

*How long, how long, in Infinite Pursuit  
Of This and That endeavour and dispute? “*

*The Rubaiyat of Omar Khayyam*

## CHAPTER THIRTY

# STILL PLUGGING ALONG: 2003 TO 2006

## 2003

No sudden shafts of wisdom had shown up to explain what we were now referring to as the mental/emotional blockage of Parkinson's disease.

The severe anxiety, inability to visualize light, and inability to really relate to the “other” (the injured) side of the body didn't seem to respond to any treatments. Not only that, most of the PDerS responded to the various mental/emotional treatment ideas as if they were anathema. Clearly, we had not gotten to the root of the underlying problem.

Some members of the growing ranks of partially recovered PDerS clearly felt that we hadn't done a good enough job. Nearly all of them felt that, despite hundreds of small improvements, they still officially had Parkinson's disease. So long as *any* PD-like symptoms showed up, anytime, anywhere, it was usually held as proof that the PD was absolutely unabated. Improvements did not count. Any remaining symptom, no matter how small, was regarded as proof of *worsening* Parkinson's.

And it was no matter that their remaining symptoms were now clearly initiated by *their* own emotional and mental ups and downs; they wanted *us* to finish fixing them.

In one lovely example, I was working a PDer who had recovered in many ways, but who still refused to spend any time noticing that he did, in fact, have a left arm. When he arrived for his weekly session, I asked if he had spent any time at all in the last week turning his thoughts to the existence of his left arm, trying to connect with it somehow – using any of the more than five techniques I'd offered him the week before.

He laughed and said that he'd forgotten. Then, in all sincerity, he said, “Can't you do that part for me?”

When I asked him how I was supposed to change his thoughts and make him acknowledge the existence of his own arm, he said, simply, that he didn't know what I might do, but *he* certainly wasn't going to do it.

Another ex-PDer, *completely*, not partially, recovered, came in for his monthly visit. He was once again working on his juggling, exercising several hours a day, and very much enjoying his retirement, although recently, as a favor to a friend, he had taken on a part-time job as an editor. When we'd first met him, he was nearly paralyzed, unable to drive, hunched over, with no facial expression.

He proudly told a PD Team member, Chris Ells, that he'd sent away for a new book, a book about exercise for people with Parkinson's. The book features exercises for people who aren't moving well, to help them stave off encroaching immobility.

When Chris asked him why, since this book was clearly inappropriate for him, he still wanted to identify with having Parkinson's disease, the ex-PDer was stunned. He had assumed that Chris would be pleased that he was continuing to fight the Parkinson's. Instead, Chris wondered sadly out loud just how long the ex-PDer wanted to identify with an illness that he no longer had. The ex-PDer replied that he didn't know. I asked him why he felt he still had Parkinson's. He said that he now took naps in the afternoon. He'd never taken naps prior to his diagnosis of Parkinson's disease.

He then completely stunned me by saying, since he still took naps in the afternoon, should he look into assisted living? Should he stop living on his own, admit that he was never going to get better, quit his job, and give up trying to recover?

I was speechless.

### ***Frustration and bafflement***

Between these two attitudes, recovered PDers who didn't want to let go of their diagnoses, and partially recovered PDers who didn't want to do the admittedly hard work of changing their feelings towards their body, we were feeling frustrated. What had all of our work actually accomplished? The people who recovered had gone on their merry way. Their doctors had told them that they had been misdiagnosed. How could we argue with that? And those who had turned into emotional basket cases certainly still had something wrong, even if it was no longer a neurotransmitter deficiency.

We were certain it couldn't be a neurotransmitter *deficiency* problem once a recovering PDer was able to move absolutely normally *when* he was feeling good: moving with no signs of cogwheeling, foot dragging, and slumped posture. Even if, when frightened, he reverted to a spurt of shuffling, no facial expression, and tremoring, we weren't willing to call that a "temporary display" of idiopathic Parkinson's disease. Heck. I had seen people shuffle, stare dumbly, and tremor violently during the cold and achy stage of flu. People can behave the same way when in shock.

These PD-like symptoms, movement inhibition and tremor, when occurring because of flu or shock, are caused by the temporary inability to release dopamine, not because of an underlying dopamine insufficiency. And we know perfectly well, based on placebo studies, that dopamine *release* is expectation dependent. A person's brain releases, at any given moment, exactly as much dopamine as he *thinks* he needs to express his feeling of joy, and no more.

Feeling safe causes an initial surge of dopamine in the midbrain. Then, joy, a feeling of joie de vivre, the sheer joy of being alive, reinforced the safe feeling and leads to a continued release of dopamine. Dopamine does *not* make people joyful. Being joyful allows the release of more dopamine. That release of dopamine may further trigger other thoughts and behaviors that lead to an increase in happiness, but the initial jolt of dopamine, if it has stopped flowing in response to fear, is released in response to feeling safe. After the fear is gone, the expectation of joy can initiate dopamine release.<sup>1</sup>

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<sup>1</sup> The reason that alcohol, methamphetamine, cocaine, opiates, nicotine, and antiparkinson's medications work is that they jump-start the dopamine release process. Instead of relying on one's own feeling of safety or feeling of joy to release dopamine, which can then trigger the thoughts and behaviors that release still more dopamine, one can use these artificial dopamine-enhancers to get the ball rolling. However, because they are addictive, they set in motion brain changes that raise the bar for the amount of dopamine needed to set off the spiraling good feelings and moves. After the drugs wear off, even more dopamine than before is needed to trigger the first manifestations, the motor and thought expressions, of safety or joy.

When a person has a bad case of the flu or is in shock, he is not able to feel his usual amount of joy. Therefore, he shuffles and mumbles and tremors and loses his balance. These are common symptoms of any condition that causes a temporary inhibition of joy.

Increasingly, it was looking as if the partially recovered PDer had some problem that prevented them from having the basic joy of living that allows for steady dopamine release. Not only that, it seemed as if they also weren't able to release sufficient adrenaline to deal with their little daily fears. What these people now had was an inability to release adrenaline *or* dopamine in adequate quantities, except during those times when they so far forgot themselves as to accidentally enjoy themselves. Then, they could move normally. But when they remembered that they were supposed to be worried, critical, or wary, or still have Parkinson's, they also lost the ability to release sufficient neurotransmitter for effective thinking or movement. Baffling. And how did this relate to so many PDer's reluctance – even refusal, in some cases – to visualize, imagine, or have a sensory relationship with the injured sides of their bodies?

Still, we consoled ourselves, our work might not have been been pointless. If nothing else, the discovery of Rebellious Qi in PDer's might someday be significant in helping to diagnose Parkinson's.

We were still pleased about the hypothesis of Rebellious Qi and its relationship to Parkinson's. We even felt that, if nothing else, it further proved the existence of channels and it might serve as a diagnostic tool for idiopathic Parkinson's – a notoriously difficult illness to diagnose correctly. This next bit explains a bit about how we came to trust Rebellious Qi as a good diagnostic tool.

### **Using the foot injury/electrical flow reversal as a diagnostic tool**

We are frequently asked if *all* the people we see who've been diagnosed with Parkinson's have the foot injury and the electrical flow problem.

The answer is a qualified yes. Early on in the project, we saw, as many neurologists can attest, that there is much misdiagnosis in the realm of Parkinson's disease. A significant percentage of the people who came to us for treatment clearly did not have Parkinson's. Sometimes this error was due to self-misdiagnosis by unqualified patients or their friends, but it was more often due to sloppy work by the diagnosing neurologist. Many times we sent questionable PDer's to get a second opinion, and the second opinion often came back negative: *not PD*.

We developed a new diagnosis procedure at the free clinic. A six-to-eight person panel observed a patient during his intensive, one- to two-hour intake that put the presumed PDer through his paces. We looked for all the classic, western-medicine recognized symptoms of idiopathic Parkinson's disease and asked a long list of questions, even before we started examining the foot or leg. Following the rigorous intake, the panel (made up of the core health practitioners in the free Parkinson's clinic, all of whom had studied Parkinson's disease as a specialty in school) voted on whether or not a person appeared to have Parkinson's disease.

This all took place *prior* to checking the foot and leg. The voting had three options: Yes, Parkinson's; No, not Parkinson's; and Uncertain. The opinions of the panel were usually, though not always, unanimous. If the vote was not unanimous, we did another round of examining and asked more questions.

After the voting, we felt the feet and assessed the Qi running in the Stomach channels of the patients.

Slightly more than twenty-five percent of the people who came to see us for their “Parkinson’s” appeared to have been misdiagnosed. This number, twenty-five percent, was close to the results of autopsy-based determinations of Parkinson’s. That study showed that twenty percent of the people who had been diagnosed with Parkinson’s were found, during autopsy, to actually have had a different syndrome (i.e., twenty percent had been misdiagnosed).<sup>1</sup>

Using our voting-on-the-symptoms method of diagnosis, we arrived at about the same percentage misdiagnosed as the various autopsy studies: we also found the same percentage of misdiagnosed when we subsequently used disrupted Qi in the Stomach channel to form a diagnosis. Most importantly, the patients who, based on symptoms, did *not* seem to merit a diagnosis of Parkinson’s disease were the same ones who did *not* have indications of unhealed foot injury nor did they have electrical currents running backwards in their legs.

On the other hand, all of the people who clearly had classic symptoms of idiopathic Parkinson’s disease, as defined by the standards of the American Academy of Neurology (AAN), *did* also have indications of unhealed foot injury and *did* have electrical currents running backwards in their legs.

So, in terms of numbers for people who clearly had classic Parkinson’s, our hypothesis about the foot injury and leg currents was holding up. By 2003, after examining hundreds of PDers, we started to feel tentatively confident that foot and Stomach Qi assessment might be considered a reasonable method to help confirm or deny a diagnosis of Parkinson’s disease.

In the midst of this jumble of people with questionable diagnoses that came to us looking for help, it seemed as if, in the case of those few diagnoses that were unclear or questionable, the foot injury/backwards-running Qi test seemed to be a sort of acid test. If a preponderance of evidence suggested non-PD, the foot and leg test supported us. Oppositely, even in cases where people seemed as if maybe, possibly, they were heading towards Parkinson’s but their symptoms were as yet very mild or intermittent, the foot and leg irregularities were usually solidly established. (These foot and leg Qi-reversal symptoms may have been evident for decades prior to the visible onset of Parkinson’s, as in the case study of Tim in the first chapter.)

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<sup>1</sup> “New AAN Guidelines Released For Parkinson’s Disease,” *Neurology Today*, Vol 6, no.7, April 4, 2006, p. 8. When I first started on the Little Project, the percent of misdiagnosed PDers, based on autopsy studies, was nearly 30%. The newer studies suggest a lower number: twenty percent. The percent of misdiagnosed is changing, but this is probably *not* due to an improvement in diagnostic skills. This change may be because of PDers taking medications. Nowadays, most PDers are encouraged to take medications as soon as they are diagnosed (despite decades of research proving that PDers who delay taking medication can also delay the onset of the dreadful adverse effects). What the autopsy people fail to take into account is the fact, proven in the EllDopa study of 2002, that the medications themselves cause brain changes. If a person takes antiparkinson’s medication for several years, his brain is likely to show signs of dopamine decrease *whether or not* he actually ever had idiopathic Parkinson’s disease. A misdiagnosed person who takes antiparkinson’s drugs may develop changes in his brain that resemble Parkinson’s disease. Therefore, the autopsy study will see the drug-induced brain damage, and declare, incorrectly, that he had been correctly diagnosed with Parkinson’s.

Also, antianxiety and antidepressant drugs may cause changes in the brain resembling those changes that occur in drug- and toxin-induced parkinsonism. Because the autopsy people are only looking for signs of decline or dormancy in certain brain cells, and are not able to determine what caused that damage, the changes set in motion from years of drug use, including antiparkinson’s drug use, may well be altering the accuracy of the autopsy tests. In other words, it may well be that the number of misdiagnoses is still just as high as ever, but the number is being hidden because of the use of antiparkinson’s and other mind-altering drugs.

We had found evidence of unhealed foot injury and backwards running electrical currents in *all* of those PDers who had unmistakable symptoms of classic Parkinson's disease. Looking at the numbers from another angle, we only found the foot problem and the electrical disarray in about seventy-five percent of the people who came to see us.

So this was very encouraging. The percent of misdiagnosed in the autopsy study was, as noted, approximately the same percent that we ended up with using our "foot/electrical disarray" exam. As the footnote below will explain in greater detail, this is only a sort of "negative proof," but still, it was encouraging.<sup>1</sup>

### **The Parkinson's Personality**

The earliest medical reference to the Parkinson's Personality that I have read of was published in the 1930s, when it was still safe to discuss personality patterns. Although it is somewhat risky, ever since the 1960s, to associate a personality pattern with an illness, the Parkinson's Personality is so recognizable that research in this field continues, despite the professional risks.<sup>2</sup>

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<sup>1</sup> Our observation that people who evidently had been *misdiagnosed* also were found to *not* have the same foot and electrical symptoms as the correctly diagnosed PDers is called, in science, a "negative proof." A negative proof cannot be used to clinch a theory. However, this type of negative proof, though circumstantial, lent additional weight to the positive proofs. "All the PDers we examined *did* have electrical disarray" is an example of a positive statement, and possibly a positive proof.

<sup>2</sup> The reason that such research is not widely broadcast has to do with current social policies: doctors are not supposed to "blame the victim." Even if particular attitudinal stances have been shown to cause or contribute to a particular illness, it is not considered wise to mention this to the patient. Suggesting that a patient is in any way responsible for his own illness is almost the same as saying that the "victim" of the illness brought it upon himself. While, in many cases, this cause-effect relationship may be absolutely true, it is not politically correct or legally safe to say so.

For example, it is not medically "correct" to point out to a lung cancer patient that his decades of smoking may have contributed to his illness. It is more correct, at least in public, to blame the tobacco companies for putting temptation in the smoker's path.

As another example, doctors currently are not *allowed* to use the word "obese" with regard to their obese pediatric (under age 18) patients. To do so is currently considered "negative" and possibly harmful to the child's self-esteem. The child might feel bad if he is termed obese because, in our culture, we tend to assume that obese people have brought their problems upon themselves. The child, therefore, may feel that he is being accused of responsibility for his obesity. This would be "blaming the victim," and it is politically, socially, and legally unacceptable. (And while I'm on the subject, an MD was *successfully* sued by an obese adult after the doctor "injured the patient's feelings" by telling the adult that he was, technically, obese.)

Of course, an MD can use the word "cancer" with a pediatric or adult patient because our culture does not consider that cancer has anything to do with the cancer patient's behaviors. Therefore, the cancer patient is an "innocent victim" and not subject to blame.

The point here is that, even though the Parkinson's Personality is discussed and even researched by MDs, these same doctors might be putting themselves at risk of a lawsuit if they ever suggested to a specific PDer that he has, in any way – for example, by having a specific personality – brought this illness upon himself.

The recent article, "Personality traits and brain dopaminergic function in Parkinson's disease," published in the highly regarded, top-of-its field journal, *Proceedings of the National Academy of Sciences, USA 2001*: 98:13272-7, authored by Valtteri Kaasinen, MD, PhD, is proof that the personality of Parkinson's is still a valid subject for research, despite the reluctance of clinical MDs to dip into this can of legal worms.

One of the problems with the ongoing research is that, although alert doctors who work with PDers often have a strong sense that PDers have a unique way of interfacing with the world, it has always been hard to put one's finger on the exact nature of the Parkinson's Personality. Each PDer is unique, of course. And yet there *is* a difficult-to-define something that binds most of them together.

Our work has given us a rare perspective. As we worked closely, weekly, with people recovering from Parkinson's, we witnessed the personality changes that typically occurred during recovery. As PDers recovered and shed the guardedness, excess intellectuality and/or suppressed anxiety that is fairly typical of Parkinson's, new personalities emerged. These new personalities could, because of their experiences on both sides of the coin, describe somewhat objectively their old, pre-recovery personalities.

Very often, the recovering PDer realized, usually *for the first time*, that his highly competent, materially successful, or highly intelligent persona had not brought him a particularly peaceful, satisfied, or joyful life. As PDers recovered and became able to compare and contrast their pre- and post-Parkinson's prioritizing and values, we were able to more deeply to understand what constituted the so-called Parkinson's Personality.

What we couldn't figure out, and what the fully *recovered* PDers couldn't put a finger on, was how to point the way to the portal to joy or contentment for those partially recovered PDers who were still hiding behind life's sofa.

Historically, after the discovery of dopamine insufficiency in PDers in the late 1950s, the Parkinson's personality, like all other symptoms of Parkinson's, *was* automatically attributed to a dopamine shortage.

The experiments performed at the end of the 20<sup>th</sup> century by the research team led by Valtteri Kaasinen, MD, PhD (previous footnote) were done to determine whether or not dopamine loss actually is the key to the personality. The researchers expected that it was.

However, researchers found that the core personality/behaviors are unchanged under the influence of L-dopa; their guess had been wrong. The researchers were forced to conclude that the Parkinson's Personality is not caused by dopamine-insufficiency. Also, research suggests that the Parkinson's Personality can be evident decades before Parkinson's symptoms appear.

Our research suggested that a combination of selective dissociation and certain mental habits that are characteristic of the sympathetic mode were causing the "personality." The use of brain altering drugs such as L-dopa does not necessarily turn off adrenaline-based mental habits, nor does it restore heart feeling if the dissociation is still in place.

Because partially-recovered PDers could sometimes move normally, we could concur with Dr. Kaasinen's research: we could assume that the personality was not related to insufficient dopamine levels.

### ***Clues to the Parkinson's Personality mystery***

As noted already, some PDers have, at some early age, usually in childhood, experienced a life-threatening (to the child's mind) fear that could not be laid to rest. Others have decided consciously to pretend that they could not feel physical or emotional pain. Sometimes this charade was instituted to mask a childhood injury that might have aroused parental wrath.

Sometimes this mental stance was a life- or mind-saving childhood or war-time necessity. Sometimes, the attitude was instituted because of chronic mental or emotional stress, including

cultural or family-based attitudes that were hostile to or did not support sympathy for physical and/or emotional pain.

This attitude of denial of physical or emotional pain helped provide an explanation for the non-healing of the foot injury seen in all PDer's: the injury remained unhealed because, according to the PDer's mind, the injury didn't happen, or, at any rate, was not painful and did not need healing.

In some PDer's, it appears (based on recovery symptoms) that the feel-no-pain attitude was *initiated* to deal with the foot injury. Other PDer's come to realize, during recovery, that this attitude was already in place due to other stressors, and that they automatically applied the ongoing mental/emotional protection at the time of foot injury.

During the PDer's post-injury lifetime, the attitude may have remained associated only with the foot injury, or the mental trick may have been expanded to protect the body and feelings from pain during other life events as well. In some PDer's, the attitude may have snowballed in the brain's compartmentalization process until the PDer might have emotional guardedness over nearly every aspect of his life.<sup>1</sup> This guardedness, once set in motion, may have allowed the PDer to have lived his life using adrenaline as his primary motor neurotransmitter. The PDer may not have used dopamine for motor function for most of his life.<sup>2</sup>

This astonishing mental achievement requires an enormous amount of emotional and mental self-control. PDer's are notoriously highly intelligent. They are also notoriously unable to be flighty, irresponsible, or flamboyant with their deeper emotions.

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<sup>1</sup> I wrote "nearly every aspect" of his life instead of "all aspects" because stories abound of people with advanced PD, people who can barely move, speak, or eat, who can move perfectly normally in highly specific, "safe" situations. I've already written about this phenomenon, but let me provide a citation. The case of the unmedicated PDer who is absolutely paralyzed except when an easel and paints are set up in front of him was written up by Oliver Sachs, MD, and published in the *World Parkinson Congress Journal: Creativity and Parkinson's*, 2006, p. 1. In this case, after several minutes of sitting in the presence of his art supplies, this man can stand up and, moving freely, proceed to paint. He can move almost normally until he stops painting, and then the paralysis resumes. The same sort of story is told of violinists who have to be helped onto the stage, but who, when the conductor raises his baton, can play as beautifully as ever. I knew one PDer who could always move perfectly normally on his birthday. I know another who moves perfectly normally and his persistent tremor completely stops when he is doing jigsaw puzzles. When he is doing these puzzles, he moves perfectly normally, no sign of movement inhibition or tremor.

Even in PDer's whose ever-increasing anxiety levels have caused the brain to incorporate more and more "compartments" under the aegis of emotional guardedness and dopamine-inhibiting fear, there *may* still be some brain arenas, such as painting, singing or, in the above example, birthdays, which have, in some PDer's, remained free from the growing emotional guardedness. Therefore, in these rare PDer's who have one or more "safe activities," or one or more brain compartments or mental arenas in which dopamine flow is still emotionally acceptable, their dopamine can still be freely released – but only during these highly specific activities.

These times of easy movement are very different phenomena from the well-known ability of unmedicated PDer's to move normally during times of emergency. The latter is due to a surge of adrenaline. The former examples are due to surges of dopamine.

<sup>2</sup> As you will read later, the symptoms of Parkinson's disease appear when the energy that comes from pure self-awareness or feeling, also known as the thrill of being, the dopamine-using heart-energy that releases either adrenaline *or* more dopamine, whichever is appropriate, begins to flag. Dopamine levels may have been at a very low, dormancy level for decades before PD symptoms appear. Only when the *emotional energy* required to maintain the PDer's powerful, and eventually, exhausting, mental wariness, one that requires using adrenaline as the neurotransmitter of choice for most thinking and movement processes, becomes, due to an increasingly shut down heart, insufficient, do the symptoms of low everything – low dopamine *and* low adrenaline – become visible.

We often wondered how this severe level of responsibility and self-control was related to the mind-body disassociations that we'd discovered while trying to get PDer's imagine, visualize, or feel their own bodies. What was the connection?

We didn't know. But starting in 2004, we no longer waited to see if the person would recover easily and quickly or slide into a condition of partial recovery. Instead, as soon as we started doing Yin Tui Na with a PDer, we also started right in on trying to get the PDer to have some sort of relationship with his feet. Simultaneous with the Yin Tui Na therapy, we worked on helping PDer's imagine inanimate light or energy in an injured area, in the "other" side of the body, or in areas that were succumbing to tremor or other PD symptoms. Some of these fairly traditional exercises and mind games were mildly successful in temporarily allowing the person to imagine a tenuous or flickering light in previously dark areas.<sup>1</sup>

But then, after spending more than a year pondering PDer's difficulty in imagining light in injured areas and their disassociation with the injured side of the body and thinking that we were up against something pretty hot, we discovered a much more severe manifestation of the mind-body disassociation than we could have possibly imagined. It had been there right along, but we had never thought to ask PDer's about it.

### *An imaginary separation of physical body and energy*

Not only was it hard for most of our PDer's to imagine an inanimate light in a specific body part; most of them, when asked to imagine their whole body filled with an animated image of their own body made out of light, did something completely unexpected. They imagined a body-of-light that was physically separated from their own body. Most attempts to integrate the imaginary body of light and the physical body were "repulsive," "disgusting," or "impossible."

For many PDer's, an entire body made of light, an imaginary light-body capable of moving as a body and being the driving force behind one's actual physical body, was *much* more of a threat than the mere inanimate light that we'd been asking them to imagine.

Many of our PDer's were extremely averse to imagining their physical body filled with animate light, even when we suggested that getting over this mind set might enable them to conquer their remaining PD-like symptoms. Much as they claimed to want to recover, they weren't willing and/or able to create an animate, light- or love-filled self-image.

After stumbling across this particular mindset, we spent most of the next two years trying to get to the root cause of this fear and aversion. We did not yet know that this phenomenon was called "depersonalization," and was a symptom of both selective and automatic dissociation.

## **2004 AND 2005**

We discovered the aversion to a "whole body made of light" when working with a PDer who had been trying hard to imagine light or energy in his arm.

After this PDer assured me that he was finally able, after much struggle, to imagine light or energy in his arm, I decided to explore yet another angle of the situation; I asked him if he could imagine that this energetic arm made out of light was able to move at the same time that

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<sup>1</sup> Rebecca Weinfeld, LAc, a PD Team member since 1999, has decades of experience as a psychiatric in-patient nurse. Since becoming an acupuncturist in 1999, she has continued her ongoing study of the new treatments for mental/emotional disorders. She's been a steady source of new ideas for the rest of the team, teaching the rest of us everything from muscle testing to "tapping" techniques.

his arm moved. I also asked him if he could imagine the arm-made-out-of-light floating up out of his body, having a life of its own, if you will.

Sadly, he was completely unable to imagine any sort of movement in the light image that he had so laboriously constructed. The light image that he had created, with sweat and tears, was only an inanimate beam of light sitting like a lump, albeit a bright lump, in his arm. He could not imagine this light moving or exhibiting any signs or symptoms of motion, or for that matter, being actually *connected* to his body.

This led us to explore whether or not our other Parkinson's patients who seemed to be stuck at some level of recovery were also unable to imagine *movement* in the body parts that they had, with great effort, manage to temporarily "light up."

It turned out, once we started asking about it, that other PDers who *had* learned to imagine light inside had also constructed only an inanimate sort of light that sat like a lump in the body, incapable of movement or any relationship with the body part. I already mentioned this phenomenon briefly in chapter twelve, in the section on depersonalization. In this chapter I will go into a few more details. Please forgive a few redundancies.

The inquiry that revealed an imaginary separation of physical body and energy went like this: "Imagine your whole body filled with light. Don't worry about any specific areas that are dark, just imagine as much of your body being filled with light as you can. If possible, this light in your body should have arms and legs and fingers and toes just like yours. Make it a really wonderful light, a light that is beautiful, radiant, full of joy. Make it a light that you can love, one that feels safe and wonderful. Can you do that?" I then gave them a few moments to let them enjoy that beautiful image. Then I asked them *where* that body of light was located.

### **Where is your body?**

I have tested this exact same question on healthy people, people who've never had Parkinson's disease. A healthy person will typically answer my question as to the location of his body-filled-with-light in this way: "Huh? What do you mean? The body of light is inside me. Isn't that what you asked me to imagine?"

Note that my instructions had been very carefully worded: "Imagine your whole body filled with light," and then the question, "Where is this body of light located?"

### ***A body floating in space***

The vast majority of my PDers answered my question "Where is it?" with the following type of reply: "It's in the mountains," or "It's floating a few inches above my prone physical body," or "It's at the beach," or "It's standing behind me," or "It's ten years old, and it's skipping over the rocks at my boyhood vacation home," or "Part of it is in my body, but one leg (or arm or some combination of limbs) is sticking out to the side, away from my physical self."

Again, I am careful to phrase my question so that the patient should assume that I am asking him to imagine his physical body being filled up with light *in situ*. I do not ask where the person imagines that a lighted-up version of himself might be *easiest* to imagine. I will share some more examples.

### ***It's safe: it's locked up***

Again, here is the question sequence: "Imagine your body being full of radiant, joy-filled light. (Long pause while the person does this.) Where is that body full of light located?"

I think the most alarming response I ever got in response to my queries was this sequence that started out with a reply of: “Oh, it’s OK.”

I replied, “What do you mean, ‘it’s OK’? Where is it? Is it inside your body?”

She answered, “Oh no. It’s locked up. Like in a cage. It’s safe.”

I was curious. “Your body made of light is locked up. Can it get out of the cage if it wants to?”

“Oh, no. There’s a guard.”

“Is the guard a friend or an enemy?”

“He’s a friend. He has a long grey beard, and he’s protecting me.”

The patient was lying on the treatment table with closed eyes. I exchanged a glance with her husband. He goggled at me with concern. I goggled back and shrugged my shoulders. Neither of us had had any inkling that this construct was in her mind, or why. But it certainly explained why she couldn’t connect her physical body and her mental image of herself made out of light.

As an aside, despite the strong insistence from a few PDerers that this inability to visualize the body is a sign of rare sensitivity of soul and advanced spiritual detachment, we have learned via the healing process that this detachment is not spiritually based: it is based on fear.

Getting back to the main problem, we started to refer to this new situation as an inability to integrate the physical body and a mental image of the energetic body. This was even more bizarre than the first mind-body disassociation that we’d first discovered, which was the mere inability to imagine inanimate light in a specific body part. Also, there was a much higher level of emotional resistance to integrating the body-of-light with the real body than there had been to merely imagining a spot of inert light in some body part. The following case studies demonstrate.

### **Some examples**

#### *Mort*

For the past few months, Mort had been working on visualizing light in his foot. I was, at this point, more concerned about Mort’s sometimes shuffling walk than about his useless left arm. His arm had been unusable for a long time.

Mort was the second person on whom I sprung the procedure of filling the body with light and then locating that body-of-light. When I asked him to imagine his body full of light, he told me that he could, and that the body full of light was floating nearby. I asked Mort to try to juxtapose the floating image with his physical body.

When he started connecting his mental image of his body-made-of-light and his physical body, Mort was able to imagine that his head-of-light was integrated with his physical head. So far, so good. He was able to get his mental image of his light-neck and his physical neck aligned. He then started moving his light image into position in his physical arms. As the mental image of arms-made-of-light started to flow into his left arm, he jerked violently and exclaimed, “That’s disgusting!”

I asked him what was disgusting. He was surprised. He had not realized that he had said anything out loud. When I asked him again what was disgusting, he replied, “Having light in my

left arm.” He had started trembling violently from the experience. I asked him what was disgusting about having light in his left arm. He answered, “It just is. It’s disgusting. There is no other word for it. Don’t you know what disgusting means? I won’t do it again.”

What is interesting is that Mort had slowly gotten to the point where he was able to imagine an *inanimate* sort of light in his left arm. However, when he tried to put a vitalized light-filled version of himself into the left arm, the experience was so foul that he refused to try it again.<sup>1</sup>

### *Haime*

Next, I tried the procedure with Haime. Haime’s mental image of his body-of-light was hovering nearby, about a foot away from Haime. When I asked Haime to imagine his light-body reinserting itself into his physical body, he was able to get the heads to match up. But when he tried to join the neck-of-light and his physical neck, he said, “I can’t do this. I’m afraid I’ll become too big.” At this point, he started crying.

When I asked why being too big might be a problem, he answered through his tears, “I will be proud. I don’t want to be proud and arrogant. I’m afraid to connect the necks.” Haime stopped coming in shortly after this.

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<sup>1</sup> Over the next year, Mort became nearly incapable of movement, even though he had been diagnosed only two and half years earlier. He knew about the therapeutic mental exercises that we hoped might be helpful, and would do them with me when he is in my office. At these times, he could move somewhat normally. However, when he returned home, he would find that he didn’t have the time or interest to actually continue these mind-retraining exercises. Considering we were trying to teach him a completely different way to see himself and the world, an hour of therapy once every few months was obviously not enough. He needed to learn to live, permanently, with his left arm. However, he was not interested in trying to actually have any energy in his arms or in his body, though he desperately wanted to not have Parkinson’s.

His defense for his inability to want to change was that his parents were not very emotionally sensitive. This type of defense, in which the PDer blames some difficulty in his past for his reluctance to attempt change, is not uncommon in those PDers who recover part way and then suddenly become much worse in certain arenas. But even without the “poor me” defense, many PDers simply did not fancy the idea of changing themselves.

While this attitude may make no sense to the idealistic reader, I can assure you that every doctor knows what I am talking about. It is an old truism that most people would rather die, literally die, than change their mental, physical, and emotional bad habits. How many people continue to smoke cigarettes even while hoping they will not get lung cancer? How many people continue to overeat even though they know that they are injuring their digestive tract, their heart, and their vitality? How many people continue to give their emotions free rein even though research has shown that people who are quick to anger have a higher incidence of heart disease?

The same human tendency for stubbornness exists in many people with Parkinson’s disease. Some PDers, while asserting that they want to recover from Parkinson’s, did not want to even try to change the fear- and adrenaline-based behaviors and attitudes that sustain the illness. As one adamant PDer put it, “I don’t want to have Parkinson’s but I want to still be ME. I don’t want to turn into a sappy sort of person!” Like another PDer who tearfully asked, “But if I get rid of my fears, what will be left of me?” some PDers, ultimately, would rather have Parkinson’s than change.

What we needed to find, then, was a way of helping PDers change that would not seem threatening or seem like work. We needed to find a method of self-change that was so mentally or emotionally rewarding, so much fun, so joy-producing, that PDers would *want* to do it, despite the fact that such a change might alter their idea of who they were, their personality. This was a big order – especially in light of the fact that so many PDers consider fun to be self-indulgent, and therefore bad, and many PDers are almost incapable of remembering what joy had ever felt like.

## *Melica*

Melica's light-body was only partly out of her body. In fact, only her left leg was outside of the physical frame. Her mental image of her light-legs had her left leg crossed over her right leg, at the level of the right knee. In point of physical fact, both her legs were stretched straight out on my treatment table. When I asked her to try to put her mental vision of her left leg back into her actual leg, she balked. "I know this will sound crazy," she said, "but if I put the light-image of my leg into my leg, I'm going to get angry. I can't stand the idea of losing my temper. I'm not going to put that leg back inside."

### **Looking for bodies made of light**

After this, I started asking every one of my Parkinson's patients to imagine his body filled with light. When they told me that they could do this, I asked them where the images were. As soon as the PDer told me that he could picture the image of himself made of beautiful light, I asked him where it was and then asked him to reinsert the image into his body. Consistently, the mental self-images were partly in and partly out of the physical bodies, or floating around in far off lands or even a different age from the patient's actual age. As for reinserting the errant body or body parts into the physical body, most PDers had enormous resistance to the idea.

Some of them cried, some just shrugged it off and said they didn't want to do it. Others were afraid that if the light-body parts got into their corresponding physical-body parts, they would discover cancer or some horrible thing in that body part. Some of them kept changing the subject repeatedly, suddenly saying things like: "Before I forget, I want to ask you if you enjoyed your weekend." One person was able to do it easily only so long as I was holding his feet.

These people were not psychotic. They were able to acknowledge that their imaginings made little or no sense, but they were unable to anything about it. They were reporting to me as accurately as possible their perceptions about their bodies and their body-based imaginations.

### ***Unaware of being unaware***

Some people, when asked to imagine their bodies filled with light, assured me that they were imagining light filling their physical forms. I soon learned to be very suspicious of these assurances. I soon began adding another query. When a PDer told me that he was imagining light throughout his body, and his whole body, in his imagination, was lit up with perfect, uniform light, I would ask him to specifically look at his problem limb. Whatever limb that person seemed to have the most trouble with, I would ask him to check carefully and see if that limb was part of the "whole body full of light."

Very often, a person with, say, extreme left arm rigidity, might tell me that he was imagining his whole body filled with light, in situ. I would then ask him to specifically look at his left arm. There would usually be a pause, and then the person would realize that, in fact, his left arm-made-of-light was sticking up straight in the air, even though, of course, his physical arm was nestled, rigid, alongside of his body.

Many of my patients were surprised to find that a recalcitrant body part was not where they thought it should be. Most often, when they assured me that everything was accounted for, that the whole body was lit up from within, I had to draw their attention to the body part that usually dragged, tremored, or was rigid. Lo and behold, *that* physical part of the body, when they really looked carefully, was *not* conjoined with the lighted-up body image; that part of the body, in the imagined body-of-light version, was missing or sticking off in a different direction from that specific part of the physical body.

This was similar to the situation with inanimate light in which a PDer might assure me that he could imagine light all through his foot. When I placed my hand directly over the portion of the foot that felt the most damaged, and asked him if he could imagine light directly beneath my hand, he would reply, more hesitantly, something along the lines of: “Well, there’s no light exactly right *there*. But I *can* see light in all the parts of my foot where I can see light...”

### **Good news**

At this point, the reader might be shaking his head and saying: “Are all PDers nut cases? Is there any hope for me if I have PD? Am I that deluded?”

To assuage these fears, I want to share my experience with Lucinda.

### ***Lucinda***

Lucinda had completely recovered from her foot dragging, her lack of facial expression, her hunched posture, and even her adrenaline-charged attitude. Her only remaining problem was her increasingly problematic tremor. When I had first started working with her, her left hand only tremored once a month or so. Now, three years later, I only saw her once in a great while, for issues other than Parkinson’s. She had stopped coming in regularly when her other symptoms went away. She hadn’t been overly concerned about her mild, intermittent tremor, and had assumed, as had I (in the early stages of this project), that the tremor would go away by itself once the foot problem was resolved.

She came in to see me because of a chest cold. While I was working with her, I asked about her old symptoms. None of them had reappeared. But when I asked her how her tremor situation was doing, she said that it was becoming more frequent, and was even starting to be a bit of a problem: whenever she was under stress, or when she was conducting a choral group, her left hand tremored noticeably. By good chance, I had just stumbled upon the body-of-light reluctance problem that many PDers had.

I asked her to imagine her whole body filled with light. She closed her eyes, and after a few seconds told me that she was all lighted up. I asked her if her light-body was inside her physical body or floating around somewhere. She replied that it was connected to her physical body. So then I asked her to look carefully at the light-version of her left arm, and tell me if it was in sync with her physical left arm. Her actual arms were flat on the treatment table alongside her body.

She started laughing out loud. “Well, whaddya know!” she said. “My image of my left arm is folded across my chest! (More laughter.) No wonder I can’t get any control over it. That arm’s not going to do me any good *there*. I’ve got to get that naughty arm image back where it belongs!”

I was so grateful to Lucinda. So many of my PDers got sullen or resentful when they realize that their mental self-image and their physical self were not connected. This wonderful woman was amused! And, for what it’s worth, she was also a musician, and, I happened to know, successfully working at letting go of resentments and blame. She told me that she was learning to trust that the universe was always taking care of her, in spite of apparent setbacks. She told me, “Every time something hasn’t gone the way I’ve expected or hoped, I think of it as a gateway moment.”

I taught Lucinda a simple visualization therapy that a few PDers had used, successfully, in their attempts to override their mind-body disassociations. Lucinda mastered it within minutes. By doing the exercise, she immediately and permanently regained complete control of her arm.

The tremor ceased. It never came back. While she was doing the exercise, she recalled that she had broken that arm when she was four years old.

A few hours later, she met some friends downtown. When one of the women gently disagreed with Lucinda's idea about something, and sided with the idea of another woman in the group. Lucinda astonished the group by declaring, "If you agree with her, you can't be my friend!" The stunned friends were silent for a moment, and then quickly took their leave of Lucinda. Lucinda told me later that, even at the time, she was wondering to herself, "Where did *that* come from?" Lucinda was immediately consumed with the thought that what she really needed was a pink tutu. Since she was downtown, she walked over to the ballet shoppe and looked at the tulle skirts. She knew, on some level, that she didn't really want to buy herself a pink tutu. She was not a dancer. She had a "conference" with herself in which she negotiated a deal: the tutu desire could be traded for the desire for a banana split. She went to the ice cream parlor, ate a banana split, and never tremored again. And from then on, when she imagined her arm being full of light, the imaginary arm was right where it should be.

I will be describing the visualization therapies in the chapters on treatment techniques. I only shared this particular case study at this point in the book, though this chapter is getting a bit long, because I can imagine the dismay that some readers might be feeling at this point. I wanted to show that these mental blocks were, in some cases, easily dispelled. On the other hand, the reader should know that many PDers struggled against these imagination-based therapeutic exercises as if their very lives were on the line. And yet, strangely enough, these PDers could usually imagine with ease a negative outcome or disaster.

### *A common pattern*

Going back to the chronology, meanwhile, the other members of the PD team were also doing the same body-made-of-light exercise with their PD patients, in order to see if their patients also had a "detached" light-body. After one week of asking all our PD patients about their body-of-light, we all knew we were up against something that we had not anticipated.

The PDers who were not progressing rapidly in their recovery or who had moved into the ranks of the partially recovered had evidently managed to disassociate their physical form from their own body-image. No wonder they had increasing rigidity, slowness of movement, poor balance, and trembling from anxiety. They had lost the connection between the idea of energy and the idea of the physical reality of their body.

No wonder they were failing to recover normal movement despite the return of normal energy flow in the legs! It was as if they had a body that was returning to correct physiological function, but a mind that was determined that the real part of the body, the energy-filled part, the beautiful part, the good part, was not connected to the physical form.

## VARIOUS LEVELS OF MIND-BODY DISASSOCIATION

Not all PDers have the same degree of disassociation. I know I'm being highly repetitious here, but during recovery from the foot injury, *some* PDers automatically resume a relationship with the injured foot and the long-missing injured side of the body. Some even remember when they decided to pretend that they could not feel pain. However, in most of the partially recovered PDers we've worked with, some level of mind-body disassociation has remained in place even after the feet recover.

### ***Mild disassociation***

Sometimes, the disassociation has been fairly mild, merely preventing the PDer from being able to cry or experience joy. Even a mild level of disassociation can make it difficult for the PDer to perform any type of mental work that involves visualizing, imagining, or pretending – *if* the visualization or imagery is directed towards a “good” mental image or a positive outcome. Many a PDer with only a mild mind-body disassociation is not able to mentally picture his own body being in a state of health, or mentally imagine, pretend, create, or visualize any sort of mental picture of himself moving in a healthy manner.

### ***A more bizarre level of disassociation: imaginary functional bodies or alter-egos***

Others have far more complex disassociations. We discovered that some PDers had formed complete mental disassociations from their physical bodies, to the point of having an active alter-ego outside their physical bodies. These alter-egos had usually been created during childhood or early adulthood. These alter egos were imagined as being physically separate from their physical bodies.

Some PDers were always aware of their imaginary mirror-image (left and right sides reversed) or correct image versions of themselves, standing silently by, just a few feet away. When some PDers were asked to “fill your body with light,” they tuned in to the ever-present alter-ego, standing nearby.

Before continuing, I will give two extremely quick examples of what I mean by “mirror image,” alter-ego personalities.

Honorina created her mirror friend on the day of her high school graduation. She was an American, attending school in Germany because her missionary parents were in China. Her mother showed up in Germany for the graduation. When Honorina asked where Father was, Mother calmly replied, “He died six months ago. We didn’t tell you because you would have wanted to come to China for the funeral, and that was out of the question. When Honorina felt her chin start to quiver, her mother said, “I do hope you are not going to make a scene about this.”

Honorina excused herself to go upstairs and get her hat. She remembers going upstairs to her room and staring at her face in the mirror. She commanded the person in the mirror, “You can do this! Don’t make a scene.” And for the rest of her life, the person in the mirror went through life with a smile on its face.

Honorina had been a vibrant, champion tennis player and lover of opera, a mother of three and beloved by all. Honorina died in her late 80s. At Honorina’s funeral, her daughter told me that she had never seen her mother express any emotion other than a proper level of contentment and or happiness. “I have never seen my mother upset about anything.”

Honorina had never told anyone about her mirror image persona until, just a year before her passing, we asked about her emotional history.

### ***Sharing my amazement***

When I first heard about Honorina’s relationship with her “person in the mirror,” I was so amazed that I mentioned the mirror idea to a few of my patients. One of them, Hope, said (I paraphrase very closely), “Oh. Yeah. I do that.” My jaw dropped. Hope continued, “My mirror image does all the hard work. When I feel like I might lose control, I just look in the mirror and say to her, “Be tough! Don’t be a wimp!” She [the person in the mirror] can deal with anything.

She never gets her feelings hurt. She's my mirror image, but I can only see her down to the waist. Maybe that's because I've never lived in a house with full-length mirrors.<sup>1</sup>

### **The alter-egos**

Those are just two examples of the “functional alter ego” phenomenon that we've found in PDer's. While this alter-ego phenomenon has not been present in a majority of our PD patients, we no longer consider it unusual when an imaginary friend pops up. One of our PD patients even had full-blown multiple personality disorder. Interestingly, all of his personalities had Parkinson's. As he started to recover from Parkinson's, a “master personality” emerged which could integrate the other personalities.

Learning about the existence of these alter-egos was helpful. It helped ready our minds for the discovery, still to come, that many people with PD have consciously dissociated from their hearts – and therefore, their bodies.

There are no hard and fast rules about the roles of the imaginary alter egos. Sometimes, an “other” self or an “aspect” of a PDer's personality is considered to be performing all social interactions and physical events so that the “real” person never needs to risk being exposed to emotions or pain.

Some PDer have reversed the roles just described: the real self – the one with feelings, the one that needs to be protected – is imagined as floating in the ether a few inches, a few feet, or a thousand miles away, while the numb physical body – a body that, via pretending, can't be hurt by physical or emotional wounds – goes through the motions of life.

Some PDer's allow their real selves to do good-hearted, sometimes philanthropic work, while their alter-egos or mirror images dealt with any physical event or social interaction, real or anticipated, during which physical or emotional pain or any sort of negative outcome might occur.

These alter-egos and mirror image personalities did *not* automatically go away when the foot injury healed. Getting rid of these not uncommon mental constructs turned out to be doable, but it required focused work on the part of the PDer and a willingness to drop the ruse: to be once again susceptible to pain and/or pleasure.

Even though we were discovering the unexpectedly wide range of PDer's' mind-body disassociations, we still had, as yet, no consistent method to help PDer's overcome these fear-based mental/emotional constructs. We experimented for several years with a wide sampling of traditional and modern self-analysis and self-love healing techniques, to no avail.

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<sup>1</sup> I heard a powerful story of real friendship from Hope after she decided to get rid of the Mirror Woman. Hope had confessed to her good friend at work about her habit of using the mirror personality instead of her physical self when she needed to be tough, and how, working with me, she was learning to not rely on the Mirror Woman any more.

But one day at lunch break Hope had gone to the muffler shop for a car part. She had tripped on an electrical cord that stretched across the grimy floor of the muffler shop. When she stood up, her impeccable white shirt was smeared with dark grease, as were her hands and knees. Hope started trembling violently and “feeling like everyone must think I'm a moron.” She rushed back to work, and hurried past her friend to get to the washroom so that she could look in the mirror and get a grip on herself.

Her friend jumped up as the grease-covered Hope went scooting past, and grabbed Hope by the arm. “You don't do that any more, remember?” Stunned by this interruption in her lifelong routine, Hope was able to calm down and tell *herself* the spine-stiffening words that she would have said to the Mirror Woman. This meant, of course, that the accident had happened to Hope, and not to the Mirror Woman, but with her friend's help, Hope was able to accept this, although it was embarrassing, and therefore emotionally painful.

## **Rewriting the Recovery Handbook**

In 2005, I started a revised edition of this book, mainly to get rid of the outdated references to Parkinson's medications that had been in the previous edition. I also wrote up a few chapters for the website about our discovery of what we were calling a "mind-body disassociation" and its apparent relationship to fear. However, the mind-body reconnecting techniques that I offered up in those chapters were techniques that most PDers struggled with, disliked, or even hated. And, except in a few cases, such as Lucinda's, the benefits of practicing the techniques seemed to be short term.

Still, we posted the information to let people in the PD community know that we were still plugging away at the problem, that we hadn't given up on those PDers who were partially recovered.

This 2005 edition was never finished. I was slowly plodding away at it, updating some of the information and posting the revised chapters on the website. But even as I was writing, I was wondering if we were ever going to find a way to get partially recovered PDers to join the ranks of the completely recovered. I was pretty sure that the Parkinson's personality, the inhibition of positive-outcome imagination, the inability to imagine one's body being full of light, and even the alter egos and multiple personalities were all related, somehow, to the problem of partial recovery. But despite all our research and treatment experiments, we had run out of ideas.

In January, 2006, I went on a silent retreat for nine days of prayer and meditation. My heart pleaded for answers to my questions. Or, if no answers were to be forthcoming, I prayed that my patients who were stuck in partial recovery might recover, even if I never understood the process behind their recovery. I started going through the list of patients for whom I regularly implored healing. I started with Hope.

I received an answer!

"She has to do it herself."

I was simultaneously thrilled and disappointed. I prayed more insistently that God please heal Hope. The answer came quickly this time, resonating in my heart. The voice repeated, "She has to do it herself."

So I demanded that He tell me what it was that she needed to "do." My heart was silent.

## **2006**

Two weeks later, we had a breakthrough. It happened on Feb 10, 2006: exactly eight years to the day from the time I first got up to speak at the local Parkinson's Support Group to say "I've noticed some similarities in the feet of people with Parkinson's. I'll give several free treatments to any person with Parkinson's who lets me examine his feet..."

