

## CHAPTER TWENTY-TWO

# RECOVERY SYMPTOMS: CHANGES IN SLEEP PATTERNS

One of the more pleasant, or more aggravating, symptoms of recovery was the change in sleep patterns.

### **Improved sleep**

During recovery, PDers who had been plagued by insomnia found that they were suddenly sleeping very well.

### **“Too much” sleep**

But some PDers found themselves wanting to go to bed early, wake up late, and take naps. They felt they were sleeping too much. Many complained, “I’m sleeping my life away.”

I reminded my patients that a person recovering from a serious injury or ravaging illness needs to sleep a lot. Since they were growing new nerve cells, muscle cells, and brain cells, they needed sleep: lots of it.

Some accepted this. Some were unable to accept it, and continued to feel chagrined, or even ashamed, about how much sleep they were getting.

### ***Concerned about sleeping too much***

Many PDers, by the time they were diagnosed, had started having a hard time sleeping through the night. In the beginning of recovery, this new ability to sleep well seemed like an answer to prayer. However, many recovering PDers soon had to pit their glorious new ability to sleep against their lifetime conviction that people who sleep a lot are lazy and bad.

Many PDers moaned to me that they weren’t getting “anything done” because they were sleeping so much. I had to point out to them that they were getting a lot done. They were growing new nerve connections, new muscles. And even if the foot injury had healed, the body might need to sleep a lot while healing other injuries that were finally accessible to the brain.

While this may not seem like a big problem to the reader, the extra hours of deep sleep was a real emotional challenge for many recovering PDers. Many PDers felt genuinely bad about themselves when they weren’t accomplishing a lot. This was a serious problem. It made recovery a time of guilt-induced anguish for some PDers.

Prior to their diagnosis with Parkinson’s, many PDers, unable to feel their own bodies and, in some cases, their own emotions, had valued themselves because they “got a lot done.” During recovery, many PDers avoided doing anything that wasn’t a stark necessity. One PDer said, “I plan my days around being able to get as much sleep as possible. If an activity isn’t absolutely necessary, I won’t do it.”

When the ability and *desire* to be a workaholic dropped away, some PDers felt ashamed and even depressed. As you can guess, depression is a condition in which the release of movement neurotransmitters is minimized.

### ***A case study in “laziness”***

I recall one recovering PDer who, like many people with Parkinson’s, worked three jobs. She was a math professor by day, a software designer in the evening, and a regularly performing professional musician on weekends. During the “increased need for sleep” phase of recovery, she found herself parking as close as possible to her classroom to minimize her walking distance, turning down music jobs, and unable to stay up at night to work on the software. She didn’t need the extra money; she was a successful single woman with no dependants, so the problem with working less was purely a self-worth issue.

While she was in the thick of this phase, she came into my office and exploded into tears. When she was finally able to talk, she told me about the above changes in her lifestyle. I asked why this was a problem. She replied, “I’m turning into the people I hate! But that’s not the problem. The problem is that I never knew I hated anyone!”

She was a very loving, kind and helpful human. She had always assumed that she loved everyone. But when she found herself minimizing her daily activities so that she could sleep more, her inner thoughts screamed at her, “You’re turning into the people you hate!” This realization, that she had subconsciously been judging – and finding lacking – those people who did *not* work three jobs and constantly exert themselves, made her deeply ashamed of herself.

She wasn’t sure what she was more ashamed of: her lack of interest in “doing it all” or her new realization that she had been looking down at people that were less active than herself.

The reader may think that patients like this were making a big deal out of nothing. But the increased need for sleep and the decrease in “getting things done,” or “making things happen,” was sometimes a devastating emotional experience for those people who had only valued themselves on the basis of what they were able to accomplish.

### ***How long did the need for extra sleep last?***

The need for extra sleep was not a straight line. Some people only needed a few extra hours a day, or a nap on weekend afternoons. Sometimes, this increased need lasted for months. In some cases, it lasted for years.

Very often, the “new” amount of sleep was actually a far healthier amount of sleep. Many of our patients had chronically shorted themselves on sleep. In some cases, the PDers never went back to their old patterns of getting by with less sleep than most people. As they recovered, they no longer felt the adrenaline-based drumbeat that forced them to sleep as little as possible. The new, “lazy person” sleep pattern was sometimes just a “healthy” sleep pattern.

Some PDers accepted happily the new amount of sleep that their bodies needed. Others slid into despair because they honestly felt that they were sleeping their lives away, with no end in sight.

In general, younger people needed much less “extra” sleep during recovery than older people. For example, one PDer in her thirties, who started our recovery program immediately upon diagnosis, only needed several days of staying home and sleeping all day. A retired PDer in his late sixties who had an advanced case of Parkinson’s found that, during recovery, he slept long and hard at night and then needed two naps in the daytime. However, there were no hard and fast rules, and there were variations and exceptions. To say nothing of the fact that some people in their thirties had an advanced case at the time of diagnosis and some people in their eighties had a mild case when they were diagnosed.

Every PDer’s symptoms are unique, etc.

### ***Shifting sleep patterns***

Some people noticed that their sleep patterns went through constant changes. For several months, a recovering PDer might have fallen asleep at nine at night and awakened at seven in the morning. A few months later, he consistently might not be able to fall asleep until three in the morning and then he would sleep until noon. And then, a few weeks or months later, the pattern changed again.

Anyone who has raised a child will recall that children go through periods when they need an enormous amount of sleep, and other periods when they don't even need to nap. These periods of increased sleep and altered sleep patterns correspond to periods during which the child does an enormous amount of mental, emotional, or physical growth.

In a PDer, these periods of increased sleep also corresponded to enormous amounts of healing and growth.

### **Two-hour intervals of deep stillness**

A few PDers noticed that, even if they didn't feel tired, their bodies fell into heavy, drugged-like physical immobility for about two hours. These two hours of stillness sometimes occurred at the same time every day, and went on for several days or even for months. This very weird type of sleep seemed similar to the sleep induced by strong pain medications such as Demerol: the recovering PDer might be perfectly conscious, deeply relaxed, and yet unable to move any part of his body – appearing to be asleep even though he was conscious.

This type of “sleep,” or utter immobility while alert, usually only occurred, if it occurred at all, for about two hours at a stretch. After the two hours of feeling drugged was over, the recovering PDer quickly resumed whatever his normal movement ability happened to be. But the next day, at about the same time, he might, once again, have two hours of gentle, but utter, immobility. And again the next day. And the next.

Only a few patients had the two-hour, same time every day, limp paralysis. Of those that did, most of them only had it for a few days. One person had it for a week. One person had it for four months. The person who had it for four months also recovered from Parkinson's extremely quickly in every other respect: all of her obvious PD symptoms were gone within two months of the time she started treatment.

### **Channel theory**

We suspect that these two-hour periods of extreme limpness and immobility corresponded to healing activity in specific electrical channels. As you will recall from chapter xxx, every primary channel has a specific two-hour period during the day when the channel is most active.

For example, the Stomach channel operates at its highest amperage level between 7 and 9 in the morning. (These times are approximate and are based on the sun and an individual's circadian rhythms. They are *not* based on Greenwich Mean Time.) If the body recognizes an area serviced by the Stomach channel that needs intensive repair, the body is most likely to do this repair work between 7 and 9 in the morning. During this channel's time, if the body is doing *enormous* amounts of healing work on any damaged places that are located on the Stomach channel, a person who is mentally relaxed may not be able to move any part of his body. He may feel limply, gently paralyzed, or very, very sleepy, from 7 to 9 in the morning – Stomach channel time. He would snap out of it when the Qi starts flowing more heavily in the next channel in the sequence, Spleen channel, from around 9 to 11.

When this type of two-hour paralysis event did occur, the person – who might have had nearly normal physical function during the rest of the day – had a bit of warning time: he felt himself slowly relaxing, over a period of about ten minutes, into the deeply calm stillness. Once he was comfortably ensconced in it, nothing short of an emergency was able to pull him out of it. And at the end of the two or so hours of gentle, “soft” paralysis, he found himself able to move perfectly normally again – until the same time the next day.

These bouts of non-moving were pleasant, even amusing, if the PDer could take them in stride. They might or might not occur on a daily basis until the area being worked on was healed. Also, after a person no longer had 7 to 9 in the morning (or whenever) soothing paralysis, he sometimes developed a new two- or so- hour stint of calm stillness at some other time of day.

For example, one person who needed a lot of repair work around his shoulder blades found himself unable to move from 1 to 3 in the afternoon for a few days while the shoulder blade area recovered more movement and feeling.

Again, it was *not* the rigid type of paralysis that a person might have following a stroke or polio. It was a time of softness, a deeply calm period during which a person might be awake or asleep, during which his ability to move was turned off. It is somewhat similar to the deep, relaxing rest that can come after a high fever has broken and a person slides into a deep, healing stillness during which he feels absolutely no interest in moving a single muscle.

This stillness did not occur if an emergency was ongoing. It happened in people who had made a decision to surrender to their bodies’ inclinations to whatever extent was humanly reasonable.

### *An example*

The PDer who had morning “zone outs” for four months could get up any time in the morning, so long as it was before 7:00 a.m. Then, at 7:00 a.m., she would become limp, unable to talk, barely able to blink. At 9:00 a.m., she would “snap out of it.” Within fifteen minutes, she would be back on her feet, functioning normally.

She rescheduled her work around this daily period of inaccessibility by changing her start time from 9 a.m. to 10 a.m. No one she worked with ever knew that she spent two hours a day awake yet utterly unable to move.

This same PDer desperately wanted to attend a particular museum showing in Victoria, BC. This meant leaving the house at 5:30 a.m. to take the ferry from Seattle to Victoria. She had always loved being on the water. She never felt safer than when she was on a boat. She went limp at around 7 a.m., as she and her best friend were getting on the ferry. Her friend helped her, almost dragging her, to a seat in the ferry café. She sat, slumped, eyes half opened, body unmoving, for nearly two hours, while her friend chatted about what the kids were doing at school. Then, about twenty minutes before docking in Victoria, the ex-PDer started conversing with her friend in what had been, up until then, a monologue. Within a few minutes, she was talking and joking effortlessly.

Her friend was mildly alarmed. “You’re normal again! You told me about these two hour ‘quiet times,’ but I didn’t believe you. That’s the weirdest thing I’ve ever seen. I’ve been sitting here wondering how the heck I was going to drag you all over Victoria. I thought you were sick or something. I was getting ready to call for a doctor, and now you’re perfectly normal!”

Absolutely normal! It's the weirdest thing I've ever seen. And you've been doing this every morning for how long?"

### **Afraid of needing sleep**

Many PDer's have decided not to enter the recovery program because they were frightened by the idea of needing lots of sleep. The number one reason that PDer's have given me for choosing not to enter a recovery program is that they cannot afford to miss any days of work. Some have also feared that, in order to explain to the boss or co-workers that they need more sleep, they might also have to confess the horrible fact of having been diagnosed with Parkinson's disease. They fear that either the increased need for sleep or the admission of having a physical illness will cost them their jobs.

Being afraid to miss work, or being afraid of appearing lazy (another popular reason for not wanting to attempt recovery) during the period of increased need for sleep, is a fear-based attitude that slams right up against what many PDer's think they need: accomplishments. As noted before, many PDer's value themselves only in terms of what they accomplish each day.

Seen in this light, it is understandable that many PDer's are *afraid* of anything that might rock the I Get Things Done boat – including recovery.

But, as noted above, in an emergency, PDer's *were* able to move. We observed that, if work was an emergency for a PDer, he was able to attend work. However, if this was the case, he also spent his days off in sleeping around the clock. Recovering PDer's seemed to be able to work around employment needs while still doing whatever recovery work had to be done – within reason.

### ***Fear that recovery symptoms will expose the PDer's secret***

Another reason often given for not wanting to enter a recovery program was the fear that, in order to explain any embarrassing recovery symptoms, the PDer might have to inform friends and co-workers that he had been diagnosed with Parkinson's. As opposed to those who merely feared momentarily looking like an idiot in public because of recovery dyskinesia, the possibility of missing some days of work due to increased sleep needs seemed to strike deeply at the hearts of those PDer's who were afraid of being "found out." Sad to say, this was *not* a rare fear.

### ***"Cure me fast so no one will suspect I've had Parkinson's"***

One PDer came to visit our program in Santa Cruz, and opened his first appointment by asking, "Can you cure me really quickly so that no one will ever know I had Parkinson's disease?"

I said that I couldn't promise anything, and asked why it mattered if people knew he'd had PD.

He replied that he was a physical fitness coach. "I make a good living because my clients think that I'm healthier than they are. If they knew I had a physical problem, they would reject me."

I told him that he might be wrong, and that if he was able to show his clients how he could confront and recover from a difficult illness, they might respect him even more. He was adamant that I did not understand, and that everyone would despise him and accuse him of being a liar if he promoted fitness when, in fact, he had Parkinson's.

I said that it seemed to me that if he truly felt that he was sick, and was pretending to be well so that he could continue to mislead his clients, then he *was* lying. He replied that he had to

lie, to be able to make a living. So I asked if maybe his problem wasn't so much that people might think he was a liar, but that they might find out that he actually *was* a liar. He agreed, and didn't seem to understand that the latter situation reflected the more poorly on him.

He then said that people would *hate* him if they knew that he was being a fitness coach while having Parkinson's disease. We went back and forth on this for some time. When I refused to guarantee that he could recovery quickly and in such a way that no one would ever know he'd been "unfit," he decided to not enter our program.

He was not the only one. Many PDers feared that, by divulging the fact of physical imperfection, they would make themselves vulnerable to scorn or even some sort of unnamed danger. After a while, we began to suspect that, in PDers with a severe mental/emotional blockage, this was actually an integral part of the Parkinson's pathology.

An injured animal, while still in the thick of the skirmish, does not want to show any signs of weakness to the enemy.

Many PDers, neurologically behaving like injured animals, or "walking wounded," feel that they are not yet in a place that is safe enough to allow them to let their guard down. Sadly, some have cultivated such a powerful attitude of wariness for so many decades that they cannot easily change. Worse still, some of them feel that any *change* in this attitude would be a sign of weakness, a sign of surrender. If I had to pick one word that many PDers dread more than any other, it would be the word "surrender."

### **Quitting the job**

Faced with the idea of possibly needing to miss a few days of work because of needing sleep, many PDers decided to quit working. They usually stated that they could recover faster if they had time off to "focus" on their recovery. We now discourage this type of thinking.

We saw that PDers who continued working during their recovery fared much better. Isolation does not encourage learning a new mindset – it allows a person to wallow in his old ways. The regular presence of others was a boon to the PDers who had never known that other people can actually be extremely helpful – even if "other" people were usually thought to be slower, stupider, and lazier than the PDer. Learning to *expect* help from others is a part of learning to feel safe. And feeling safe releases dopamine. Dopamine release does *not* occur when a person is hiding from challenge.<sup>1</sup>

### ***Help in unexpected places***

Those people who continued working and who even shared with co-workers the fact that they had Parkinson's and that they were trying to recover found an enormous weight lifted from their shoulders when they learned – often to their shock and amazement – that their co-workers are able to take their "failure to be perfect" in stride. Some even received unexpected support and strength from co-workers.

We now recommend that a person continue working or performing his normal activities of daily living to the best of his abilities, while allowing recovery symptoms, including his increased need for sleep, to manifest during his weekends and his "down time" in the evenings.

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<sup>1</sup> Some recovering PDers really have a hard time understanding that dopamine release is *not* the result of feeling good. Dopamine release occurs when 1) a person feels safe and 2) a person *expects* to experience the joy of being alive *whether or not* he gets to do what he wants. Staying home from work to avoid doing something is the exact *opposite* expecting to feel the joy of being alive no matter what the circumstances.

Once in a while, when he really needs to make an exception and grab a few hours, or even a day or two of nothin' but sleep, fine. He needs to learn how to feel his body and respond to its needs – even sleep needs.

