

CHAPTER TWENTY-ONE

RECOVERY SYMPTOMS: MUSCLE SORENESS

Arm swing: bicep soreness

When, during recovery, PDers' arms first started to swing, the bicep muscles hurt. This arm swing pain was *not* recovery dyskinesia. Dyskinesia means “abnormal movement.” Dyskinesia occurs when a muscle first gets back on-line and clumsily starts relearning how to respond correctly to the brain signals.

Arm soreness occurred after the arm muscles become *correctly* operational and started being used a few thousand times a day.

Prior to recovery, many of our PD patients no longer had the synchronized electrical pattern that automatically swings the arms – using the correct muscles. When, during recovery, the biceps, the muscles that *correctly* perform arm swing, started to automatically contract in synchrony with the opposite-side leg stride, the arm muscles felt sore at first, even a bit painful, when walking. The reason was this: the muscle contraction automatically occurred with every single step.

Even if the new arm swing was very tiny, almost invisible, in the beginning, that tiny movement was the result of contraction in the feeble biceps. This muscle might not have been used for years. During recovery, the biceps automatically – without the PDer thinking about it – made a healthy contraction a split second prior to every opposite-side footfall, thus forming the arm swing.

If a recovering PDer walked fifty steps, the convalescing biceps contracted and relaxed fifty times. If he walked for half an hour, the bicep contracted and relaxed more than a thousand times.

When the biceps began to work, they might have been going from zero contractions per day to many thousands. The biceps usually felt sore from the unaccustomed work out. Over the next few weeks, walking often became difficult because of the accompanying soreness in the biceps. Whether the PDer *tried* to swing the arms or not, the reconnected biceps did their healthy contraction in time with the footfalls.

Several recovering PDers who previously mourned the loss of arm swing reported the irony of trying to *prevent* their arms from swinging. “My arms are *so* sore. When I go for my morning walk, I cross my arms over my chest and try to pin my biceps down so that they can't move. Sometimes that helps. But sometimes, even though the arms can't really move, the darned biceps are still doing their repetitions in time with my walking. It's getting so that the arm soreness is limiting the distance that I can walk. I used to go three miles a day. I've cut back to half a mile a day because of how the soreness builds up in my arms. I have to admit, it's a good pain. It's like the soreness I used to get when I was in high school sports, after doing those conditioning exercises. And I can tell that my arms are getting a lot stronger. But this last week, after half an hour of steady walking, I was so sore in the arms that I just wanted to go home.”

This soreness and pain eased up when the muscles in the arm became accustomed to the thousands of daily repetitions that a healthy person makes while walking. But for a short period, maybe a few weeks or a month, the new arm swing and the resultant workout for the budding biceps was a bit painful.

Prior to recovery, PDer's often assured us that they were still swinging their arms, or could if they thought about it. They were surprised when the arm soreness began. Truth was, even if they'd been swinging their arms or doing biceps building reps at the gym, they hadn't been using their biceps.

A healthy arm swing uses the bicep. In Parkinson's disease, the bicep muscle tends to become atrophied and not responsive to brain command.

We'd observed that our PD patients whose arms still *did* swing a tiny bit were usually *not* using the normal arm-swing muscles. It looked to us as though, when a PDer's biceps atrophied, he used other arm muscles to create an arm swing.

When other muscles take over the job of an injured muscle or help stabilize an injured area, it is referred to as muscle splinting. Muscle splinting is a common, normal occurrence.

For example, some PDer's generated an arm swing by *throwing* the arms forward using muscles from the torso and the back of the shoulder. Others had an arm "swing" in which the hands and forearms stayed in front of the torso, sashaying from left to right, in time with the footfall. This is not correct arm swing. In these cases, various muscles were splinting for the inaccessible biceps. The correct arm swing is generated when the arm is *pulled* forward, from the front of the arm, using the biceps.

Although I wrote in a previous chapter that limp muscles were not atrophied, the bicep *was* atrophied: an exception to the rule.

(The chronic tension in the upper arms that causes the arms to stay bent at the elbow seems to be the result of rigidity in the muscles on either side of the biceps: muscles that, in happier days, splinted for the non-functional biceps.)

Prior to recovery, no amount of gym work on the part of PDer's ever helped the biceps get strong. If a PDer worked out in the gym, doing exercises that are supposed to develop the biceps, the only muscles that got stronger were the ones that splinted for the biceps. As long as the biceps remained out of reach of the mind, no number of weight lifts did anything for the biceps. The biceps did not work.

One PDer said that, ever since she was about twenty-five, she had not worn a sleeveless shirt. She knew that her arms didn't look right. She was very fit, and her arms were strong. She hadn't been able to explain exactly what was wrong with the look of her arms. After she recovered and her biceps returned, she suddenly realized what had been wrong with her arms: they'd been missing the bulge of the biceps. She started wearing sleeveless shirts again – not only because her arms looked normal again, but also because she no longer *worried* about whether or not she looked "right."

But the main point in mentioning the biceps situation is this: the biceps hurt when a PDer started unconsciously using them again. The pain eventually eased up as the biceps got accustomed to doing their correct job.

Back soreness

Up until now I have frequently stated that any given recovery symptoms might or *might not* have occurred in and given patient. “Every PDer’s recovery is as unique as his symptoms!” has been my constant cry.

But when it came to back soreness, this recovery symptom was almost universal. In our limited experience, all but two recovering PDers had back soreness.

The small-of-the-back soreness was usually referred to as back “pain,” but it was not pain in the classic sense. It was soreness, like a gentle ache or pulling in the small of the back. Standing up straight was an instant “cure.”

The back soreness probably occurred because the muscles in the small of the back had been over-relaxed, over-stretched. They possibly became overstretched over the years as the muscles in the front of the torso became contracted.

During recovery, when the rigid muscles along the front of the torso began to go limp, the muscles in the small of the back were once again able to contract. These back muscles might not have functioned correctly for years. When they began to contract a bit, they were over-keen at first; they tightened up slightly more than necessary.

Then again, they sometimes tightened up only briefly, then relaxed, then tightened again and relaxed again: the back “pain” came and went as the muscles played at finding their correct tension level. The soreness was felt when the muscles were tightening – *if* the PDer happened to be standing in his habitual, forward-leaning posture. When the lower back muscles tightened up (while bending forward), only one maneuver would stop the mild soreness that occurred: standing up straight.

This soreness was *not* true back pain. Back pain that is due to injury or pathological spasm usually causes a person to stand crooked, in such a way as to minimize the pain. The small-of-the-back muscle tightness that occurred during recovery from Parkinson’s disease did *not* feel better if the PDer stood crookedly to “favor” the pain. Chiropractic treatment, hot or cold packs, and other back treatments did nothing to reduce the new health and vigor in the back that was causing the soreness. The only thing that made the healthy back muscles feel good was standing up straight, allowing the back muscles to assume their correct position and strength.

This back soreness lasted for weeks or even months. During this time, leaning forward aggravated the soreness. By leaning forward, I mean the type of gentle leaning forward that occurs while washing the dishes or reaching across the bed to straighten the blanket. These gentle, forward-leaning movements caused a mildly unpleasant pulling sensation in the newly firmed up muscles. However, this problem was not severe, and could be easily remedied by throwing the shoulders back and employing good posture.

We asked complaining PDers to keep in mind that, if a person has back soreness that can best be remedied by throwing the shoulders back and standing up straight, this is not a real problem: this is your body teaching you to stand up straight once again. This is a recovery symptom.

Cases of no back soreness

As mentioned in chapter xxx, in two patients, the back muscles did *not* pull tight. Healthy tension in the back failed to automatically kick in. These recovering PDers found themselves bent far forward, with the face nearly touching the knees.

In these two cases, we did try many acupuncture and moxa techniques to strengthen the low back. These techniques did not work, even temporarily. Because both of these cases occurred prior to our discovery of the mental/emotional blockage that caused partial recovery, we did not explore the possibility of psychological inhibitions in these two patients.

Frequent urination: oversensitivity of the bladder nerves

At about the same time that a PDer experienced small-of-the-back soreness, he often felt drastic changes in his sensitivity to bladder signals.

In his youth, the pre-PDer may have had powerful bladder control. He may have been able to be out and about all day without feeling a need to urinate. This was not because he had a “strong” bladder. In these PDers, this lack of “need” to urinate occurred because his bladder nerves were somewhat numb. Only the very strongest signals from a *very* overstretched bladder could generate a strong enough signal to get through the relatively numb area in the low back, near where the bladder nerves enter the spine. The feeble bit of signal that got through to the spine and then traveled to the brain was all the PDer might have gotten, even if the bladder was actually saying “I’m really overstretched down here.”

Also, when an animal is highly dissociated from a high degree of trauma, when he is behaving as if dead, the animal might not register signals from the bladder. Those signals can wait until a safer time.

The combination of dissociation and/or an overstretched, numb area in the small of the back may have been the cause or at least contributed to this not uncommon symptom of Parkinson’s disease.¹

Oppositely, a few PDers had a lifelong weakness of the bladder, with a need to urinate every hour or so. This need for very frequent urination can be related to a high level of fear – the sympathetic system rather than the dissociative system.

At any rate, during recovery, as the spinal nerves of the low back began to be invigorated, at about the same time that the back soreness began, the nerves from the bladder also began to return to healthy sensitivity.

During the decades that the PD was silently worsening, the PDer’s brain had, in many cases, become accustomed to a very low signal from the somewhat numb bladder nerves. Because the “fullness” nerves from the bladder (the “stretch receptors”) had barely gotten any signal through to the brain, the brain had slowly trained itself to respond to the least little signal, if any, from the bladder. The brain learned that even the smallest signal from these nerves indicated a very full bladder.

Some PDers actually got few or no bladder signals during the day, unless the bladder was horribly full. The only time they felt genuine bladder fullness might be at the first urination of

¹ One PDer told me how, during World War II, his buddies highly resented his ability to stay in a foxhole all day. The other soldiers had to leave the safety of the fox hole every few hours in order to use the latrine trenches, thus exposing themselves to risk.

I heard many fascinating bladder stories, and other health stories, that all helped me put together the fullest possible picture of Parkinson’s disease. Our modern system of medicine, in which a neurologist sees a PDer for a quick fifteen minutes, twice a year, almost guarantees that doctors will not be able to make the fascinating connections between seemingly unrelated symptoms: connections that led us to an in-depth understanding of Parkinson’s. A PD team member or I spent about an hour every week or every month with each patient. We got to know their medical histories and idiosyncrasies in great depth. This was how we came to spot similarities among PDers, such as the bladder situation, that was never even guessed at by doctors who were always pressed for time.

the morning. A few had trained themselves to urinate at regular intervals regardless of whether or not they felt any real urgency. Sometimes, they got home from work at the end of a long day and, as they noticed how much urine was passing, said to themselves, “Huh. Looks like I forgot to use the toilet when I was at work today. Again.”

In recovering PDers, as the bladder signal nerves began to revive from their partial dormancy, they began sending healthier, more vigorous signals. The brain, accustomed to a tiny nerve signal, misinterpreted these larger signals: it assumed that extreme bladder stretching was occurring. When the recovering PDer’s brain started receiving what seemed like massive, steady surges of bladder information, the brain’s response was to assume that the bladder was constantly, *painfully* full.

Eventually, the PDers’ brains recalibrated their responses to the healthy bladder signals.

But until then, while the brain was still recalibrating the meaning of vigorous, healthy nerve signals from the bladder, some recovering PDers felt the “need to urinate” signal getting triggered every few *minutes*. This was very frustrating, because the amount of urine passed each time in response to the panic call could be measured in teaspoons, or even droplets. Nevertheless, the brain signals were adamant.

The recalibration of the bladder urgency signals occurred over a matter of a few days, a few weeks, or a few months. Just as the increased sensitivity in a previously numb foot tapered off when the brain accommodated to it, the increased sensitivity to the bladder signals tapered off over time.

Going through hell

If this bladder urgency phase occurred at the same time as the extreme limpness in the legs phase, the recovering PDer found himself in a difficult situation. Some PDers needed help to stand up and get to the toilet. During the night, they quickly exhausted their spouses with their constant demands for help. Some PDers referred to this phase of recovery as “hell stage.”

Some PDers merely went through a mildly annoying period of increased bladder sensitivity. Others found the bladder sensitivity-limp legs combo to be the most trying part of the recovery process.

We suggested that, if the bladder urgency was severe and preventing one from getting sleep, a man might want to get an external (condom-type) catheter to wear at night. For women and men, we also suggested that there was no shame in wearing adult diapers at nighttime.

Bladder infection

We also warned that a bladder infection can cause symptoms of bladder urgency. It is reasonable to ask the doctor for a urine test (urinalysis) if one develops symptoms of bladder urgency. Many people develop bladder infections during times of stress. Recovery from Parkinson’s can be stressful.

Bladder infections are a serious illness, and must be treated. Bladder infections in younger people are usually associated with frequent urination, burning pain when urinating, dark colored urine and sometimes fever.

However, in older people a bladder infection may be nearly symptom-free, in terms of bladder-specific problems. In older people a bladder infection can be present with no fever, no pain, or not even noticeably frequent urination. But even if no fever is present, a bladder infection is still a serious health problem. In older people, a bladder infection can cause extreme weakness and mental instability, even if there are no obvious bladder symptoms whatsoever. If

there is any possibility that a recovering PDer might have a bladder infection, he should seek diagnosis and treatment.

Many PDers, having read about recovery symptoms, have wondered whether or not they should risk entering into a program that warns of such humiliation and inconvenience. Is recovery from Parkinson's disease worth it?

Everyone who has fully recovered has felt so grateful for the return of a healthy body that the recovery symptoms, in retrospect, were nothing to complain of.

“You look terrible!”

Very often, PDers started to look haggard during the phase of frequent urination and its corollary of poor sleep.

Part of this was due to the fatigue, but part of this was due to the greatly increased expressiveness of the face. If, prior to recovery, the PDer had a fairly inexpressive face, and his face was now projecting “I feel exhausted and discouraged, I can't get up out of chairs, I pee all the time, my feet hurt and I'm crying a lot,” his best friends often told him how bad he was looking.

This new development – frank concern from friends – was a completely new experience for some PDers.

When these comments arose, PDers were often deeply concerned. They were going through so many changes and they couldn't be certain that these changes were for the better. When someone said, “You look terrible,” the PDers usually incorrectly understood this to mean, “The Parkinson's is getting worse.”

Also, PDers often did not have the social skills to know how much information should be shared with concerned friends; PDers, in many cases, were not accustomed to being on the receiving end of sympathy.

Prior to recovery, most of the PDers we've worked with didn't mind *giving* sympathy – but they didn't like to receive it. Many did not even know how to deal with the *idea* of receiving sympathy. So when concerned friends started to speak up, it was an ego-challenging time. And then, the emotional discomfort and the fear that the Parkinson's was getting worse very often caused an increase in mood-based symptoms.

We had to wonder if one reason for this outpouring of compassion from friends and co-workers was that the PDer had finally ceased projecting supreme competence. Spouses of several PDers assured us that the PDer had, for decades, unconsciously projected the signal “I don't need your help.” Many projected an air of inapproachability, especially with regard to personal matters.

In the past, the PDer's facial immobility might have conveyed internal strength or lack of compassion. After recovering tone in the facial muscles, that immobility was gone. The PDer no longer had a poker face. As the PDer's face became more expressive, emotions such as sadness, fatigue, boredom or resentment became apparent.

Also, prior to recovery, most of our PD patients admitted that they had probably been adrenaline-dominant for a lone time. Adrenaline tends to push people away. In the past, a PDer's friends might not have felt safe about offering compassion, even if they thought the PDer could use some.

During recovery, as a PDer's face became expressive, his protective walls crumbled, and his adrenaline dropped, he often started to come across as a person who *could* be comforted. His wounded body and fatigue sent signals to his family and friends: "I'm tired and sick and I need help." Any sensitive human can pick up on these electrical, chemical, and body language signals. But many PDer's had no experience at being on the receiving end of compassion.

Some family members were grateful that the PDer was becoming more "humanized." But sometimes, when a PDer started coming across as more vulnerable, family and friends were horrified by the PDer's changes. The PDer often had been "The Rock" or "The Capable One" of the family or social group. When the PDer became less heroic (less adrenaline-driven) and more "human," family members sometimes resented the changes in family dynamic and the new need to step up to the plate.

The change in facial expression

Many a PDer who assumed that his friendship was shown through his actions, who imagined that he was projecting sincerity and friendliness, and who prided himself on his never-changing look of stern intelligence was stunned when a "friend" or co-worker told him, during recovery, "I always assumed you didn't like me because you always frowned at me" or "...because you never smiled at me." Some PDer's were outraged by these confessions. Others were thrilled by their deepening appreciation for how emotionally frozen they had become and by the "miracle" of their recovery.

If the PDer was still living in fear, negativity, or anxiety, he often projected his own fear- or cynicism-based motivations onto those who would help him or be concerned for him: he assumed that people were being condescending, scornful, or judgmental.

For those PDer's who had tended to be aloof or "able to stand alone," we gently suggested that, during recovery, if family and friends started to express concern that the PDer looked exhausted, looked worried, or suddenly looked his age (instead of looking sort of frozen), he should celebrate. He was recovering from a long descent into lifelessness and separateness. He was coming back to life after decades of emotional separation. He was emotionally rejoining the living. And the living can be very loving and compassionate: they may express concern for what they perceive to be a person going through a challenging time.

Other PDer's, those who had worked to keep their hearts open despite the body's steady decline in physical functionality, those whose mental/emotional blockage was directed only at the foot injury and not towards a generalized fear of emotional pain, did not need coaching as to the *bona fides* of their family and friends. They appreciated the family and friends' concern and the caring spirit in which it was offered.

