

Cowards die many times before their deaths; The valiant never taste of death but once.

- Shakespeare's Julius Caesar

CHAPTER THREE

STILL FEARING PAIN

PARTIAL RECOVERY CASE STUDIES

Chip

Chip experienced most of the foot, face, and body recovery symptoms, including recovery from the constipation that had plagued him for years. He had not yet felt the “brain shifts” that can occur during recovery, but his tremor was greatly reduced. He was once again able to chase his nephews around the dining room table. He was certain that he was recovering.

However, the morning that he had to see the dentist for some serious tooth repair work, his wife found him lying on the living room floor, curled in a fetal position, trembling violently – far more violently than he had ever tremored before. He was unable to initiate movement, unable to open out from the fetal position. He relaxed slightly after his wife canceled the dental appointment but he remained extremely shaky and barely able to move for most of the morning. Over the next three days, he slowly came out of his panic. When he saw me the following week, he announced, “The Parkinson’s is back. You obviously didn’t get rid of all of it. There must be more foot injury that you didn’t clean up. Or maybe there’s another injury somewhere else, maybe in my arms or neck.”

After our session, he felt fine once again. The next week he said that he’d been able to chase his nephews over the tidepools at the beach, a feat that requires excellent balance and timing. Except for a faint tremor now and then, his Parkinson’s symptoms were gone. But two weeks later, on the day of his rescheduled dentist appointment, he was back on the floor, fetal position, trembling violently.

The next time he saw me he complained that I still hadn’t gotten to the root of the Parkinson’s disease. I suggested that maybe there was a psychological angle, something to do with dentists. He disagreed. He insisted that he had *no* fears.

I said that Parkinson’s disease wasn’t something that came and went. I pointed out his improved posture, gait, arm swing, facial expression, everything related to Parkinson’s, and he confirmed that he didn’t have Parkinson’s except on his go-to-dentist days. He also pointed out that, when he was lying on the floor, immobilized, trembling, he had *all* the symptoms of advanced Parkinson’s disease. Parkinson’s is defined by its symptoms. If he had the symptoms, then he had Parkinson’s. I was the Parkinson’s specialist; I should fix him.

He had the dentist reaction several more times. He also started to have a new trigger for his bouts of parkinson-like symptoms: *thinking* about still having Parkinson’s. Whenever his mind strayed to the thought that his Parkinson’s wasn’t gone after all, he would start to tremor and stiffen up. His feet stuck to the floor and he could barely walk. If he got distracted from those thoughts, the symptoms went away. Over the next year, he became almost constantly preoccupied with the fear that the Parkinson’s would never heal. Every time his mind touched on

this subject, he stiffened up and tremored. But even so, if he “forgot to have Parkinson’s,” as he expressed it, he could move normally.

Team members and I continued working with him for more than a year. But then he applied for disability pay and stopped seeing us.

Hope

Hope experienced a collection of recovery symptoms, including a small spinning sensation in her head, but not the full brain shift. Some of her symptoms cleared up completely, others were greatly reduced. She still walked with the slight limp in her left hip that she’d had all her life. Her small, intermittent tremor departed her left hand and settled in her right hand. Her vigor and facial expression returned completely, and she started riding her bicycle again for the first time in years. For several years it seemed as if the Parkinson’s was on its way out.

However, within hours of learning that her best friends and their daughter had died in a car crash, her tremor became larger and nearly constant. Over the next two years, she found herself moving a bit more slowly.

But one week, when she showed up for her weekly session with me, she reported something odd: on the previous Friday, she’d woken up with a tiny bit of a head cold. She wasn’t sure if she would go to work or call in sick. She puttered around the house for an hour and decided to go back to bed. As she was climbing back into bed, she realized that she’d been moving perfectly normally and hadn’t had any tremor the entire time she’d been puttering around the house.

I asked her if she had any idea why she’d been able to move normally for that hour.

“I wasn’t really sure I was going to get up for the day. I was still wearing my bathrobe, so it didn’t matter.”

“What didn’t matter?”

“Anything. Since I might not be getting up, I didn’t need to be worried about anything.”

“What are you usually worried about?”

“Nothing. I’m not afraid of anything. But I notice that when I first wake up I don’t have any symptoms until I think of what I need to do that day. And of course, I didn’t tremor much on that Sunday when the power was out.”

This was news to me. “Why not?”

“There’s no way anyone is going to call me from work and expect anything of me on a Sunday when the power’s gone out.”

“Are you usually afraid that someone’s going to call you from work? Would that be a problem?” (Hope owned the business that she worked at.)

“Well, you know how it is. They always expect something of you.”

“If no one expected anything of you, would you not need to tremor any more?”

“I don’t know. There’s *always* going to be something they’re going to want from you.”

Hope had another symptom that was steadily worsening. Like many other PDers, she had cramping in her toes once in a while. The cramping usually lasted up to ten minutes. But recently, it would sometimes last all day. She had a breakthrough when she realized that it only occurred when she wore her nice boots. She started wearing only shoes. Within a few months, her toes cramped up after a few hours of wearing shoes. She started wearing only sandals. Within a few months, her toes cramped after a few hours in her sandals. She started wearing cheap flip-flops to work. Her toes didn’t cramp in the flip-flops except for short periods of time, while she

was worried about something specific. She still wore shoes once in a while, for short periods of time, but she noticed that her toes started cramping while she was starting to put the shoes on! A few months after noticing this, she realized that something really strange was going on: her toes cramped up when she *thought* about shoes. That's when she finally realized that it was the *idea* of shoes, especially *nice* shoes, that was causing the toe cramps.

Hope told me about her mother, a cruel woman who openly resented having had children. For example, the father had never been allowed to give little Hope a hug because he "belonged" to the mother. Mother had more money than she knew what to do with, and she collected shoes. She had hundreds of pairs of shoes, many of them never worn. When Hope was a young child, she had regularly thought to herself, "You should love your children more than your shoes." Together, we managed to work through her mixed feelings about shoes, and her toe cramping decreased significantly, but she was still bitter about her mother.

Hope's tremor continued to worsen. It got so that it only let up when she was certain that "no one was going to expect anything" from her.

As an aside, she had no memory of ever having cried prior to recovering from Parkinson's. But even though she could now cry and felt much more open to feeling emotions and expressing emotions, she remained emotionally guarded. As she informed me one day when the tremor was severe, shaking both arms and her chin, "The whole point of life is to protect yourself from feeling strong emotions."

In Hope's case, her intermittent plunges into worsened tremor or stiffness were clearly triggered by thinking about work, car problems, or responsibilities in general. Her toe cramping was related to thoughts of shoes, especially nice or expensive shoes.

But unlike Chip, she never again had the full-blown collection of PD symptoms that she'd had when I first met her. Most of her symptoms never returned. Her expressionless face, dragging foot, bent arms, inability to open doors, carry things, or go up stairs without keeping a death-grip on the handrail were permanently gone.

And at some point, she told me that she'd sat up in bed in the middle of the night and said out loud, "I've been making this way harder than it needed to be." As of this writing, she is working on changing her "protect from strong emotions" credo, and she is starting to see a decrease in her tremoring.

Duke

Duke moved as slowly as molasses even though his foot injury had healed. He'd had some recovery symptoms in his face and feet. However, even though he now had facial expression and could once again initiate normal-speed *speech*, he still had difficulty initiating normal-speed large motor movements.

Before I can go into details of Duke's case, I need to mention that some patients continued to dissociate from their entire bodies in times of stress, even after their foot injuries were gone. As we saw in the case of "Chip and the Dentist," ex-PDers very often cannot move easily during these dissociative periods. During these intervals, they feel as if they are outside their bodies, observing themselves from the outside but unable to *feel* that they exist *inside* their own bodies. By the time I was working with Duke, we'd developed some exercises that had helped partially-recovered PDers learn how to stop dissociating so that they could completely recover. However, the biggest stumbling block for many PDers was forcing themselves to do the sometimes painful work.

Getting back to mild-mannered Duke, he'd just finished doing one of the more carefree and pleasant of the dissociation retraining exercises when he exploded with a rare burst of emotion. The technique he'd been doing involves lying down, relaxing, while pretending to *feel* what it's like to walk or lie in the sun while pretending to be some animal such as a kitten, pony or elephant. Most PDers enjoy this technique. After they finally master the concept that "feel the sensations" does *not* mean "*observe* yourself from the outside," they are usually able to imagine what it might feel like to be or move like an animal – even if they are as yet unable to imagine what it might feel like to be or move like a human.

After an hour of being various animals, I asked Duke if he'd enjoyed the experiment. He snapped at me almost viciously, "No! I don't *want* to feel!" Duke was stunned by what he'd just said and how he'd said it. He apologized and meekly assured me that he truly did want to feel. He added, "I had no idea. I guess I've got my work cut out for me."

For his homework, I asked him to figure out some animal or person that he was willing to feel like. The next week he told me that he'd chosen Sammy the River Otter, a favorite book character from his childhood. Sammy is happy. Sammy likes to have fun. That weekend, while "feeling" like Sammy the River Otter, Duke had easily driven the winding mountain highway that connects our beach town to inland California. He'd felt so good after driving in a relaxed and responsive manner that he drove another twenty miles to visit some friends. He'd had a great time and moved better than he'd moved in years.

But the following week, his movement was once again maddeningly slow. I asked him if he'd tried being Sammy the River Otter. He became angry again, and said, "I don't want to be anything but me. I want *me* to be able to move. I don't *want* to have to be a river otter.

I suggested that *he* didn't like feeling his own body, and Sammy did. As long as he was determined to be his old personality, a personality that, by his own admission, didn't want to *feel* anything, he might not be able to move well. Except when using adrenaline, a person has to be able to anticipate the *feeling* of moving his body, or at least be able to *imagine* movement, before he can make it move.¹

As an aside, the degree of numbness and lack of proprioception in many PDers is very high. Prior to recovery, many PDers insist that they are not numb because they are able to feel externally applied stimuli. However, when they recover, they are usually stunned to discover that they can have awareness of, that is to say, *feeling*, in body parts even when there is no external stimulation or pain coming from the area.

I suggested to Duke that maybe his current personality was just as false as Sammy the River Otter's. Maybe his *real* personality *did* like to feel his body and was also able to move perfectly normally. He started crying, and said, "But I had a perfectly happy childhood. Sure, my father was in the Navy so he left for sea when I was six months old and I didn't see him much while I was growing up, and my mother always needed everything to be just so, but I was fine with that. I'm not afraid of anything. And I *do* feel. I'm not numb."

He called me a week later and left a message: "I just realized that I *am* numb, physically and emotionally. I was really observing my wife, and I noticed how much she *feels*, physically

¹ Dopamine-induced movement, as opposed to adrenaline-induced movement, must be processed through the imaging area of the brain before it moves to the actual motor function area of the brain. People with Parkinson's disease do not activate the imaging part of their brains when they try to move. This part of the brain is also shut down immediately following severe trauma or severe blood loss. Citations supporting this new research appear in chapter xxx, which discusses brain processing during dissociation.

and emotionally. She gets excited about everything and she feels every little thing in her body. *I don't feel anything. I have my work cut out for me.*"

Rudolph

Rudolph recovered quickly from Parkinson's disease. When I lectured in Germany, he translated for me. On the second day of the talk, when the PDers in the audience got to introduce themselves and share a bit about their symptoms, Rudolph stepped up, last of all, and introduced himself as a person who had recovered from Parkinson's. Everyone in the audience was stunned. Some did not believe that Rudolph had ever had symptoms of Parkinson's disease, or else were determined that that his symptoms must have been mild.

But within a year after being fully recovered, Rudolph told us that he still had Parkinson's disease in his right arm. It was only a problem when he was shifting the gear level in his car. Still he was concerned: his greatest fear, after all, was losing his ability to drive a car.

Aside from having Parkinson's disease in his arm when he was in the car, he could move beautifully. He could run after his two sons when they played at football (soccer). But his arm stiffness while moving the gear shifter worsened. After a period of years, he was barely able to move the gear shifter. As his arm's "Parkinson's disease" increased, his fears started to build. Whenever he caught himself thinking about never recovering from Parkinson's, he felt his facial expression fade and his movement became labored. When he forgot about the Parkinson's, he could move easily. But as he became more and more preoccupied with not being able to recover, his stiffness appeared more and more often.

During his visits to Europe, Chris often treated with Rudolph. Chris Ells is the member of our team that represents our work at the Yin Tui Na Centrum of Amsterdam, a non-profit that was organized, in large part, for the purpose of supporting our work in Europe.

When Chris worked on Rudolph's arm, the arm felt perfectly healthy. Chris started to suspect that Rudolph's lack of arm use had more to do with the fear of not being able to drive than it had to do with the arm. On one of his visits, Chris led Rudolph through a long series of movement exercises. Cleverly, without drawing attention to it, Chris led Rudolph through every one of the movements that are used while moving the gear-shift lever. Rudolph did all of them easily, fluidly. Rudolph was sitting down, exactly as he would be in a car. Chris, pretending to be assessing strength, had Rudolph do the same gear-shifting moves while Chris pushed against him, creating resistance.

Rudolph did all the gear-shifting movements beautifully, effortlessly.

When Chris was finished, he explained to Rudolph that his arm was fine, and that the problem had nothing to do with the arm, and nothing to do with Parkinson's disease. Parkinson's disease symptoms *do* worsen or lighten up with mood, but not to the extent that Rudolph's symptoms manifested. What Rudolph had was an arm that didn't work when he was in the car. Rudolph admitted that his greatest fear was losing his ability to drive, but he didn't see why that was related. It was the Parkinson's, and not the fear, that was causing his arm to freeze up in the car.

Chris suggested to Rudolph that his fears and negative thoughts were causing him to manifest symptoms of psychogenic parkinsonism. Rudolph asked how often Chris would need to perform Yin Tui Na on his already healed foot in order to make the fears and negative thoughts go away. Chris, and then later, I, assured Rudolph that we could treat him for anxiety and fear, and guide him through some psychological exercises that might help him. But we also made the

point that, ultimately, overcoming his fears was his own job. He was actively creating fears. He needed to stop doing that.

Rudolph was stunned. He told us that it had never occurred to him that he was responsible for his own thoughts. He said, “I just assumed that, if thoughts showed up, they had the *right* to be there. I assumed that I was *supposed* to pay attention to them. It never occurred to me that *I* was responsible for the nature of my own thoughts.”

Rudolph was well educated, a published author, and a long-time practicing Buddhist and, like most people with Parkinson’s, extremely intelligent. Also, like most of our patients with Parkinson’s, he assumed that his *actions* should be under his own conscious control but that his *fears* were *real* things: his fears were legitimate; his fears were *not* mental constructs. His fears, like this thoughts, simply *were*: he could not be expected to have any amount of control over them.

We walked Rudolph through some of the exercises we’ve developed for learning how to experience physical or emotional feelings without reverting to dissociation at the first sign of pain. We started by encouraging Rudolph to feel the physical pains of experiences that he had already “processed” mentally and that he hadn’t considered traumatic at the time. He cautiously allowed himself to actually feel and then neutralize the physical knot in his stomach that he’d *never felt* when his girlfriend dropped him for his best friend back in high school. As he *felt* and neutralized this and an assortment of others pains, he started laughing.

While slapping himself on the forehead several times in a gesture of sudden realization, he exclaimed sheepishly, “I’ve been doing this to myself! I’ve been doing this to myself!”

Summary of the above four case studies: Chip, Hope, Duke, and Rudolph

These cases, and many others like them, suggested that some people with Parkinson’s who’d recovered from their foot injuries, who’d experienced unmistakable recovery symptoms, nevertheless still had a strong mental or emotional trigger that caused them to tremor or freeze up in some body part now and then, or to even have a body-wide episode of immobility in certain circumstances. Sometimes these people moved perfectly when they weren’t having an “attack” of Parkinson’s, as some called it. Of these, many noticed that their worst times were when they started thinking about having Parkinson’s – which they thought about more and more. Many also used the exact expression, “Forgetting to have Parkinson’s” to describe those times when they move perfectly normally.

Many of them noticed that the PD symptoms that are directly caused by the electrical chaos set in motion by the foot injury, such poor circulation and muscle function in the foot and face, a decrease in sense of taste and smell, poor temperature regulation, and foot dragging, did *not* return. And when they *were* moving easily, they often moved better than they’d moved in years.

When they were moving easily, they often reported that it was the first time in *decades* that they’d moved with dopamine. Movement with dopamine is somewhat effortless, and *feels* distinctly different from adrenaline-based movement. If one hasn’t experienced dopamine-based movement in a long time, the difference is quite distinct, even “impossibly” effortless.

For example, one recovering PDer told me that when she’d gotten up off the sofa recently, it didn’t take any work. She had merely thought about standing up, and the next moment, she was standing up, as if “by magic.” She burst into tears and bitterly asked out loud of the empty room, “Is this how easy it’s always been for everyone else?” Although she had not developed Parkinson’s until she was in her forties, she had *no* adult memories of ever having

moved without first consciously willing herself to activate her limbs. She had always moved with intention and will power. She'd had no idea that most people moved by imagining the feeling of movement and then letting the body express that thought.

The changes that we saw in recovering PDers suggested that they had healed from their injuries *and* that they *could* access dopamine for movement initiation.

However, when some of the recovering PDers started to manifest the more "mood influenced" symptoms of Parkinson's, such as tremor and immobility due to a fear-based inhibition of dopamine, their symptoms sometimes became far more problematic than they had been previously.

We hypothesize that this abrupt worsening of symptoms during times of fear may have been due to a decrease in adrenaline levels. When the foot injury healed, it was suddenly much harder for many recovering PDers to summon up the adrenaline and the adrenaline-based personality that they'd always used to make themselves "get going."

After the foot injury healed, if they panicked, they felt as if they had neither adrenaline *nor* dopamine. Thus, when some of them, like Chip, were panicked or anxious, they were *far* worse off than they'd been before, back when they'd merely had idiopathic Parkinson's disease and a vigorous habit of relying on adrenaline.

We slowly came to appreciate the significance of some of the partially-recovered PDers protesting vigorously that they did *not* want to learn how to feel and they especially did not want to learn how to feel pain. Several PDers pointed out to us that the "whole point of life is avoiding pain." But when these people did overcome their tendency to dissociate at the first hint of unpleasantness, they were delighted, amused, and usually a bit sheepish. Everyone who recovered from the dissociation component admitted that it was simple, and that they had been solely responsible for setting it in motion.

As an aside, we found that those people who were determined to blame parents, politics, or circumstances were also unable to change their mental habit of dissociation. Only when they started taking responsibility for changing their own thought habits were they able to stop dissociating from their bodies.

