEDICATION MYSTERY BEGINS

The two officially diagnosed patients who were unmedicated started having the same curious recovery symptoms that the earliest trio had manifested, but the rest, the medicated patients, started having very, very different symptoms, such as Rose's horrible burning mouth pain, increasing muscle spasms, or hallucinations. It did appear as if the medications were actually causing problems of their own.

Most patients who were medicated planned to reduce their medications and found themselves unable to do so. It wasn't so much that they didn't want to; many were starting to feel overmedicated, and their side effects from the drugs were worsening. They told me week after week that they were intending to reduce their meds any day now. When the next week's visit rolled around, they hadn't started yet on the medication reduction.

At this naïve time, they all believed that since they obviously were going through powerful changes in their bodies, most of which corresponded to recovery symptoms seen in other patients, they would of course eventually recover from Parkinson's and could easily stop their medication at that time. One day they would wake up, spring out of bed, and never take a pill again. Even though their PD had developed slowly and they were warned that the recovery symptoms occurred gradually, they fully expected that their deliverance from the medication would be abrupt. The expectation of a Day When I Suddenly No Longer Need the Drugs was standard issue. That day never came.

Olli

Olli was one of the first pioneers. He was 63 years old when he joined our project. He had been diagnosed three years earlier. When he joined our study in February of 1998, he was taking Eldepryl⁴⁴ (5 mg, two times a day) and 600 mg of levodopa per day (two 25/100 Sinemet and two 50/200 Sinemet CR). When he started working with me, he had

⁴⁴ Almost all of the pills go by an assortment of names. Please see the drug list in the first appendix to find the various names by which your familiar drugs are also known.

symptoms of slowness, no arm swing, loss of voice, tremor on the left side, and slow speech. Through the masking effect of his medications, those were the only symptoms I could be certain of. Of course, there was no way of knowing what he would have been like without his meds.

After several months of receiving treatments, he was feeling less rigidity, had a deeper voice and his face was becoming more expressive. More importantly, he felt that he was changing, somehow, deep inside. After one strange rolling sensation through his head, after which his tremor dropped almost to nothing, he felt that he was different inside and associated this difference with recovery from Parkinson's. Since he felt better, his rigidity was going away, his voice was deeper and his face more expressive, he just decided not to take his pills one morning.

On the day that Olli didn't take his pills, he felt great all morning and all afternoon. Then, at five o'clock in the wintery evening, crossing a parking lot in the dark, he suddenly couldn't take a normal size step. He couldn't move his feet, and then he fell, crashing to the ground. After that day, he resumed his medications and refused to ever consider reducing his levodopa even though he started developing dyskinesia from the drugs. It was rash and dangerous of him to stop taking these powerful medications all at once. The drug insert warnings say not to quit the drugs abruptly. In a worst-case scenario, a person can go into drug withdrawal and experience fatal respiratory distress, which means, in case I'm not being clear, death.

Afraid to reduce his levodopa medication ever again, he rapidly became overmedicated, as indicated by the increase in dyskinesia. I wondered what Olli's doctor would say. At his next check up, Dr. Grumb ignored Olli's concerns about the dyskinesia and observed brightly that it did appear that Olli once again had a bounce in his step, and that his voice and facial expression had returned. The doctor pronounced these changes to be due to a delayed (several years) reaction on the part of the medication. He encouraged Olli to increase his medication levels and plied him with a sheaf of brochures from the makers of the latest dopamine agonist drug. Since Olli had finally accommodated so well to the drugs, as evidenced by so many physical improvements, Dr. Grumb suggested that it only stood to reason that even more medication would make him feel better still. Since it clearly was taking a long time for the drugs to become effective – years, in Olli's case – Olli might be wise to increase his medication now in anticipation of advancing Parkinson's. Olli declined the offer of extra medication, but as he was leaving, the MD reminded him roguishly, "Don't forget, if you're going to a party on a Friday night, go ahead and double your dose!"⁴⁵

Olli decided to keep working with me, since he was feeling so much better. He felt certain that he no longer needed the medications, but decided to keep taking the drugs as a sort of supplement. Over the next few months, he felt better and better. He went through the usual symptoms of recovery: extreme fatigue, the characteristic back pain, relearning to walk. Aside from a slight residual tremor, it did appear as if all of his symptoms were gone.

But following these changes, he started getting a different set of symptoms. His blood pressure became very hard to regulate. His facial grimacing worsened. After several months, his tremor returned, but it was jerkier, more staccato, and more insistent than it

⁴⁵ Doubling a dose is specifically forbidden in the drug instructions from Sinemet's manufacturer.

had been. It was at its worst an hour after taking each dose, and then ebbed when the dose's benefits wore off. He became more sensitive to the timing of the medication. His voice started disappearing, worsening an hour after taking a pill. The hoarseness lasted longer with each dose over the course of the day. An hour after his evening dose, his voice would utterly disappear and stay gone until bedtime. His balance suddenly became unsteady, after having been steadily improving for so many months. It was as if he was regressing into the Parkinson's, and yet, he often appeared overmedicated at the same time. He stopped the Eldepryl during this time and noticed an improvement in temperament; he burst into tears much less frequently. Two months after stopping the Eldepryl, his voice lost a tremulous quality that he had attributed to the Parkinson's disease. But he simply could not bring himself to ever again decrease the L-dopa by any amount.

Olli had been assuring me since the beginning of his treatments that it would be easy for him to quit his medication when the time came; he was a mental health doctor and he was completely aware of the difficulties of reducing psychotropic drugs. He assured me of that almost weekly. In the beginning, I had been relieved that I had a patient in the program who could negotiate through the reduction of his own drugs. But as time wore on, he would say at every session, "I don't know what's going on...Every day I decide that I am going to reduce one pill by just a little bit, but at the end of the day, I find that I haven't done it yet. I just don't understand." This went on for over a year. Every week, as he noticed more symptoms of overmedication, he told me that he was planning to reduce his pills. Every week, he forgot to do it.

When his tremor suddenly became much more powerful, he was almost relieved, and declared that he could not reduce the meds until his tremor got better. So I read to him from the insert that comes with the L-dopa pills (Sinemet) the Adverse Effects section in which tremor, bradykinesia and freezing are listed as side effects of the medication. His eyes bugged out. His language, always colorful, became fluorescent. Sparks flew. When he cooled off enough to use full sentences, he blurted, "The drugs I'm taking *cause* tremor? But I'm taking them to control tremor!"

It was at this point that he realized that he was in trouble with his drugs. He never was able to reduce his medication, even for a brief trial of just a small amount, just to see what would happen. As his symptoms began to worsen, Olli recognized many of his symptoms as being similar to the problems of his drug-addicted patients. He suspected that he was addicted to a powerful stimulant. His adverse effects and On-Offs continued to worsen, and he increased his medication for the temporary relief that it gave. He was adamant that he wanted to reduce his medication. He swore that he hated taking the pills and was eager to get off of them. And yet, for some reason, he never did. He added a dopamine agonist to his drug regimen. He noticed that his friends who were also in the study who were slowly, steadily reducing their drugs seemed to be regaining voice and movement while he was rapidly getting worse. He was chagrined that he hadn't decreased his medication sooner.

When his ticcing and facial grimacing become constant and he needed a walker to maintain his balance, he stopped coming in.

COMPARING PATIENTS

Within a year of starting the research, we suspected a physiological difference between medicated patients and unmedicated patients. We tried to explain it away with math: we proposed that the medicated patients were simply more advanced than the unmedicated. This specious logic did not hold up; patients who had been diagnosed less than one year and were taking medication had more difficulties in recovery than patients who had been diagnosed three or more years earlier but had refused the drugs.

I had one patient in his seventies who had had PD for over six years and, due to fear of the drugs (his wife was an MD and had done her research), had been stumbling along on sub-therapeutic levels of the drugs. He progressed towards recovery much faster and had fewer drug-related side effects than the ones on full dosage.

We looked for other reasons: differences in age, attitude, and symptoms. It appeared that the only similarity in all those patients who started recovering but then developed the rapid, even bizarre worsening of symptoms was this: they were taking antiparkinson's drugs.

Altered minds

Medicated patients even thought differently than unmedicated patients. Their thought processes and memory weren't as keen, although they appeared bright eyed and clever enough and often felt that they were smarter than most. One mental characteristic of most drugged patients was incapability in making objective observations about their own condition. For example, when they were writhing, they often imagined that they were moving lightly and with great subtlety. Their mental differences, together with the physical adverse effects, led us to suspect that we were dealing with two separate illnesses: the PD and the drug effects.

Crawling skin, jerking bodies

There was another thing we'd noticed: we could tell by the feel of their skin whether or not patients were medicated. Our hands could detect an unpleasant feeling in medicated patients, as if there were snakes crawling under their skin. Their skin gave off an erratic electrical discharge as well. Those of us who had a keen sense of touch found it unsettling to do massage – the massage that is used in the treatment of the old foot injury – on these medicated patients. Also, the subtle movements of energy and anatomy were difficult to perceive in drugged patients – the medication causes drugged patients to respond with jerking or vibrating that mimics the anatomical movements of recovery, but these are actually superficial, drug-related twitches.

Replications from abroad

Emails started coming in from other practitioners describing scenarios in which their medicated patients had worsening adverse effects from the medications shortly after they began to demonstrate recovery symptoms. The people who were taking meds had different problems in recovery than the patients who merely had Parkinson's disease.

No two the same

Any PD specialist will tell you that each PDer is unique. No two have the exact same symptoms. And yet there is a consistent logic to the disease, its progression, its treatment,

and the symptoms of recovery. The unmedicated patients were recovering in the same way. But medicated patients each went off on their own tangents. We started looking forward to the unmedicated patients. While their cases were challenging, they were still comparatively straightforward. The medicated people were quagmires; their recovery symptoms and medication-related symptoms quickly became baffling and unpredictable.

Masked Symptoms

There was another problem in working with medicated patients, as far as research was concerned: we had no way of knowing just exactly what symptoms a medicated person actually did have. A very advanced PD patient might appear perfectly normal during his best On times from the meds, or he might appear exaggeratedly nonfunctional if he was having an Off time. It all depended on when in the drug cycle we chanced to see him. I've had many a hearty laugh with patients who recall such doctor visits: "I went to my neurologist and it happened that my medication was working well for the first time in a week. He told me I was at the perfect level with my medication after he watched me stroll down the hallway and touch my nose. I told him that I had hardly been able to move all week, and he just shook his head and told me I was exactly at the right levels. An hour after we left his office, I couldn't move again."

I also heard the reverse: "I was at my annual checkup with my neurologist and my medication was Off right then. He went into a panic and told me to grind up a pill and take it right away. My wife tried to explain that I would be On in half an hour, but he just couldn't believe how bad I looked. He told me to double my medication."

(By the way, please forgive the lengthy asides. There will be more. I would love to present all the information I've gathered in some sort of straight-line progression, but in truth, there was information coming in from all sides at once.)

The gist is this: under those layers of medication, the doctor and even the patient may not be aware of what his PD symptoms actually are.

Mistaking side effects for symptoms

The patients who have been taking the drugs for years and have side effects from their medications think they know what their symptoms are. They are often wrong. Most patients assume their On/Offs or their dyskinesias (excess, uncontrolled movements) are their most troublesome symptoms. As for rigidity, poverty of movement, balance trouble or tremor – the actual symptoms of Parkinson's – they may not be so concerned about these. These problems may be masked by their medications. But returning to the main point, when a person is taking drugs, it is impossible to know what his symptoms are, so it is impossible to know just how much progress he has made during recovery, or how much recovery work there is still to be done. Just imagine: we were trying to treat people who weren't sure what their actual symptoms were.

Better off with Parkinson's?

After several patients became wildly overmedicated to the point of pain, we began to wonder if some medicated patients were better off never recovering; since the medication appeared to be more powerful and more addictive after people recovered than it was while they still had PD, and since many recovering patients apparently did not have the ability to willingly decrease their medication, we had to ask ourselves if possibly these

patients would have been better off if they had never entered the program. Certainly, Zoe would have been better off.

Zoe

During this time, we'd been working with Zoe, a delightful woman in her early 60's. She had been diagnosed six years earlier but was still trying to keep up with her weekly yoga class. She was taking Sinemet CR 50/200 six times a day, a pill every four hours. (She woke up in the night to take her midnight dose.)

She did well in our program. She regained her ability to sweep the sidewalk and wash her own hair. Her walk had a lilt again and her tremor was gone. She was shaping up to be one of our greatest success stories. But then she hit that phase of recovery where it is just impossible to get up in the morning. (There is a stage during recovery where people feel heavily sedated for two hours, usually from about seven until about nine in the morning.⁴⁶) When Zoe got to this stage, she grew alarmed. She interpreted her inability to rouse herself promptly in the morning as a sign that she needed more medication. She tried doubling her 6:00 a.m. dose. Still she was tired and sleepy from seven until nine o'clock. So she tripled her 6:00 a.m. dose. She was still groggy. This threw her into a panic. Even though I told her repeatedly that all the other patients at this stage of recovery weren't able to move from 7 to 9 either, she refused to believe me.

Even though she was able to move better than ever during the rest of the day, even twitching and grimacing (new symptoms that indicate overmedication), she was terrified of the helpless, anesthetized feeling she experienced for two hours every morning. By now she was taking 8 pills a day instead of 6. A few weeks later, she came beaming into my office telling me how well she was doing. She was up to 10 pills a day and felt just great. She was no longer groggy in the mornings. Evidently, she said, what she had needed was more medication. She felt so good that she increased her medication again the next week, up to 12 pills a day. Now she was taking a total of 600/2400 (carbidopa/levodopa), far more than the manufacturer's suggested daily amount, and she looked as if she could waltz through the ceiling.

She no longer had any symptoms of Parkinson's, but she was strangely euphoric. She laughed, sang, threw her arms around with abandon, and acted very suspiciously like some of the subjects in Oliver Sack's early study using L-dopa on non-Parkinson's patients.

Then the diaphragm trouble started. She noticed that if she was more than twenty minutes late with her pills, she became unable to breathe. Her diaphragm would seize up and she would gasp for air as if someone was choking her. She went to the hospital during one of these choking fits and the doctors were puzzled; her blood oxygen levels were within normal limits. She was evidently getting enough oxygen although she was bent double, terrified, and gasping for air as if she was being choked. Her breath would come in great staggering rushes, and then pause in between while she turned a bit purple in the face,

⁴⁶ There are certain physiological processes that take place at specific times of the day. Stomach channel healing is especially strong between 7 and 9 in the morning. Many PD recoverers go through a phase when they cannot move, when they are as if heavily anesthetized during these hours. This can last for a few days or several months, depending on the speed of healing in the individual.

and then there would be another huge gasp. It was horrible to watch. So she increased her medication. The breathing problem got rapidly worse. She increased again.

Zoe saw Dr. Pender every six months. On her first visit to him after she started in our program, he noted that she was doing very well. He even wrote on her chart that she might be overmedicated. Zoe brought me copies of her doctor's notes. At her next visit with Dr. Pender, he wrote in her chart that possibly she had been misdiagnosed.⁴⁷

But the next report was even more important. Zoe showed me a photocopy of the notes Dr. Pender had written up: he had noted that he did not know why this patient had pretended to have Parkinson's disease for six years.

I was excited. Zoe's doctor was a big shot at an important clinic that specialized in PD. I could understand his feelings; if he had misdiagnosed her, he was in a bit of a spot.

Therefore it must be that the patient had pretended to have PD for some crazy reason of her own.

Having decided that she had only been pretending to have Parkinson's, he told her that, based on her flailing dyskinesia and breathing problems, she was dangerously and unnecessarily drugged. She should stop taking her medication immediately. She should reduce it slowly, but promptly. He did not define "slowly."

Shortly after that, she increased her medication again.

I asked Zoe to keep a chart of her medication, the time she took it, and certain symptoms of overmedication, including her gasping. She tried many times to take half a pill less, two or three times during the day. What we noticed from her detailed charts was that for two days at the slightly lowered dosage she had fewer episodes of the labored breathing. But within three days or four days at the most, she would feel helplessly panicked, even though the breathing was less strained, and she would go back to the higher drug levels. This back and forth behavior went on for months.

She couldn't explain the panic. She was taking 14 pills a day at this point, 2800 mg of levodopa. She would reduce by about 100 mg/day, have a very slight improvement in the breathing, maybe not have as lengthy a struggle with the breathing, and then, within four days, she would be back at the higher level. This went on for month after month. The breathing pattern was getting more powerful. It overwhelmed her when the breathing attacks hit.

Finally, Zoe's husband got involved. I had been telling him for some time that I was concerned about his wife's drug levels and her breathing. He vigorously asserted that she was an adult, and that her pills were her own responsibility, and that he didn't want to get involved. I replied that from what I was seeing in my office, there was no way in the

⁴⁷ Patients with Parkinson's disease can't recover: Parkinson's is defined as incurable. Therefore, the official proof of our success is when the MD declares that a patient was misdiagnosed.

I was so pleased with Zoe's possible change of diagnosis that I wrote to her clinic with a signed release form and asked for copies of all her records. Dr. Pender was highly antagonistic to our program. So I wasn't surprised but I was disappointed when the clinic sent me only a partial file – they had left out her two most recent visits. I called the receptionist and asked why the two most recent reports had been omitted. She was baffled. She remembered putting all the records on the doctor's desk for his approval before sending them to me. She couldn't imagine what had happened to the two missing ones. Dr. Pender was out of town for two weeks and couldn't be asked about the missing paperwork, so she, on her own initiative, sent me the two that I was missing.

world she would be able to reduce her medication without some kind of support, but he pooh-poohed the whole thing.

It was only after Dr. Pender told Zoe to reduce her meds and she increased them instead that her husband started getting concerned. He asked me what he should do. I explained that I couldn't give any advice, but that he should visit the MD again and get specific advice about how to deal with the medication. Meanwhile, every time it neared the hour for her next dose, his wife would have the feeling of being suffocated, the horrible, loud gasping sounds, and the grasping for breath, her eyes bugging out in terror. Only another pill could bring relief.

Dr. Pender suggested that Zoe should cut the pills in half, and take them a little closer together for better coverage. Zoe ended up taking her pills closer together, and she inadvertently increased her total dosage as well. She was up to 16 pills, 3200 mg/day of levodopa. This time her husband called me on the phone and demanded that I tell him what to do. I said that they should see the doctor. Now the husband raised his voice with me. He screamed, "What good would that do! She won't obey!"

Zoe wasn't able to follow her doctor's advice – his suggestions seemed to make the symptoms worse. Zoe and her husband showed him their detailed, daily charts of the timing of the pill doses and her symptoms, but he wasn't interested. At this point, after all, he had concluded that she was only pretending to have Parkinson's so that she could get her hands on the drugs. He refused to see her. She went to another neurologist who, seeing from her charts that she had Parkinson's, renewed her prescription.

The breathing problem became so severe that they decided to have Zoe hospitalized. The hospital, not realizing that it takes nearly ten weeks⁴⁸ for any decrease in this medication to be stabilized, treated her with strong sleeping drugs for three days while decreasing her medication, and then sent her home with her L-dopa at half the level it had been. Within a week of being home, her drug levels were back up, and from there, they increased further, to 18 pills, 3600 mg of levodopa a day.

I was no longer treating Zoe. Her condition was out of control. She went back east to stay with family because her husband was afraid to leave her home alone. She wasn't making much sense; she was increasingly illogical and emotionally overwrought. Her arms and torso were in constant movement. I did not see her for over a year. When I last saw her, on a visit to her home, she was taking 20 pills of CR 50/200 carbidopa/levodopa a day – 4000 mg a day of levodopa, more than double the highest recommended amount. She was in constant motion, and her eyes were dilated like those of a cat. Her pupils were so large and round that the light reflecting off her retina glowed like the eyes of a lynx at midnight. She was alternately euphoric or sobbing. It was terrifying.

Through the grapevine I have heard that she is back east again, and that her husband is planning to have her admitted to yet another hospital. They will try once again to stabilize her over several days. I hope for the best. She remains in my prayers.

⁴⁸ This number, ten weeks, also known as "two to three months," is coming up with increasing frequency in books on addictive drugs. It was first recognized in the cocaine addiction pattern and is now noted in drug books in reference to many of the psychoactive drugs, such as Paxil. However, most doctors, including most neurologists that prescribe L-dopa, are not familiar with this time frame. Most of them still imagine that it takes a few days, maybe a week, to stabilize a drug at a particular level despite the drug inserts that note that drugs such as Levodopa may take months before the drug shows its effect. Most MDs evidently do not read the drug instructions; in our experience, most of them expect a patient to have results within a few days and prescribe accordingly.

TREATING TWO ILLNESSES, NOT ONE

People who were taking drugs for their Parkinson's disease apparently had two problems, not one: they had Parkinson's disease, and they also had drug-related problems. If they ever, even briefly, had been overmedicated, manifesting adverse effects, they seemed to have permanent brain damage from their medication. Even if most of their PD symptoms vanished and they stopped the drugs, they might have residual, long-term, drug-induced symptoms such as tardive dyskinesia. These manifestations of the brain damage are similar to the symptoms of Parkinson's disease; in fact, they are called "drug-induced parkinsonism" in medical literature. Despite a similar name, there is a significant difference between the two conditions: Parkinson's, based on our findings, appears to be treatable – brain damage from excessive antiparkinson's medications may not be, at least not by any method known at this time.⁴⁹

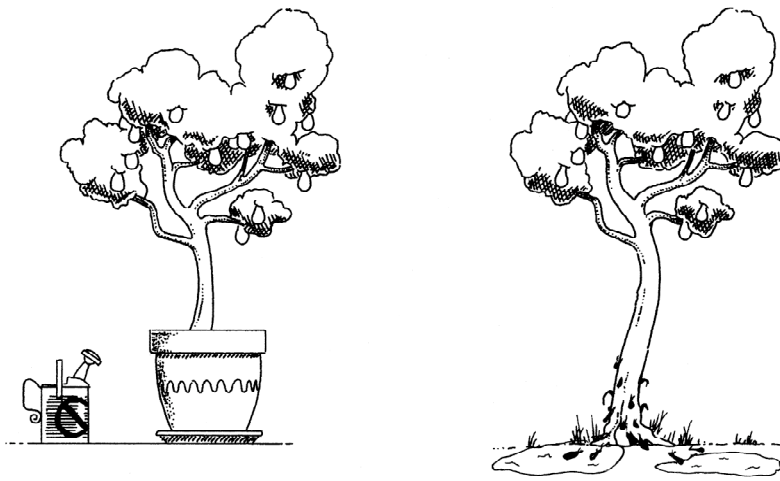


Fig. 2.1 Different root causes

Both plants have clumps of dying leaves hanging down; the plants look identical. The plant on the right is doing poorly because bugs have invaded the roots and are sapping the trees nutrients: a remediable condition. The plant on the left has been fed poison: the roots have all died. Although the dead leaves of both trees look similar at this early stage of the process, the plant on the left cannot be restored to health; the plant on the right can recover if the bugs are removed. (Explanation for Fig. 2.1 is continued on the next page.)

In the case of drug- or toxin- induced parkinsonism, brain damage from drugs and toxins may well be permanent; all current research indicates that this is the case. The root problem in idiopathic Parkinson's, an electrical disarray, appears to be treatable. PDers who are taking medications have *both* problems: a treatable, backward-flowing electrical system and permanent damage from their drugs.

⁴⁹ In Parkinson's disease, "although dopamine is depleted, the cells in the striatum are preserved. This is unlike the PD-like disorders (drug- and toxin-induced parkinsonisms) where, in the striatum, the dopamine content is decreased and the cells are lost." A. Lieberman, MD, "Curing Parkinson's Disease in our Lifetime," *Parkinson's Report*, National Parkinson's Foundation, Fall 2000, p. 10.

Summary

Wrong doses, ignored warnings

The examples of Olli, Zoe, and the well-meaning but unhelpful, even obstructive reactions of their neurologists, may give you a sense of our bafflement and helplessness during these early times in our study. A large part of the medication problem appeared to be ignorance on the part of doctors as to how these medications worked and the correct dosing. This ignorance contributed to conditions such as Rose's writhing and thrashing and Zoe's inability to reduce her medication.

We realized, to our dismay, that most doctors were not only failing to prescribe according to the manufacturers' recommendations, they were blithely ignoring the published drug warnings. But most curiously, it appeared as if the drugs did not work in the ways that they were purported to work, especially with regard to drug half-life and brain adaptations.

The next chapter will share hypotheses that we developed that, unlike the existing "facts" about dopamine-enhancing drugs, actually seem to correspond to what happens with people who take antiparkinson's medications over an extended period of time.