

“There are three kinds of lies: lies, damned lies, and statistics.”

Mark Twain

26. STATISTICS AND CONCLUSION

ACCOUNTING FOR THE VICTORS AND THE DEAD

There are two frequently asked questions about the Parkinson’s medications. This chapter will address both of those questions.

The first is: “What are the numbers, the statistics for your project?”

People understandably want to know exact numbers of patients who have recovered, who have gotten off their meds, had brain implants while medicated or unmedicated, switched from levodopa to an agonist, reduced their drugs and felt better, reduced their drugs and felt worse, and, of course, how many of the people in our program would be in the program again, knowing what they know now.

It is only reasonable that I share these numbers with you, and I will, at the end of this chapter, but first I must make something perfectly clear: we were not instructing our patients to decrease their medication. All patients in this program who did decrease their medication did so on their own initiative. All patients who did not decrease their medication, up until a year ago when we stopped accepting medicated patients, received the same forms of Yin Tui Na treatment as unmedicated and drug-reducing patients for the first two years.¹

However, our discussions about the drugs undoubtedly did influence some patients to have a go at decreasing their medication. As we learned more about the drugs, we did inform those patients whose symptoms corresponded to the adverse effects of their drugs that their symptoms might be drug related (but they would have to ask their doctor to be sure). We also shared information about what other patients were doing with their drugs and what was happening to them. We operated the clinic with the goal of sharing information and making observations. We were never in the business of trying to run a double-blind experiment in which patients were kept in the dark as to our intents and purposes. Nor did we try to create a situation in which similar patients were compared while doing different drug regimens. We never used placebo medications to determine the psychological effect. We were not running a statistically significant study. Our patients made their own decisions – with or without benefit of a doctor.

In the second two years of our clinic, we did start to modify the treatments that we gave to overmedicated patients; when patients appeared at the clinic with drug-induced dyskinesias, we often chose not to perform treatments that could possibly lead towards recovery or even a temporary increase in dopamine production; we also explained that choice to the patients.² When, on the other hand, patients showed up at the clinic

¹ About two years into the program, we started a new policy for overmedicated patients.

² Some of the traditional acupuncture calming treatments, such as Four Gates or Yin Tang, can cause an increase in dopamine. Therefore, we did not use such treatments on patients that presented with dyskinesia, dystonias that worsened with medication, overly fast speech, brightened eyes, or other symptoms of overmedication. Instead, for these patients, we sometimes used strong stimulation of a needle at KI-1 – the point near the center of the sole of the foot – to bring the Qi away from the midbrain and

manifesting symptoms of drug withdrawal, we often employed the standard ear acupuncture treatments for relief of drug withdrawal symptoms, rather than using Yin Tui Na to address the Parkinson's.¹ We tried to treat, at each session, the situation that was dominant in that particular patient at that time. This meant that, in the second two years of our program, after we knew a bit more about the drugs, medicated patients often received different treatments than the unmedicated patients.

Our clinic operates Asian style, with all the patient tables in a large open room with no dividers, so that all the patients and practitioners are visible and audible to all the other patients in the room. Patients heard each other discussing their drugs, the drug side effects, and their drug reduction experiments. The members of the Santa Cruz PD Team also shared with patients in our private practice the things we were seeing in the free clinic and with the other private patients.

We did not see ourselves as advocates of any particular health-nut, anti-drug program, or as pro-drug proselytizers. We did not start with any ideas in particular about the medications. We actually started this program with the assumption that the local doctors were correct, and that these drugs were harmless and could be stopped easily at any time if a patient was found to have been misdiagnosed. We maintained this position for over a year; the earliest editions of my books, in which I passed along the advice of local neurologists, are testimony to this position.

The number of patients who decreased their drugs while participating in our program is not necessarily indicative of who felt able to reduce drugs: medication reduction was not a tenet of our program – not everyone in our project entered the program with the intention of decreasing the medication. We did not run our program as a drug-reduction program. Therefore, the numbers that came out of our study do not represent patients who all wanted to decrease their medication, and then succeeded or

create a mild state of emergency to decrease the dopamine levels in the midbrain. We would not perform Tui Na on overmedicated patients, or do anything that might make them feel peaceful or relaxed.

Even if the medicated patients were not overtly showing adverse effects, performing Tui Na on them was often a waste of time. Their body could not respond to the gentle support of the treatment by calmly dealing with old injury. Instead, the body would use the support of the treatment to work out the excess effects of the current overdose of medication. In my many experiences with practitioners who had been pleased to report that their medicated patient was responding to the FSR with “lots of movements,” I would almost always find, when I worked with the patient, that the responses were merely drug releases. The deeper releases of old tensions could not occur when a patient was over the top with drugs.

Also, a beginning practitioner can rarely distinguish between the native Qi flow and the various electrical forces just under the skin that are set in motion by the drugs. Each of the drugs creates a distinctive electromagnetic force that can be felt with a sensitive hand. Most practitioners, feeling this distorted energy field, imagine that they are feeling native Qi. So many people have written to me to say “I felt for Qi in my patient’s leg, and you are wrong about it being Rebellious (or deficient): it is surging!” They are dubious when I suggest that what they are feeling is drugs. But if their patient comes to them after making a drug reduction, or more than eight hours after taking a pill, they realize that the Qi in the leg is quite different.

Some of the best learning experiences in this regard are the weekend classes. Each class has up to twenty patients and their practitioners. The students (and caregivers and spouses) are allowed to spend a few minutes simply resting their hands on the legs or feet of each of the patients. They are usually shocked to realize that, even with little training, they can quickly ascertain the difference in the under-the-skin sensation not only between medicated patients and unmedicated, but between the various, specific drugs.

¹ See Appendix 4: NADA protocol (ear acupuncture).

not. The numbers offered below are simply a count of what happened to all the medicated patients during the first few years of our patients' experiments and our observations.

What the numbers do not mean

If the numbers below state that a patient increased his medication, this does not mean that he needed more medication in order to be functional. Zoe, for example, continued to increase her medication even after her doctor told her that she didn't need any at all and that she was dangerously overmedicated. In the numbers below, she is listed only as a person who increased her medication, with no mention of the fact that she was overmedicated to the point of near death.

Many of the people who increased their medication did so although they knew they were overmedicated – they could not resist the lure of the medication. Others increased their medication because their doctor told them to and they had no interest in disagreeing with the doctor.

Conversely, some patients who are taking less medication are not necessarily recovered. A person who is listed as having reduced his medication may or may not be having reduced function as a result of the drug reduction. It would be impossible to say, without a full page report on each patient, what level of functionality a person has at this moment in time, and whether the medication reduction – bearing in mind the extended time-frame for observing the effects of a dose change – has led to a decrease in function.

While this may seem as if we are being coy and withholding information with the intent to obfuscate or even mislead, it is just the opposite. Without a complete recounting of exactly what symptoms a person had and how they have changed and are still changing, any report of drug increases or decreases could be misleading. Unfortunately, increasing interest in our program requires that I publish this drug information now, without full case descriptions of every patient. Hopefully, over the next few decades, every patient from the project will have his story written up. At that time, the individual case studies will provide more meaningful information than this list of numbers.

Difficulty in quantifying changes

For an example of how difficult it is to state whether or not a person is doing better or worse, I heard from a patient who now is consistently better in these areas: his life-long constipation (a frequent companion to Parkinson's disease) has not returned since it began to improve six months ago. His sleep is much better, his facial expression has returned, his arms are no longer held rigid. His energy levels are returning to a satisfactory, high level, after having been very low for nearly a year (since starting treatment). On the other hand, he sometimes has more difficulty than before in turning to the sides – but sometimes less than before – and his tremor is wild. He feels he is in the middle of a profound change – but is he getting better or worse?

Therefore, I am not going to make statements as to whether or not these patients are improving or declining. More on this subject is explained in the book *Recovery From Parkinson's Disease*. This current book is simply a record of some of the remarkable events that we witnessed in our medicated patients while they were members of our Parkinson's project.

Who is included

In choosing which people to include in the count, I have eliminated those patients whom I worked with only briefly, including the hundreds of people I have treated and interviewed at weekend workshops around the world. I have also not included the hundreds of patients that I know only through the Internet. Unless I have had a somewhat lasting relationship with a patient, and been able to observe him or her for some period of change, I have not used him or her in putting together the case studies in this book or in the numbers, with one exception – Buzz.

Buzz was included in this book even though I never worked with him as a health practitioner. I met with him over two days after he was already off his medication and moving easily, with no remaining PD symptoms except for tremor. I knew his acupuncturist, Eileen, only slightly from her attendance in a two-day class. I did communicate with Eileen via the Internet, and, after meeting Buzz, I had very pointed communications with her in which she told me about her other eight patients and the course of their progress. Everything she told me squared so well with what we were seeing in our program that I must credit her experience. Still, I don't know if I would have included his story in this book, especially in light of how dangerous it might be for someone to emulate him, except for the fact that Buzz has already been interviewed on television and has made his story available for many people via the Internet. Since he is already known, and I did want to make the point that his drug reduction was not risk free, I have included his case although he was not my patient.

And now, the numbers please:

63 medicated patients participated in our program over a long enough time frame that I can reasonably use their information for this compilation of statistics. Many more came as one-time visitors or attended weekend classes. These short-term patients as well as those who did not stay in the clinic for more than a few months were helpful, and often demonstrated important principles or drug-related symptoms, but their drug dosage changes would not be meaningful for this list.¹ The project started in February of 1998. This chapter is being written in March of 2003.

Completely stopped taking medication: 18

This number includes patients who were not taking much or had only taken drugs briefly when they joined us, but it also includes Hjalmar, Chris, and Lance, who had used drugs for decades before starting with us. This number includes those, like Earle, who are doing well without the drugs while gaining in strength, and Hjalmar, who is still very weak and sleeping much of the day.

Stopped all medication and then started up again at very low levels: 4

This includes Becky, Coach, Sammy, and Taylor Paul. The Taylor Paul update: he is down to 100 mg/day and doing so well that when his doctor saw him at the store, the doc asked if he had increased his medication again, even going above the 500 mg/day that had been prescribed during Taylor Paul's hospital stay. When Taylor Paul told him

¹ We were also fortunate enough to have 36 unmedicated patients in our program.

that he had in fact decreased significantly, and was feeling stronger every day, the doctor said he couldn't understand why Taylor Paul was so opposed to the medication.

Began an abrupt increase in medication: 5

People in this group have increased medication despite (or because of) doctor's orders, and are considered by family or friends to be completely illogical and grossly overmedicated. This group includes Zoe, Birdie, Angus, Brad, and Euclid. All members of this group began to experience distinct symptoms of recovery before they flipped out. Angus, Brad, and Euclid had all reduced their medication down to a "sub-therapeutic" dose and were doing extremely well with the reductions. They had been confident that they were recovering when they abruptly went into drug mania, and they remain there at the present time.

There are many people that I have learned of over the Internet or have met in classes who would fit into this category. This is the most frightening group, in my opinion. The fact that over 12% of our medicated patients fell into this category should be alarming to anyone who is taking medications and considering embarking in a PD recovery program. Four of the five were specifically warned about the possibility of abrupt addiction after we had seen what happened to Zoe – all four were confident that they knew what they were doing and that it could not possibly happen to them.

Increased their dosage levels: 6

This number includes Olli, Stephanie, Rudyard, and Lila – though there is some debate in the PD team that both Lila and Rudyard should be included in the abrupt increase/illogical group above. However, both Lila and Rudyard still seem able to somewhat understand that the medication may be responsible for their worsening side effects, and so they are included in this group. Included in this group is a patient who got a deep-brain stimulator (battery operated wire implant). He was unable to sleep after getting the implant. After more than fifteen harrowing months without more than twenty minutes sleep every 24 hours, he started taking Sinemet. The levodopa helps calm him down enough so that he can now sleep. Like most implant patients, he was taking Sinemet prior to the implant and continued to take it after the implant, though at a slightly reduced level. After a year of FSR, he no longer needed any Sinemet – his movement was normal. However, the sleep problem was killing him. Although the levodopa did not help him sleep prior to his FSR treatments and recovery, after he regained flexibility and feeling in his legs and had the implant, the levodopa paradoxically acted as a sleep aid.¹

Decreased their medication by up to 50%: 7

This group includes Nat, Moses, and Maurice.

Decreased their medication by more than 50%: 4

No members of this group were discussed by name in the preceding text.

¹ Other patients who suffer from rigidity find that L-dopa can help them sleep. Insomnia can be a symptom of overmedication and can occur after a crash. Therefore, many overmedicated patients must take L-dopa, a stimulant, to get to sleep after crashing.

Decreased their medication by more than 66%: 8

This group includes Rose, Sonny, Hua To, Yves, and Laurel.

Stayed the same: 5

These people, for the most part, were among our first patients. All of them dropped out of the program within less than a year. They were taking large doses of medication, and as their treatments proceeded, their dyskinesias grew worse. They all assumed that the worsening of dyskinesia and other drug adverse effects were simply a worsening of their Parkinson's disease and concluded that the program was not working.

Lost touch: 5

These were people that we met with or worked with for a considerable time but who moved away. Although they contributed to our general knowledge about the medication, we do not know what they have done with their medications since they left.

More information about the patients

Of the people in the groupings above, five have passed away: Rose, Birdie, Honoria, Eli (described in Appendix 2), and Francis. Eli passed on following a massive stroke, and Francis, not previously described in this book, died of pancreatic cancer.¹

Four of the group had brain implants: Rufino had decreased his medication from 1000 mg/day to 50 mg/day of levodopa prior to this implant surgery in early 2002, and he has now been completely off antiparkinson's drugs for more than a year. His doctors say that he has responded better to the implants than any of their other patients. They have called him their "implant poster boy." It may be that the reason is this: he is their only patient that has not had to keep increasing his medication, adding drug side effects to the inevitable implant side effects, and he is also their only patient who no longer has Parkinson's disease. When his case was discussed at a recent convention of implant doctors, the docs refused to believe the statement by Rufino's doctor that he was not taking medication. A curious response! Another implant patient, as described earlier, is tortured by an extreme form of insomnia.

The third implant patient moved out of the area shortly after her surgery. She was in the first group of twelve patients, before we knew anything about the medication. She had been reducing her medication and was making remarkable progress in recovering from Parkinson's when her name came up on the implant wait list. She was told that she

¹ Although there is not enough room for every case study in this book, I would like to slip in one more. Restored mental function is one of the most appreciated, and often unexpected, results of getting off the medication. Ten days before Honoria passed on, at age 87, her family took her off all medication. Her liver was failing, and the nurse suggested that the anti-PD drugs were hard on the liver. Her family was stunned to see that, within 24 hours of getting off all the anti-PD drugs, she was mentally focused and keenly, incisively intelligent for the first time since she had started taking bromocriptine at the time of her diagnosis ten years earlier. Four years prior to her passing, her daily drug regimen included Sinemet (three 25/100), Bromocriptine, and Mirapex (2 mg/day). She had been in our program nearly three years and had made great improvements in mobility and decreased her medication. At her last visit with Dr. Rafferty before her passing, he asked her what had happened to her cane; she'd been dependent on a cane for years, ever since she had become nearly house bound with poor balance. She replied honestly, with a twinkle in her eye, "I left it in Reno at one of the casinos."

had to decide – if she didn't have the surgery that month, she would never be put on another wait list.

Despite her conviction that she was recovering, her husband felt she should have the surgery – thus covering all the bases. She had the implant surgery. In the days immediately following her surgery, she noticed that she could move well with no medication. When she started with us, she had been taking five pills a day and had gotten down to where she felt very comfortable with two pills a day, just prior to the implant. Within a week of the implant surgery, she was again taking five pills a day. I asked her why she had resumed taking five pills a day since she insisted she no longer needed them. She replied, "I don't need them to move anymore, but they make me feel so good and they ease my back pain." A month later, they moved away.

The fourth is a long, sad story. When this man first got the implants, he was able to reduce his medication by half, down to 300 mg/day levodopa, as well as decrease his Mirapex. After a year with the implants, he was back at 600 mg/day and full Mirapex. He was having dyskinesia from the medication, and even so, was rapidly losing motor function.

At this point he started in our program. As he started to respond to the FSR, the implant caused increasing internal agitation and feelings of burning static in his skin. He started turning the implants off at times, which incurred the wrath of his doctor. Then, after feeling the return of sensation in his feet and legs after several months in our program, he started a rapid decrease in his medication. This incurred the wrath of the people he was living with. Unfortunately, due to the rapid improvements that he made, his medication became more effective and the side effects much worse. The side effects of the implants also worsened. He was forbidden to work with me ever again. It was a long, drawn-out saga, but he is in much more pain now than he might have been had he not started with our program. We no longer accept patients with brain implants into the recovery project.

This concludes the numbers and statistics on the project.

The Second Question

In closing – and I bet you thought I'd never get to this! – the other frequently asked question is: "Are the antiparkinson's drugs good or bad?"

That is a foolish question. The drugs, used judiciously, can provide tremendous benefit. The drugs, used injudiciously, can cause problems much, much worse than mere Parkinson's disease. Some of the most tragic cases I have heard from were people diagnosed with Parkinson's on the basis of a mild tremor or bothersome draggy foot and immediately placed on very high levels of medication. Within six months, some of these people started suffering the excruciating dystonias and On-Offs that are associated with overmedication. They have then been instructed to further increase their drugs to treat their "worsening" Parkinson's.

On the other hand, the medication, and not our program, has been the best choice for certain patients. Let me give an example.

Lemual

A local woman called me to make an appointment for her husband – he was only 75, and he had just been diagnosed with Parkinson's. I asked her to read our *Patient's Handbook*, available for free on the Internet, and call me back. She called the next day, said she had read the whole thing, and I made the appointment for the following month.

On the day of the appointment, her husband slowly shuffled into my office with an expressionless face and extremely delayed vocal and motor response. He was hunched over, his arms bent at the elbow in the classic PD position. He couldn't move his head to the left or right. He had a very mild tremor. He came through the doorway with difficulty. He crossed into my office with difficulty, and, appearing deeply confused, sat down on the chair very slowly.

I asked him how long he had been moving slowly. His wife answered this and all my following questions. She laughingly said that he had been moving "funny" for over fifteen years. She laughed as she described the "funny" way he used his arms while eating, and how she'd been making fun of him eating that way since before he retired, twenty years ago. He had quit golfing fifteen years ago because he couldn't move right any more. But he had been fine; he never had Parkinson's until a month ago.

After an hour, I finally extracted from her, between gales of laughter, that he had not tremored nonstop until a month ago. Prior to that he had been increasingly hunched over, rigid, slow, and silent for more than fifteen years. However, because our website made the point that recently diagnosed patients seemed to respond the best, the wife kept repeating that he had only been diagnosed a month ago and was therefore a good prospect.

Finally, he spoke – slowly and softly – but with determination: "I am seventy six. I have lived a good life. In my family, we all die by age seventy. My parents died just before they turned seventy. My brothers and sisters all died when they turned seventy or seventy-one. I'm ready to go. I've had a good life. There's nothing left that I want to do. I am ready to go."

His wife, embarrassed, started chattering about how he had been diagnosed only recently, and asked how many weeks I thought it would take for him to recover.

This man was in a condition of advanced Parkinson's disease, but more importantly, he did not want to get better. He was ready to move on. Whether it was because he wanted to shed his unresponsive body or his overly responsive wife, I couldn't begin to guess, but he was in his right mind, and he clearly had no interest in our program. This was going to be awkward.

I had an idea, and crossed my fingers for luck. I turned to his wife and said, "OK. Let's start making sure we've got everything ready for when he recovers. Have you picked a care facility yet?"

I will try to recreate the conversation to the best of my ability:

"What do you mean? If he's going to get better, why would he need a care facility?"

"During the recovery stage when he grows very weak, he may need help being moved to and from the bathroom, help getting dressed, help with feeding. You are no longer young yourself, and I don't want to see you trying to carry him to and from the car during the months when he is recovering."

"What on earth are you talking about?"

“Didn’t you read the *Patient’s Handbook*? It describes very clearly the stage of recovery when a person is extremely weak and may need help even to move.”

“Well, I told *him* to read it – I didn’t have time. He forgot to read that part! Lemual! Did you read that part! Why didn’t you tell me!” Lemual just sat there, unblinking. She turned to me and said, in conspiratorial honesty, “He doesn’t always remember everything he reads.”

“Maybe you need to go home and read the book. This program can be very grueling. Also, Lemual has advanced Parkinson’s disease.”

“That’s where you are wrong. He was only diagnosed in the last month.”

“That’s because you never took him to the doctor for a diagnosis. He has not been moving normally for over fifteen years – the funny way he moved, that made you laugh so hard, that was Parkinson’s disease. The tremor started late in him – but he had Parkinson’s disease right along. His condition is very advanced.”

“Well for goodness sakes! Then what do you think we should do? We can’t afford a care facility!”

I told her that she should see another neurologist and I recommended Dr. Rafferty. I warned her that, since he might recommend medications for Lemual, she must know that the medications for Parkinson’s disease can take a long time before the effect is obvious. It might be three months after Lemual started the medication before there was any visible change.

I asked her to let Dr. Rafferty know that she and Lemual didn’t want a quick result – they wanted a safe one.

I suggested that Lemual might find that the drugs slowly, over several months, might gradually allow him to move better, and that, if used judiciously, the drugs might help him move fairly well for the rest of his life. I also warned her that if the drugs were increased too quickly, hoping thereby to restore him quickly to a level of movement that was unrealistic, these drugs might backfire and worsen the Parkinson’s.

I asked her to read the warnings on the drug insert carefully and keep an eye on Lemual for adverse effects, and tell Dr. Rafferty about them right away. I explained that there are many different drugs available; each one has slightly different side effects. I did point out that if Dr. Rafferty suggested changes in the drug amounts over the months or years, to keep in mind that people in our project found that increasing or decreasing them slowly, over months, seemed easier on the body than increasing or decreasing them quickly.

I added that Lemual seemed a little depressed and offered that the medication might help him find more joy in life – but only if the drugs were used correctly.

“Dr Rafferty appreciates the risks and will be willing to work with you to make sure that Lemual gets the best possible results from the drugs. Be careful with the medications – using them is a double-edged sword, but they can also be a Godsend. Let me know how it turns out.”

I helped Lemual to his feet, and he slowly thanked me. As I helped him to the door, he paused and said again, “I’ve had a good life. I’m not depressed, and I’m not afraid. I’m ready to go.” This time, his wife didn’t say anything, and they walked out into the sunshine, out to their car.

One of the reasons I had recommended Dr. Rafferty was that Mark and Margaret, whose case study is in Appendix 2, had the deepest admiration for him. He was the oldest neurologist in town, as I have stated. He had worked with Hjalmar and many of my long-time PD patients. When Hjalmar had gotten off his drugs, Dr. Rafferty had been sad to see him using a walker, pleased to learn that he had recovered his mind, but, most of all, he had respected his decision.

When Mark started our program, at age 68, he had been taking Sinemet and Artane since Dr. Rafferty had diagnosed him eight years earlier. After Mark got off his drugs, his next visit with Dr. Rafferty showed that the good doctor had been doing some thinking on the subject. By this time, several other patients of his from our project had also reduced or gotten off their medication.

“You know,” started Dr. Rafferty, after they broke the “no drugs” news to him, “we used to think that the drugs were the answer. And now, it seems that the drugs were, as often as not, a part of the problem. We were wrong. I was wrong.”

Dr. R. listened attentively while Mark and Margaret told him about the harrowing six months of drug reduction and the reemergence of Mark’s wit and personality after the drugs were gone. They told him that the dyskinesias – for which Dr. Rafferty had tried adding agonists, digestion inhibitors, and increases in Sinemet – had gone away when the levodopa had gotten down below 100 mg/day. They told Dr. Rafferty how excited they were that Mark, for the first time in years, could get in and out of a car by himself. Even more important, according to Margaret, was that Mark was his old self again. She used the same words as Sophia had used: “I’ve got my husband back.”

Dr. Rafferty shook his head and said again, “I was wrong about the drugs.”

For the next six months, at every weekly meeting with Mark and Margaret, Margaret made the point to me anew: “I admire Dr. Rafferty so much. It must be so hard to say what he said. He told us he had been wrong. I have never heard a doctor say that before. I admire him so much!”

So, in answer to the question, “are these drugs bad or good?” I can only answer, “That depends.”

Finally, in closing, I would like to dedicate this chapter to you doctors, especially you neurologists, who have lived through these rapidly changing times and have kept your minds and hearts open. Though I am approaching the subject of medicine from the perspective of electricity, and you are approaching from the perspective of chemistry, we are all striving for the patients’ greatest good. We drink from the same cup.

