

“Honest men esteem and value nothing so much in this world as a real friend.”

The Fables of Pilpay, Panchatantra (circa 326 B.C.)

25. BECKY AND MIRAPEX

AN AGONIST FOR BECKY; HELP FROM FRIENDS

When we left Becky in December of 2001, she was frail and gaunt, but completely off the drugs and optimistic about the future. Over the Christmas holidays, her friends were saddened by her inability to participate as tirelessly as she used to in their delightful dinners, theater events, and outings. In February of 2002 they put together a position paper for Becky. They said that they would no longer invite her to their events, provide transportation, or assist her in any way unless she resumed working with Dr. Leslie. They were doing this out of love. They were saddened to see her weakness, and they were certain that all she needed to return to her old self was a hearty dose of good medication.

They had no idea that her drugs had caused her tremor to transform into El Twitcho. They refused to believe that the Breath Monster was a side effect of the medication. They were unaware of the dangers of the medication, but they knew that Becky had slid from the driving force of the group to the most needy member. They felt that our program was probably a health-nut cult, and that Becky had been brainwashed. How else could one explain Becky’s preference for weakness and frailty when it would be so easy to be healthy? After all, there are medications that treat Parkinson’s disease – why wasn’t she taking them?

They delivered an ultimatum: either Becky stopped working with me, attending our clinic, and never saw me again, or else they would never see her again.

Becky was devastated. She asked me to meet with them. They agreed to meet, requested four copies of the planned agenda, and then decided against meeting with me. Becky asked me to write up a small paper listing the adverse effects of the drugs. One of her friends, a nurse, dismissed the list of adverse effects, stating that “adverse effects only occur when the drugs are used incorrectly, or for the wrong illness. Parkinson’s drugs don’t have adverse effects if they are used for Parkinson’s.”¹

¹ Strangely enough, while some doctors, particularly European doctors, have been very open to our ideas, American nurses have been, in general, much more opposed to our work than their MD masters. While most nurses will resent this idea that they are subordinate to doctors, the blind defence of MD-approved protocols by most nurses speaks volumes. While doctors themselves often disagree about various processes and procedures, many nurses remain loyal to the idea that, although the doctors may promote opposite theories, the doctors are always correct – whatever correct may be. (My doctor, right or wrong!)

I have friends, ex-nurses, who have quit nursing due to this strange loyalty and illogic that is often required of those who would serve under the doctors’ banner. It is due to this prevalent attitude, more than any legal or technical regulation, that I refer to their “MD masters.” I don’t see this attitude so strongly in Europe or Canada, although I do know people in those countries who have quit nursing rather than be silently obedient to medical attitudes and procedures that they knew to be negligent and dangerous. Fascinating!

At our last “official, goodbye session,” Becky demanded rhetorically, “Why does it have to be a fight? Why does it have to be one way or the other? Why can’t we all get together and take what is best from each kind of medicine?”

We talked a long time about what was most important for Becky. I stammered a bit and tried to explain that I would love her no matter what she did. My door would always be open to her, and she could call any time. She needed to look into her heart and make a decision. I would support her no matter what she chose.

I had known Becky for over twenty-five years. I had worked closely with her in a doctor-patient relationship for four years. We had met weekly in my office, plus an hour a week at the clinic. My students had provided transportation for her to and from the clinic. One student and one clinic FSR volunteer felt a deep connection to her: during her worst stages of drug withdrawal, they had bathed her, given her massages, put lotion on her dry skin, and brought her food and herbal medicines. These two helped her when she moved into a seniors’ complex and helped her decide on the best Feng Shui arrangement of her furniture. They came to her apartment every week to provide massage, ear acupuncture, or just help around the house.

It was all done for love – no money changed hands. They, like her friends and myself, simply loved Becky. Her fiery spirit, unquenchable sense of humor and droll self-deprecation emanated love. I always felt uplifted after an hour with Becky. She was, and is, an inspiration to all of us in the clinic.

Cult status

Becky’s friends felt that these students and I must be cult members. Why else would we be treating her for free? Why else would students take time from their busy days to dote on an old lady? There was something suspicious about our program. Of that they were certain.

Return to Dr. Leslie

Becky called me later in the week. She had gone to see Dr. Leslie. Dr. Leslie had agreed, finally, that Sinemet might not be the answer for Becky, and put her on Mirapex. Becky was to start at a low dose and work up to a therapeutic level over the next two months. Dr. Leslie’s nurses praised her roundly for overcoming our brainwashing.

I told Becky that I was grateful for the information, and, although she wasn’t allowed to see me anymore, I would be glad for any information she could give me in the future regarding her responses to the drugs and her general health.

The following Tuesday at 2:00, Becky’s old time slot, I walked into the waiting room of my office. There was Becky, grinning away.

“What are you doing here? I thought you couldn’t come anymore!”

“Shhh! Ha ha! I’m here on the sly! What they don’t know won’t hurt them!” She lifted one eyebrow and peered over her shoulder as if looking for spies, and winked at me conspiratorially. I wished that Dr. Leslie could see Becky’s so-called “lack of facial expression” at that moment!

Such hugs!

We continued to meet once a week as before. Whether or not her friends knew about it, I have no idea. But she took the medication, as ordered. She was determined to have it both ways.

A therapeutic dose of Mirapex is somewhere between 2 and 4.5 mg. Because this particular drug can cause blood pressure decrease, narcolepsy, and stomach problems, patients are instructed to start with extremely small doses. The drug comes with a starter kit containing doses of one eighth of a milligram, one fourth, one half, and one mg. To start, a person takes one eighth of a milligram three times a day for two weeks. Then the fourth of a milligram pill is taken three times a day for two weeks, and so on. After two months of gradual increases in dosage, a person is supposed to begin to feel the effects of this drug.

What we have seen repeatedly is that patients actually feel the effect within two months whether or not they make the gradual increases. It appears that this drug, if taken at low doses, can be as effective in some patients as the higher doses. However, it can take three weeks to two months before a solid, beneficial result occurs. Time, rather than amount, appears to be the more important factor.

Of course, from a marketing perspective, it may be that patients would be unlikely to take a pill for two months if there is no immediate effect forthcoming. Psychologically, it may be easier to take graduated amounts, knowing that you are building up to an effective dose, and that, as soon as you are ready for the big guns, you will see the effect. Compared to taking the same small dose for two months, hoping that at some point the accumulation will begin to be felt, the “graduated dose” approach is easier to understand, and probably better compliance is obtained. On the other hand, most of my patients were recovering from Parkinson’s, so who knows how they differ from PDers. Maybe PDers do need the larger amounts! Becky, at any rate, noticed effects of the drug within days, while taking the three eighth-of-a-milligram pills, an officially “ineffective” dose.

Becky no longer typed her journal. She used her pocket tape recorder and, as often as something of interest occurred to her, she recorded it. When she arrived for each visit, she gave me a verbal recap of the week. Then, after her acupuncture needles were inserted, I sat down and transcribed the week’s tape. Her first report after starting Mirapex stated:

The tremor has suddenly gotten bigger. I’m nodding off to sleep more (narcolepsy). I even fell asleep in the theater!

I’m still having improvements in stride, voice, and vocabulary, but that has been steadily improving ever since I got down to 50 mg/week [not per day] two months ago. I really feel good about not taking the L-dopa anymore. I’m having a bit of eye trouble. I’m wondering if it’s the hallucinations that they warn about with Mirapex.

[She opened the session the next week by asking me if I was wearing a clown suit. I assured her I was not. She was still taking the minimum, “non-effective” dosage. Her report was telling:]

Am I having hallucinations I wonder? Oh yeah, they’re there! They aren’t bad. For example, if I see someone down the hallway, they look like they’re wearing a clown suit. My own clothes are covered with salmon-colored webbing, and there are kittens or other little animals playing just at the corners of my field of vision now and then.

I'm sleeping until 4:00 a.m. now before needing to use the bathroom. Yesterday I had a busy day. Walked two blocks to the drugstore, then took the bus across town for groceries, and that about wore me out.

How's my mood? As well as could be expected! The tremor is getting more annoying, but I can enjoy the hallucinations. The tremor at night is much worse. I suspect it has something to do with the medications.

[My own notes for this visit say that she seemed unnaturally buoyant and slightly illogical. Her actual responses to questions were more rambling than the edited version above.]

[Her third week was downright worrisome:]

I'm having new kind of tension. My symptoms feel more "concentrated" in my hands and feet; there is a lot of tension in the extremities. I feel more stimulated, more "go for it and never mind the consequences!" I am taking baby steps at times, but I don't seem to care as much. Sleep is still good though, and I've gained two pounds. And, if you don't mind my asking, have you dyed your hair bright blue? [I had not dyed my hair. It was still a middle-aged grey-brown.]

Week four:

I was worried about the tension in my hands and feet, and so I decreased the medication. Last week I was taking 3 one-eighth pills, so this week I started only taking two pills, a one-eighth and a one-fourth.

[I tried to explain to her that she was still taking the same amount, except that she was doing it in two pills instead of three. She had an alarmingly difficult time understanding what I was saying. She was giddy, laughing, and illogical.

[She explained more about the hallucinations. They were pleasant visual transformations in which, for example, stepping stones on the lawn turned into gamboling squirrels, cats, or puppies. Fire hydrants turned into small children waiting for the school bus. Stop signs became tall, smiling figures that waved as she walked past. None of them were frightening, and she didn't mind them in the least. She couldn't tell if they were real or not, but they didn't particularly bother her one way or the other.

[I have seen other people who rather enjoy their Mirapex hallucinations. In all the patients in our limited experience, the Mirapex visions are cute, friendly, and harmless.

[Becky greatly preferred the Mirapex group to the set of mental disturbances she had experienced six years prior when taking Eldepryl for a few days. When Dr. Leslie had first diagnosed Becky, he had prescribed Eldepryl, excited by the drug maker's claims that this drug prevented worsening of Parkinson's, a claim they no longer make. Becky had violent nightmares. One night she found herself in her closet struggling to pull everything off the hangers in her attempt to wrestle with the bear in the closet that was trying to kill her. Another time there were monsters in her room. She had promptly stopped the Eldepryl and started Sinemet. The nightmares ceased.

[Different hallucination-inducing drugs cause different types of mental illusion. Specifics are provided in Appendix 2, in the descriptions of the specific drugs.]

Week five:

[She was still taking the same dosage as the week before and thought for sure that by now she had reduced her daily intake. She felt that it had been a good week. She was still growing in manual dexterity, as she had been since December. This week she was having an easier time getting clothes on and off. She had gone for a walk to the burger joint a long block away and had felt just fine.

[The most interesting experience of the week was on the day when she forgot to take her morning pill. She was doing very well until mid-afternoon when she suddenly remembered that she hadn't taken her pill yet. She immediately started having baby steps and shaking, and they didn't stop until she swallowed the forgotten dose.]

Week six:

When I first get up in the morning I'm fine. I have breakfast, and then around nine, I take the first pill. About an hour after taking the pill, the tremor gets worse for a few hours and then slowly ebbs. The baby steps are worse starting about an hour after I take the pills also. They get better again after a few hours. The same thing after the afternoon dose. If I eat a lot at bedtime, I sleep better. And I don't have baby steps at night. I'm fine during the night. Slept until five this morning without waking up! Wonderful!

My son's not worried about me anymore. He's suddenly in a confessional mode: now he's worried about himself. He blames his mood swings on my years of bad parenting. He's having bad mood swings, he says he's an alcoholic – I had no idea – and he's been smoking dope. I can't say anything to him without him blaming me for his problems. Says I should never have had children. Then he cries and wants to take me out to dinner.

Meanwhile, my friend Virginia Lee is plotting with Dr. Leslie. Virginia Lee is a *nurse*, and she loves the idea of Sinemet. Since the Mirapex isn't working the miracle she expected, she's going to try to get Dr. Leslie to change his mind and put me back on the "miracle drug" while I'm still in a compliant mood.

Week seven:

First day of spring! I walked to the library to return the taped books and got some others. I was very shaky all day ever since an hour after taking the first pill. My hands and feet are so tense, Terry came and massaged just my hands and feet and back. [Terry was an FSR volunteer from the clinic.] I'm so shaky from the pills; I only took half a pill instead of a whole one for my afternoon dose."

Week eight:

Shake! Shake! Shake! Frequent urination at night, and now the Breath Monster is back. I'm taking baby steps all the time now, and I really need the walker! I'm going out for a half hour walk every day; I *have* to get out; I'm so agitated. My appetite's reduced. I'm not ravenous like I used to be.

The pills don't seem to work very well. They have very little beneficial effect; I'm more shaky than ever. I had the Breath Monster two days ago and again this morning. It's a gloomy morning. I have even more tension in my legs, arms, and upper body. It all gets worse after the first pill of the day. Maybe from reducing the pills last week? I will stay at this level for a week to stabilize, though I am tempted to increase the dose a bit to get some benefit. On the other hand, everything seems worse after I take the pills.

Week nine:

The pills don't seem to be doing any good at all, and I have a new problem that I've never had before: I feel like I'm always about to tip over.¹ My brain feels always slightly out of whack; I'm even using my cane indoors. Outdoors I have a mad clutch on my walker. The forearm and upper arm muscles are *so* tight. At night I must force myself to relax; I feel my muscles clench in anticipation of the stress of going to bed. The Breath Monster is frequent now, or at least always lurking in the background. My shaking is so much worse; I shake like a madwoman. It's so violent I bruised my own nose putting my glasses on. I wanted sympathy and nearly called you at home. The hallucinations are the same as before. Lotta baby steps. A hard, hard week.

I'm so depressed, I don't know what to do. I'm so down. Earlier today I went for a ride up the coast with the girls. It was absolutely gorgeous. I thought of all the times I hiked there with the Sierra Club, and now I'll never do that again; so sad, so depressing. I'm feeling very down remembering the old days with Hit and Run Theater. Those days are gone; those people have scattered with the wind.²

Maybe the depression is from the drug reduction? People are coming up to me and saying I'm looking better, but inside I just feel gloomy.

Week ten:

El Twitcho is back, that strong jerking that shakes my whole body. It just comes an hour after the pill, and then after an hour it goes away. I think the pills cause it. The Breath Monster is still there but less compelling. He may have been the result of the drug decrease. [Actually, it was the return of the Breath Monster that had led her to decrease her dose two weeks earlier.]

Fewer baby steps – those have backed off a bit. Now I can feel when they're about to come on and I just step back and reconnoitre. I walked in the grass without the walker! I'm more confident now. One day I had no baby steps. I'm getting a little better at cutting up my own food at meals; that's been hard for over a year, but slowly it's coming back. I still can't cut meat or peel an apple; I can't exert pressure with my fingers. And the muscle cramps and tension are still

¹ Balance problems are a recognized adverse effect of Mirapex.

² As you will read in the appendix on Mirapex, deep, intractable depression, rather than paranoia, is characteristic of withdrawal from this agonist. Although the paranoia from levodopa withdrawal is more ferocious, it does not last as long as the depression from decreasing Mirapex. The former is usually over within ten weeks; the latter can last indefinitely.

there, but less than a week ago. I think the Mirapex reduction is starting to show a benefit.

I did exercise class this morning. There's a lot to do at the seniors' complex, but I don't always feel like doing it.

My mood is up and down. I'm sometimes impatient with people around me. They talk such nonsense! Not the fun kind, but the "Oh! She shouldn't wear that dress," petty stuff with no inherent interest. Funny mood today; world news and chatty neighbors all annoy me. I don't care what we're having for breakfast, but everyone else is so fussy. Who cares! They all want to argue about the breakfast menu! As for me, today I'm walking better, but who knows what tomorrow may bring?!

By the way, look how much better I can get up on the table and position myself!

[This was mid-April. Since December she had slowly and steadily been recovering her strength and motor skills. Whether this was coming from recovery from Parkinson's or simply recovering from her traumatic Xanax/Sinemet reduction is impossible to guess. Added to the mix was the Mirapex, which was undoubtedly having some beneficial effect on motor function, although it was clearly too strong for her even at the lowest possible dose. She was still taking less than a sixteenth of the suggested minimum therapeutic dose. Clearly she was not tolerating the medication well, and yet we must add it into the equation. Whether it was helping or hindering her motor recovery, it is impossible to guess.]

Week eleven:

Not a bad week. The baby steps are bad on alternate days. I'm going for a lot of walks, trying to be outdoors a lot. Went to exercise class three times this week – I do most of the exercises sitting in a chair. I was able to read most of an article in a magazine! It was slow, but I could read it. Maybe my eyes are improving? The only really annoying thing is the tremor – it drives me nuts. Could I decrease my meds again? I almost forgot to take it last night...I wonder what would have happened?

I went to a dinner party last night at the X's, we partied 'til midnight, and last night I slept like a baby.

Good news: the hallucinations were gone for three days in a row. Then they were back briefly, but that's OK. Actually, I miss them. They were fun. The halls looked like mosaics, people were wearing technicolor. Now the halls are plain paint sometimes and people are wearing plain clothes. So many times (with the hallucinations) I was tempted to say 'I love your outfit!' but then realized the outfit wasn't there! Ha!

And so it went. Her friends grew angry with her when she told them, in all honesty, that she was not increasing her medication. There were certain that, if only she would increase the drugs as prescribed, she would return, magically, to her old self, ready to hike, perform on the stage, and be the life of every party. However, they were appeased by her low doses of medication. They didn't abandon her.

She tried a few more times to increase the dose, and every time it was the same: her symptoms worsened. Eventually, in response to these worsenings, she decreased and went through a long period of morosity and agitation. She is still taking one or two of the one-eighth milligram pills per day; she has never been able to tolerate any more than that. She suspects that she might do better if she were to stop her medication altogether, but she has promised her friends that she will take her pills, and she is determined to meet them halfway. Also, if she is taking even just a little of the medication, she figures she is appeasing Dr. Leslie. Should the question arise at the doctor's office as to why she is taking so little, she can explain that she gets worse when she increases, and that the hallucinations are too severe. That answer, she expects, will keep the doctor at bay.

My students discuss Becky

Each week, after the patients leave the clinic, the students and volunteers have an hour-long discussion/seminar during which we discuss the various patients and the topic of the week. One week during the seminar, around the time that Becky started taking Mirapex, one of Becky's intern practitioners struck up an impassioned protest of Becky's decision to resume taking medication. (It had possibly been triggered by Becky's surprised outburst when she entered the clinic, "Oh look, you've redone everything! How nice it all looks!" Of course, nothing in that barren clinic had changed – the only new thing was Becky's Mirapex-driven hallucinations.)

The other seminar students angrily joined into the protest. They accused Becky (in her absence) of weakness and lack of purpose, and worst of all, of giving in to her friends though she knew she was right and she knew they were wrong.

They demanded to know why I hadn't prevented her from starting Mirapex after she had gone through such tortures getting off the Xanax and Sinemet. Why hadn't I forced her to make a decision: her friends or our program? It would have been in her best interest. If only I had pressured her, she would have done the Right Thing! How could I, her doctor, have "let her go" without a fight?

The energy in the room moved up into the ultraviolet zone as clinic interns and acupuncturists protested Becky's medication choices with uncharacteristic warmth. The mood was ugly, and the discussion turned in a dangerous direction: how could they somehow tell Becky what to do without violating the code that forbids an acupuncturist to give prescriptive advice about the medications? The students' circle was foaming with ideas.

No one even noticed as I got up from my seat at the head of the circle and left the room to fill my water cup, hoping that words would come to me to explain to the class just what I was feeling.

My emotions had been so mixed when Becky had first told me she could never see me again. Ever since she made the decision to obey her friends, I had not said one word about her subsequent decisions to increase or decrease her drugs. I had promised that, whatever she did, I would support her, and my only hope was that we might stay in touch. I had never allowed myself to dwell on "might-have-beens" of "should-have-dones." I had never really given her decision any thought other than how much I would miss her if she stayed away.

The class was expecting me to lead the discussion on how I might stay within the confines of the law and still manage to convince Becky to get back off the drugs. I lingered by the water cooler, asking my heart for counsel. I knew I couldn't give them what they were expecting.

Slowly I set my cup on the counter and slogged back to the room. I could almost see the heat waves pouring out the classroom door.

"Class, may I have your attention please?" I must have been using my best teacher voice because even though I didn't feel like any kind of authority right then, the tumult stopped in mid-fuss, just like in the movies.

"Becky made the right choice." (They all sat up straight and gawked. I didn't yet know where I was going with this, but it seemed I'd gotten their attention.)

I told them that Becky knew that the medication had side effects and that the drugs made her physical and mental symptoms worse. She had been through hell with the other drugs, and she had no reason to believe that this new drug would be any different. So she knew that by taking these drugs, she would probably be putting her health, and even her mental health, on the line.

She was certain that her increased pain, tension, and shaking were from the drugs. She knew that Mirapex gave her hallucinations – the one thing she had always dreaded. Now that she was hallucinating constantly, she knew her mind was unstable – her brilliant mind, her greatest point of pride.

"She is aware, objectively, of these problems," I said, "and she has chosen to abide by them, even if it kills her."

I explained that health comes and goes. Every body that is cured of an illness must still someday feed the flames of the funeral pyre. But love, especially the love of true friends, is eternal. The joy generated in the company of friends is the reason for our existence. What is the point of health if we have no friends? But true friends will be there for us even when we are sick.

Her choice had boiled down to this: her health or her loved ones. She chose her loved ones instead of her health.

Becky has the great good fortune to be a part of a tight circle of friends that has been together for over thirty years. They do activities together several times a week. They have parties, go to shows, travel, and discuss literature, politics and theater. They have taken in stride Becky's increased need for transportation and her slower pace. Becky is still a full-fledged member of her group, despite her disabilities.

Her friends had not rejected her because she was sick. They were understandably upset with her because they wanted to help, and she wouldn't let them. They were suspicious of me, not because they were jealous of my relationship with Becky, but because they felt I was not looking after her best interests.

"While you may disagree with their choice of medical methods," I suggested, "you should not doubt for a moment their love and sincerity."

Maybe it was saying the word "love" out loud that led my train of thoughts off on a track not usually traversed in the clinic.

I tried to explain that Becky had been in a rare position. She was torn between our program and her friends – but *not* because she didn't know which would be more effective; she knew that her friends were staunchly misinformed. She knew that they disbelieved in any drug adverse effects or dangers. She knew the drugs were harming her

from her own experiences with the drugs. She had seen patients coming and going in our clinic for four years, sharing their drug horror stories. So Becky wasn't torn between them and us because she didn't know which team had the answers. She knew which group had the answers in terms of health. But she also knew that she could never convince her friends of what she'd learned. So her choice was this: her health or her friends.

"Many healthy people are unhappy and friendless," I continued, carried away by my own words. "Health does not imply happiness, or happiness health. Many of the greatest saints were sick or covered with sores, sores that they ignored, while they joyfully imparted physical healing and hope to unhappy souls. St. Francis of Assisi was covered with lesions, and he healed lepers and even raised the dead by the power of his love and faith.

"Becky chose friendship over health. She chose the most noble and lasting of all relationships over the fleeting joys of physical comfort."

I suddenly realized where I had been going with this. I didn't have an answer, I had a question:

"How many of us here, with our obsessions for health and dramatic cures, would be brave enough to do the same?"

There was a long silence. Recognizing a good exit line when I heard one, I dismissed the class.

Walking out to my car, I was conscious of a warm glow, despite the chill of the spring night. While speaking, I had finally understood why I had not minded one way or the other when Becky chose to resume taking drugs.

I try (most unsuccessfully) to stay emotionally detached from my patients, so that I can see them scientifically, objectively. My biggest failure in emotional detachment had been that joyous day when, thinking I would never see Becky again, she had shown up in my office at her regular day and time. She had come even though she had been "forbidden" to ever see me again.

Becky, bless her sweet heart, would do anything, even take make-you-crazy drugs, to maintain her friendships. It had finally dawned on me in this seminar, while defending Becky's choices, that, when Becky had chosen friendship over health, she had included me in her list of friends worth fighting for.