

RECOVERY FROM PARKINSON'S DISEASE

A PATIENT'S HANDBOOK

Janice Walton-Hadlock

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TABLE OF CONTENTS

TABLE OF CONTENTS	5
<i>INTRODUCTION</i>	7
Greetings!.....	7
How are acupuncturists licensed?.....	7
PREPARING YOURSELF FOR RECOVERY: READY, SET, WAIT	9
This will be easy, right?	9
A Quick Review of Parkinson’s Disease	10
Cycles of Good and Bad Days	11
A Question from Many, Many Patients	13
SYMPTOMS OF RECOVERY	15
<i>EARLY CHANGES</i>	15
The Good Part	15
Blood Circulation.....	15
The Seemingly Not-So-Good Part	15
Tremor.....	16
Rigidity and heaviness	16
Pain.....	16
Bruising.....	17
Emotions.....	17
Questions from Patients	17
<i>SECOND STAGE</i>	19
The Good Part	19
Warmth.....	19
The Neither Good Nor Bad Part.....	19
Tingling	19
Sleep.....	20
Heaviness and Rigidity.....	20
Questions from Patients	20
<i>MID-STAGE RECOVERY</i>	23
Unexpected difficulties	23
Red Rash.....	23
Weak muscles.....	24
Swollen Ankles	27
Social Smiling.....	27
Frequent Urination.....	27
Hell Stage	29
The corollary.....	31
Side-To-Side Headache	34
Top-To-Bottom Headache.....	34
Front-To-Back Headache	35
<i>Recovery Dyskinesia</i>	37
What is dyskinesia?.....	37
A Natural History Interlude.....	42

The Three types of Dyskinesia.....	43
Adrenaline-based Dyskinesia.....	43
A Non-medicated Combination of Shakes.....	44
Medication-based Dyskinesia.....	45
Recovery Dyskinesia.....	47
Face.....	50
Vision.....	50
Neck.....	51
Shoulders and arms.....	52
Hands.....	53
Chest.....	53
Breathing problems.....	53
Abdomen.....	57
Buttocks.....	57
Legs.....	57
The Back.....	58
Summary.....	59
Questions from Patients.....	61
<i>LATE STAGE</i>	62
Decrease in Adrenaline.....	62
“So What?”.....	62
Panic Attacks.....	63
Arm Pain.....	66
Vain about Veins.....	67
Sleep.....	68
“I’m so tired. I’ve never felt anything like this before in my life.”.....	68
The Speed Up.....	77
Medication.....	77
Tremor.....	79
Reappearance of old habits.....	80
Lastly, It’s BACK!.....	81

INTRODUCTION

Greetings!

This chapter, a subset of the larger work, *Recovery From Parkinson's, A Practitioner's Handbook*, is designed to also stand alone as a handbook for patients who are going through the various stages of recovery from idiopathic Parkinson's disease. Every practitioner should make a copy of this chapter and provide it, free of charge, to every new patient, and the patient should be required to read it before beginning treatment. In our clinic we require that the patient sign a statement attesting to having read this Patient's Handbook.

This work is still in its infancy. Because of the eventually debilitating impact of this disease, we want to share our experiences, findings and hypotheses in the hope that our colleagues' patients might also benefit.

However, until we have several years of follow-up on our Parkinson's disease cases plus independent evaluations by conventional western MDs confirming that symptoms have indeed abated, all practitioners and patients must understand that the treatments proposed by the Parkinson's Disease Treatment Center are entirely experimental and unproven. Until further research confirms the events and causes of the events which occur during recovery, the hypotheses proposed herein are unproven.

This handbook was collected from the weekly reports of patients who were undergoing treatments. We have assembled selections from these reports for the benefit of other patients who are undergoing the same treatments. We are including questions from patients from around the world which have been sent to our clinic. A few questions are composites, as we get the same questions over and over, but the phrasing of the questions, for the most part, is taken verbatim from our correspondence.

In the handbook we make hypotheses as to the causes of these symptoms. These statements are hypothetical, and unproven using western methods. However, the hypotheses may well be accurate, and at any rate they so far fit neatly with what we have actually observed in years of clinic. Even if they are at some later date proven to be inaccurate, they are the best hypotheses to date in terms of making sense of processes of recovery from Parkinson's disease. Please make an effort to understand just what is going on. If you truly grasp the principles involved, you can anticipate or make sense of the otherwise bizarre symptoms which occur during recovery. This handbook is not a complete roster of all the symptoms which might occur. Each patient has his own unique variants of the symptoms. But if you understand the principles we are working with you will see that even the most unexpected symptoms may actually fit into the pattern of gradual, steady recovery.

How are acupuncturists licensed?

In the United States acupuncture is regulated state-by-state. In some states acupuncturists are considered to be physicians or primary care providers. In other states their status as health practitioners is somewhere below that of a primary care giver. In still other states, acupuncture is not yet legal. In one state in the United States it was determined, in 1999, that "acupuncture is not medicine," therefore acupuncturists are not practicing medicine without a license, and

therefore need no licensing whatsoever. Also, Yin Tui Na, a form of light-touch energetic body work distantly related to massage, which is the backbone of the treatment, need not necessarily be performed by an acupuncturist, but can be done by anyone with training in light-touch energetic body work. Since a combination of practitioners may be working on a patient, I use the word "doctor" or "practitioner" to refer to the body worker, Yin Tui Na specialist, or acupuncturist who is performing the treatments for Parkinson's disease as developed by the Parkinson's Recovery Project. When referring to an MD I use the words "prescribing physician" or "neurologist," or, of course, "MD."

Disclaimer: Please understand that the use of the word "recovery" in this handout is not a guarantee that every person with Parkinson's who is treated with acupuncture and the other treatments described will respond in the same way, in the same time frame, or even respond at all. Parkinson's disease and Parkinsonism are names for a group of symptoms which have various causes. **Our work is on Idiopathic Parkinson's disease.** Most types of idiopathic Parkinson's disease, the most common form of Parkinson's disease, **seem to respond** to the specific massage and acupuncture techniques described in the Practitioner's Handbook. The use of the word "recovery" in this handbook refers to the events which can occur when the appropriate, specific form of treatment is applied to these specific types of idiopathic Parkinson's disease. The Parkinson's Disease Treatment Center does not use the word "cure," nor are there any guarantees that all persons with Parkinson's disease will respond to the treatments developed by the Center.

(overheard in clinic)

“But didn’t you read in the handbook that these things might happen to you? Why are you so shocked and outraged by what’s going on?”

“Sure, I read the book, but I assumed these things wouldn’t happen to me.”

PREPARING YOURSELF FOR RECOVERY: READY, SET, WAIT

This will be easy, right?

Recovery from Parkinson's disease can present a bewildering array of symptoms which are very different from the symptoms of Parkinson's disease itself. People often confuse the improvements or symptoms of *recovery* with the continuation or increase of the original symptoms. The better educated you are about idiopathic Parkinson's disease, what may cause it, and how it may have developed in your body over time, the better prepared you will be to make sense of the *reversal* of these symptoms. In this hand-out, you will learn about some of the ways that your symptoms may change during recovery.

Your acupuncturist, or a person trained in Asian medical theory, should be happy to explain to you the likely cause of Parkinson's disease and the thinking behind the treatment approach.

Do not expect an overnight cure. Recovery from Parkinson's disease means restoration of all the tissues that have been damaged during the decades of illness. This is very different from taking a pill which ameliorates symptoms. The treatment duration will vary from nearly one year to several years, depending on the individual case. Factors influencing prognosis (length of time of recovery) include the type of Parkinson's disease being treated (Simple or Complex, which depends on the original cause/s), complications of additional illness, and the degree of physical degradation present. Although "months" and “years” may sound like a long time, remember that your Parkinson's may have been developing during a period of up to six decades, most likely since childhood. Dozens of months are small in comparison! And you will notice encouraging signs and improvements very early in your treatment. Please keep these improvements in mind when the difficult stages appear, and try to make sense of your changing symptoms by asking questions of your doctor. Let the brief descriptions presented here of some of the experiences of others help guide you through your own process of recovery. Remember, though, that not all of the stages presented here will occur in everyone. You may have some but not necessarily all, and they may occur out of the order described here. Use this guide as an aid in your understanding of the possibilities. Don't be discouraged or fearful. Know that others have gone this way before. And always talk with your doctor about your progress.

As an additional aid, many patients have found that it helps to keep a daily symptom diary, and share the diary with their doctor. The recovery process can sometimes proceed with alarming swiftness. It is not a jolly, painless process. Once the recovery processes have been set in motion and have achieved a certain momentum, they cannot be turned off. The body will restore proper function as quickly as it can. The sensations which accompany treatment of Parkinson's disease have been compared to those of being on a roller coaster and may be hard to keep track of mentally. On some days during your treatment program you may feel fairly stable. On other days surprising changes may occur. Some days the old familiar Parkinson's symptoms will be dominant. On other days, if those symptoms appear to be gone, a cheerful optimism may

pervade. On still other days, erratic new patterns, just the opposite of the old ones, may suddenly occur. On yet other days, it may seem that a combination of everything is happening at once: old symptoms, new symptoms, combined with new vigor and mobility or aching and fatigue. It is easy to become alarmed at the seeming randomness, to lose sight of the goal and to disbelieve the steady, regular improvements. The diary may become your best reminder of how much you have progressed.

Remember, every recovery is unique. **You will not have *all* of the symptoms discussed in this writing.** Please do not be disappointed if you do not have the full array! Some recoveries are fairly uneventful. In general, the younger the patient, the more vigorous and intense are the recovery symptoms. In an older patient, with advanced Parkinson's disease, the recovery will be more gradual, and the intensity of the recovery symptoms will be greatly diminished. Many of the very powerful symptoms of late-stage recovery, including the relaxed-state dyskinesia, will be quite gentle for older, weaker patients. It seems that the recovery usually follows the maxim "the body will recover as quickly and as energetically as the individual can bear." Trust your own body to know just how fast and how energetically it can recover. It may be hard to trust a body which has seemed bent on betraying itself by being unresponsive for so many years now, but in fact, once the impediments which caused the Parkinson's disease are gone, the body will be eager to restore itself to proper functioning.

Please let your neurologist know what you are doing. Keep everyone informed. There will be stages when you may want a mild muscle relaxant when the nerve repair to long-unused muscles sets in, causing episodes of muscle tension. Some patients find that the muscle tension is best relieved by Epsom salt baths.

Your acupuncturist, unless also a licensed MD, will *not* give advice on medications. When you feel that you should reduce your Parkinson's medication, you must work with your prescribing physician. Hopefully, your various health care providers will work together on this to maximize your quick, successful recovery.

A Quick Review of Parkinson's Disease

During the gradual, decades-long development of Parkinson's disease, many subtle physical degradations occur in muscle and nerve tissue. They happen slowly, and are usually unnoticed. Though they are worse in the extremities, they also occur over the face, neck, and in a wide swath over the muscles that run down the chest, in the line from the collarbone to the pubic bone, and from there over the lateral muscles of the legs (p. 39, fig. 1). In a majority of cases the degradation also occurs in a line from the hand to the shoulder (p. 40, fig. 2).

The results of these degradations include the following:

- 1) Capillaries (smallest blood vessels) slowly die back. For an example, look at the blood vessels in the arch of your foot, and you may see the discoloration and large blood vessels which indicate the poor circulation in this area. The palms of the hands may also be more mottled than they should be. These are some easily visible indicators of system-wide capillary change.

2) There may be increasing numbness throughout the affected areas. The nerves in certain areas have become dormant, though they are not dead. Most people with Parkinson's disease do not suspect the extent of their numbness. When sensation begins to return they are shocked to have return of awareness in areas which they didn't know were numb.

3) The muscles in the affected areas may receive irregular, weak stimulation, if any. This is different from the obvious lack of conscious motor control. This is absolute weakness, such as may be seen most easily in the sagging facial muscles. There is a misconception that, since the muscles are rigid, they are strong. In fact, they are both rigid and *weak*. They may have not been used correctly for years, and have not received normal nerve stimulation for decades.

4) The midbrain may undergo myriad changes. The most studied of these are the dopamine and dopamine receptor changes, but there are dozens of other chemical and electrical processes which have also altered through the years and are no longer in optimal condition.

During recovery your body will be repairing all four areas: blood vessels, nerves, muscles, and brain tissue. This is a big order for an adult body. So eat right and get plenty of rest. Then start to notice how your body is changing in subtle ways as you recover from Parkinson's disease.

Cycles of Good and Bad Days

Keep the roller coaster image in mind. For six months I was baffled by a strange phenomenon. At the end of a day, sitting around the dinner table, I would mumble, "I had a really discouraging day. Every single one of my patients was much worse than last week. Every single one. Maybe I'm making them worse? Maybe I should abandon this project..." But then, the next week I would find myself announcing proudly, "Every single one of my patients took tremendous strides forward this week! I think I'm on to something!" Time passed. I would find myself again muttering, "Everyone was worse this week. Every single one. What am I doing wrong?"

My teenage son caught on before I did. At dinner one evening, between mouthfuls, he noted, "Every week everyone is the same. Either they all get better, or they all get much better, or they all get worse. Either you must be exaggerating or there's something going on. It's not reasonable that a dozen people would all be in sync by chance." I went back to my calendar. Sure enough, about twenty three days earlier, everyone had had a horrible week. Twelve days previous they had *all* been doing better. I checked the month before that. The patient charts were full of synchronized quotes along the lines of "I'm really much better this week" followed eleven or twelve days later with "I'm going backwards. Just when I thought I was doing well, I suddenly got much worse." I checked the charts for the approximately two week intervals. It had not been my imagination or exaggeration. Patients were in fact having synchronized reports of big improvements or big setbacks, and the pattern, stretching back for half a year, seemed to have a twenty three day cycle.

The swings can be quite dramatic. As an example, during an "up" swing in the cycle one patient reported, "Last week, for the first time in five years, I went for a walk without my walker. I went a tenth of a mile. It was incredible. I've felt great for several days. I'm getting ready to

get rid of the walker!" Twelve days later, the same patient reported, "Yesterday, my feet stuck to the floor and I literally couldn't move. That has never happened to me before. It was absolutely terrifying. I could not lift my feet. It was like that for 90% of the day. It was the worst Parkinson's day I've ever had in my life. I had thought I was doing so well..."

Also, it seems as though the swings are not all of the same intensity. For example, in August of 1998, there was a week in which people felt that they were worse than they had ever been in their LIFE, no matter what stage of recovery they were in. In January of 2000, there was a three day period where everyone was in deepest despair over the intensity of the seeming setback. During this super-low, a woman who had nearly recovered suddenly had three days of uncharacteristic tremoring and immobility. It was gone in a few days, but it had been terrifying at the time. It is very helpful if your practitioner is working with a group of PD patients, rather than just one, so that you may compare your ups and downs, or else you may be utterly discouraged by these swings. On a more upbeat note, these more intense swings are usually followed by a very long period of many months in which the up and down swing pattern is quite mild. And despite the days of super-lows, the over-all direction is one of slow, steady recovery.

Although everyone feels bad to be going through a horrible time, a seeming setback, the patients are relieved to hear that everyone has bad weeks at the same time. "Did the guy who was just leaving have a really bad week? Good! Me too. I'm just glad I'm not the only one, it's so much easier, knowing that we're all going through the same thing...that I'm not the only one."

Other sources of variations in symptoms

Another source of seeming setback can be anyone of the following events. It appears that the following can all cause depletion of dopamine at a very deep level which lasts longer than the period of the actual event, so that it may take a week or even a month after the event has passed before the patient feels back on track. The following circumstances appear to cause dopamine to be used in higher quantities. Try to avoid the following types of circumstances:

- 1) Any flu or illness. Even when the illness has passed, the PD will be much worse for up to several weeks. Take good care of yourself.
- 2) Hypothermia. Getting chilled to the bone can make all of the PD symptoms erupt with a vengeance, and they may sustain their increased vigor for weeks.
- 3) Any anxiety producing event. Anything from a bit of public speaking to an anticipated vacation appears to cause dopamine to be used in higher quantities. It is possible that taking anti-anxiety drugs may actually increase your PD in the long run, however, so try not to deal with anxiety by increasing your medications.

A Question from Many, Many Patients

Q. How long will it take to recover?

A. It is absolutely impossible to form statistical prognoses at this early stage in our work, for we have treated far too few patients. However, for the benefit of those patients whose practitioners are not, in fact, doing the work correctly, and therefore not moving towards recovery, consider that there should be some signs of progress within four months. This means that there should be some lasting change in the body. There may not be any change which seems to make the patient feel better, but there should be some objective change occurring. The change

may be only in the shape of the feet. I had one patient whose feet took nearly a year of FSR, or Forceless, Spontaneous Release, the Yin Tui Na work prescribed by this text, before they were ready for needling, and before he was able to notice any other changes in his symptoms. However, after four months, he was able to move his big toe. This was significant, because when we began treatment his entire foot was utterly rigid, as if there were no joints present anywhere from the knee down. So the movement of the big toe, after four months, was a major breakthrough.

Most patients will notice greater changes than this within four months, but these changes will not be recognizable to the novice as recovery from PD. These changes will, instead, appear to be problems, such as increasing sensitivity in the feet, an awareness of heaviness in the legs, increased need for sleep, or a feeling of sadness which steals over the body. These changes, noted in the recovery handbook, are your best indications that the causes behind your PD are being affected, and are slowly being reversed. The actual symptoms of PD may not begin to change for a year or more.

What if there are no changes whatsoever in your body after four months of weekly treatments? Consider finding a new practitioner. In our clinic we have had some patients who were treated by another practitioner for over a year with absolutely no lasting changes. Within four weeks of the time that these patients switched over to our clinic, definite symptoms of recovery began to appear. Their previous practitioner admitted that she hadn't been doing the FSR, and justified it by saying that her training was in vigorous massage, and she had been substituting strong foot massage in the place of FSR, and then doing needling, regardless of whether she detected any changes in the feet. She assumed that because the patients could feel her vigorously inserted needles, the blockages must be gone. To her credit, she attended our classes several times, and read and reread the material, but in the end she could not understand why it should matter what style of Tui Na was used, nor why it should matter whether or not she could personally feel the energetics in the foot.

SYMPTOMS OF RECOVERY

EARLY CHANGES

At the beginning, following your first few treatments, you will probably not notice any changes whatsoever. While this may be disappointing to many patients, remember that it is best to move slowly and safely. Though indiscernible, subtle changes are already occurring. After several visits you may begin to notice some changes.

The Good Part

Blood Circulation

The first of the positive changes may appear as early as the second or third week. There may be a subtle warming of the hands and feet. This is due to increased capillary growth in the extremities. Many people with Parkinson's disease have noticed problems with extremely cold hands and feet, or at least an aversion to cold. As capillary growth resumes in the affected areas, carrying more blood into and out of the extremities, the temperature regulation of these areas becomes healthier. This change is subtle, and sometimes it is the caregiver who notices it when their charge stops complaining about cold feet.

In addition to temperature change in the extremities, there may be a visible change in the skin and blood vessels of the inner arch of the foot and inner ankle. The skin of the foot, with its mottled red and blue blood vessels characteristic of Parkinson's disease, will begin to return to a healthy pink. In advanced Parkinson's, when the feet have begun to look and feel like raw bread dough, a faint pinkness may appear under the skin.

The Seemingly Not-So-Good Part

The above change in the circulation may be accompanied by seemingly negative changes as well. As increased blood flow, and therefore energy, begins to move into areas long abandoned, the nerves and muscles of these areas will begin to be stimulated. This can cause what seems to be a worsening of all your symptoms beginning around the 3rd or 4th week. This is due to increased energy surges pouring into both the recovering areas and the still predominantly incorrect electrical systems in the extremities and head.

Some of these symptoms are listed below. Most people with PD are keenly aware of their personal set of symptoms, and are grateful that they do not have all of the symptoms listed in the literature. For example, someone may be grateful to have "only" tremor in the leg, as opposed to rigidity, or vice versa. However, as that body begins to recover there may be "symptoms" which are actually signs of recovery, which are new to the individual. For example, if the PD symptoms were mostly on the right, they may suddenly appear on the left. If they were primarily tremor, they may suddenly change to rigidity. If there had been stiffness, it may change to tremoring. If one had been blessed with no facial symptoms, one may suddenly develop speech slowness or some other facial pattern. Nearly anything is possible as the body begins to sort itself back out. This can be alarming to the uninformed patient. The doctor, however, will be encouraged by the strong changes that are going on, and if you have done your homework, you will be too.

The following are some very specific things which may occur as you begin the early stages of recovery. These are all *Maybes*. No one will have all of the following. Some patients may have only a few of them, if any.

Tremor

There may be changes in your tremor. There may be an increase in your in tremor. There may be a change in your tremor. There may be onset of tremor, even if there is no history of tremor.

For example, a patient with constant, low level tremor may switch over to on/off tremor, of greater, even violent, intensity. Another may have the opposite; a history of on/off tremor with varied intensity will suddenly become a constant, low level tremor. A patient with only arm tremor may switch to leg tremor, or vice versa. Or the sides of the body may switch. And, although I go into more detail on this at the end of this book, I will mention here that the tremor will be the last symptom to go away.

Rigidity and heaviness

There may be less of the functional rigidity, and stiffness. However, due to increased sensation and awareness in the limbs, there will be greater sensation of rigidity and heaviness. One patient described it thus: *"I can walk down the street twice as fast, and twice as smoothly as before, but my legs have never felt so heavy and stiff."* As increased circulation brings better nerve function, you will be able to discern just how stiff and rigid you really were. This is disconcerting, because you will notice that you are in fact moving more quickly, and friends may be remarking on how spry you look, and yet, the improved sensations being forwarded to the brain are reporting, "There was something seriously wrong here that was not detectable before! Be concerned!"

There may be change in the responsiveness of the limbs. This may manifest as looseness or slowness in the limbs. The legs may seem wobbly. If they have been stiff for a long time, you may have been using them as canes instead of as proper limbs. As they begin to relax, they will seem unsteady and overly flexible. One patient reported, *"It's as if I have to learn to walk all over again."* A word of caution: if the arm and leg movements become too loose and too erratic, it may seem that it's time to cut back on the dopamine. The incorrect thinking here is that the looseness of movement constitutes dyskinesia from too much dopamine. The appealing thought that you may be ready to reduce your medication may be premature. Or the opposite thinking may occur, that the absence of muscle control comes from not enough dopamine. In this case you will be tempted to increase your medication. In general, it is best to maintain a steady course with your medications at this stage. Wait a bit. Do not experiment with your medications without the consent of your prescribing physician.

Pain

There may be an increase of pain. Areas which didn't hurt before may become heavy, painful, or experience muscle cramps, especially the muscles in the low back and along the backs of the legs. Epsom salt baths are helpful. Massage and yoga are wonderful. Speak with your neurologist or MD about muscle relaxants. There will be a stage, later on, when the back cramping becomes quite significant.

Bruising

There may be the seemingly random appearance of painful and/or bruised areas. If at the time you injured your foot, hip, head or shoulder, which you may or may not remember, you also injured another body part, expect to feel some pain in that other body part. This will be an unfinished injury which is finally getting healed. Also, some patients have experienced bruising which they cannot explain "showing up" on parts of their body. This is also unfinished injury which is finally able to be recognized and treated by the body as brain awareness of these areas returns. These bruises are very different from fresh bruises, as they are not nearly so tender, and they go away in two or three days, instead of two or three weeks. They may be the black and blue type, or the bright red, "bleeding under the skin" type.

Emotions

There may be an increase of sadness. Sadness is the main emotion. Some patients have bouts of anxiety or free-floating anger, but the most consistent emotion is sadness. Some patients find themselves crying for no reason, others feel on the verge of tears for weeks at a time for "no particular reason." One patient reported, *"If I watch the evening news I burst into tears. It just seems so sad, all of a sudden. I was even crying at 'Oprah' the other day!"* This is very different from depression, which is associated with hopelessness and a slower metabolism. This is pure sadness. Although most patients will be aware of this profound sadness, a few are not. One patient responded, *"Why do you keep asking about sadness? I'm always a very cheerful person. I'm never sad...although I have noticed that the last two weeks I wake up from a sound sleep with tears streaming down my face, for no reason at all."*

The sadness does not seem to be coming from logical emotion. It is just as if a vat of overwhelming, non-specific sadness was dumped from nowhere. It may last for many weeks. Some patients and caregivers confuse this with the depression which is sometimes a symptom of Parkinson's disease and worry about decline in mental state. If you are aware of the near universality of this "recovery sadness" you can appreciate it as a sign of good changes on the way.

Questions from Patients

Q. ...also, it says in the handbook that my feet will get warmer. This is wrong. I never used to have any feeling in my feet, but now they are freezing cold. They also hurt. Why do you say that the feet will get warmer, when they get colder.... Am I getting worse?

A. No. Your feet, and consequently, the rest of you, is recovering. As the circulation returns to your feet, the long dormant nerves are coming back to life. You are able to feel your own feet again. And they are cold. Not as cold as they used to be, but they are still colder than they should be, for it will take many, many months to completely restore the circulation to your feet to the point where they are warm most of the time.

I read in your letter that for nearly twenty years your feet have been purplish gray in color, and icy cold to the touch. You note that first your wife, and then your caregiver, often complained and worried over them. And yet, during this time, you never complained of cold feet. Now, suddenly, your feet are improving in color, they are nearly pink in some areas, and they are much warmer to the touch. However, your caregiver is surprised that you are now constantly complaining about how cold your feet are.

What has happened is this. As circulation begins to be restored to the feet, your feet are warming. This warmth is awakening the dormant nerves. The nerves can tell that your feet are still a bit on the cool side, and so you are now complaining often of cold feet, even though the actual temperature of your feet is much warmer than it has been in years.

I have heard this from so many patients with regards to cold in the feet, hands, head, knees, or various body parts. Also, I have gotten the same question, only with regards to new aches and pains, at various points of the body. Your example, though describing feet, might be considered to apply to all the various parts of the body which have been affected by PD. If you understand the principles involved, and you understand that you were numb for so many years, you will be able to see that your new aches, pains, and sensations of cold or warmth are wonderful heralds of returning life.

Q. I've had six treatments, and I'm noticing strange things happening in my feet. Sometimes they will suddenly feel cold, like coolness moving through my feet, and I realize that I have more feeling in my feet than before. And then, maybe a minute later, they will be flooded by warmth. This cold, followed by heat, has happened several times. Why aren't my feet staying warm?

A. Your feet are beginning to behave normally. After years of poor temperature regulation, maybe even Reynaud's syndrome in the feet, you are beginning to be able to regulate foot temperature. When you register coolness in the feet, your body will now increase the blood supply so that your feet warm up. Eventually, it will be so routine that you will not notice it. The reason that you are so keenly aware of your feet is that you have been more numb than you realize for many years. Your body will soon adjust so that your conscious brain is not bothered with the otherwise automatic adjustments in circulation.

Q. During today's treatment I became aware of a difference of feeling in my left, so far, untreated leg. It felt more tense and heavier than the other. Why should I feel this in my good (left) leg, and feel nothing in my PD side (right)?

A. Although "Qi," a Chinese word, refers to all the wisdom, matter, and energy of creation, I am herein referring only to Channel Qi, the continuous electrical microcurrents which direct cell growth throughout living organisms. The (channel) Qi which is beginning to run in the legs will run the same in both legs. This is one of the wonders of the body's electrical system: electrical currents run somewhat symmetrically even when the physiology is not parallel. In other words, if Qi can be restored in the right leg, it will instantaneously begin to run in the correct pattern in the left leg, as well. In your case, what is happening when this Qi begins to run? The leg which is less damaged, and which therefore has some remnant of nerve sensitivity remaining, will be the leg which first feels the changes which are occurring. Both of your legs have become damaged, over the years. The more damaged one is more numb than the less damaged one. This explains why most patients feel the recovery symptoms - which are often unpleasant, as you've noticed - more intensely in the healthier leg. Eventually, the weaker side will begin also to experience these symptoms of recovery as the sensory nerves are awakened from their dormancy.

SECOND STAGE

The Good Part

Warmth

There may be increased circulation in other areas of the body. In the early stage there was return of circulation in the extremities. In this second stage, other areas of the body may begin to experience increased circulation, which brings with it new warmth or even hot flashes. Usually these are areas which were never perceived as cold, because of the absence of functioning sensory nerves in the area. One person, who had never noticed coldness in the face, described it as feeling like a *"pilot light glowing deep in the cheeks, and the next week there was faint warmth spreading over the cheeks. After two weeks there was consistent warmth in the face. It feels great, I love it!"*

The Neither Good Nor Bad Part

Tingling

There may be tingling in the skin. These sensations of faint tingling, which may be either painful or pleasant depending on the individual, may occur anywhere along the line that runs over the body from the lower eyelid down the center of the cheek, past the corners of the mouth, down the front/side of the neck, over the collarbone, down the chest, through the nipple, down to the pubic bone over to the side of the hips and down the front/outside of the leg, over the top of the foot and all the way down to the big, or first, toe, and the second and third toes. The second line runs up the arm from the thumb to the front of the shoulder. (See pages 39 and 40, fig. 1 and 2.)

These tingling sensations are due to the return of stimulation to the sensory nerves which have been damaged or weakened due to lack of circulation. This tingling can be unsettling. The sensations have been described by patients variously as: *"...a warm golden glow, tingling and sparkling over my face and foot. It felt touched by God;" "It felt like spiders crawling over my neck for a few minutes at a time, several times a day for two days;" "There was a sweet tingling over my face and lips for two hours last night;" "It feels like a rake being scraped gently over my foot;" "My toes were tingling all night, I couldn't sleep;" "I felt pins and needles all through my scalp;" "I felt horrible pins and needles in my feet" (or hands, and various body parts); and finally, "It was horrible, it was like recovering from frostbite, a horrible stinging, and it's gone on all week, oh! It hurts so much."* The patients have reported everything from "wonderful tingling" to "horribly painful stinging."

There may be sharp sensations in the feet. These sharp sensations may occur especially in the soles of the foot near the big toe. This is an area which has probably been slightly numb for years, and as sensation returns, there may be some pain. It may come and go, and it may be sharp, like a pin prick. Then again, the sensation may be pleasant, instead of painful. One patient experienced good feelings in the foot. He reported, *"It felt like someone was massaging the underside of my right foot. It went on for several days."*

This sensation of tingling, ants under the skin, or spiders crawling over the skin may occur again in later stages of recovery. It may occur on the scalp, the arms, the torso, the hips,

and the legs, in addition to the feet. Every time you regain sensitivity in a new area there may be several weeks or months of this. You may have tingling in these areas during the earliest stage of recovery, and then again, during the later stages, it may occur again, with greater intensity, as you develop more acute sensitivity in the nerves.

Sleep

There may be an increase in the need for sleep. The need for sleep increases during this stage, as the body is actually regrowing various structures. The tiredness is sometimes accompanied by a refreshing *ability* to sleep. If your Parkinson's disease was at the stage where sleep was becoming difficult, it can be a wonderful thing to suddenly be able to sleep again. This restoration of deep sleep patterns is a refreshing surprise. Patients have said, "*I'm sleeping so well, I'm ashamed of myself!*" and "*I used to feel so stiff, and couldn't ever relax enough to sleep very well. We even bought a new mattress, but nothing helped. Now I could lay down on a gravel driveway, and I'd sleep like a baby!*" It seems to be reminiscent of that period of tremendous growth during the teen years, when sleep is so desirable and important for the growth process.

Heaviness and Rigidity

There may be an increase of the sensation of heaviness. For example, although the face may have been sagging for years, you will not have had much sensation associated with it. As you recover sensation in the face you may notice that your face feels almost painfully droopy, as if it is heavy and lifeless. This is not an increase in "the mask," but merely your renewed ability, long absent, actually to feel and be aware of the sensation of your own weakened face.

The same feelings of heaviness may occur in the neck or chest muscles, the abdomen, or the legs. This is not an increase in actual heaviness. This is an increase in *awareness*. The nerves which convey information back to the brain are working correctly again. You can finally begin to acknowledge the true extent of your body's damage during your Parkinson's years.

Questions from Patients

Q. After each week's treatment I feel more at peace with my body, with no awareness of symptoms at times when in a relaxed position. For a while after the treatment, I have felt more buoyant which seemed to be at least in part due to the feeling of moral support and collaboration. But it doesn't last. Is my practitioner doing something wrong?

A. There is nothing in the Recovery Handbook about feeling particularly good after a treatment. Most of the significant symptoms which you should be on the lookout for are the fairly unpleasant things: feeling of bugs crawling under the skin, burning pain, rhythmic recovery dyskinesia, etc. It is, of course, a wonderful thing when the supportive environment and manner of the practitioner augment the treatment with a residual feeling of peace. However, this is a superficial feeling, and no indicator that your Parkinson's is going away.

As an aside, many acupuncturists, especially those trained in China, treat Parkinson's disease using a form of "scalp acupuncture," which was determined to be the politically correct way to treat Parkinson's disease in China in the 1970's after PD was determined –in the west-- to be (erroneously) a disease of neurological origin. The Chinese medical establishment, long regulated by the government, has always taken care that Chinese medicine be acceptable to the west. Several times, in the past 150 years, acupuncture has actually been outlawed in China

because it conflicted embarrassingly with “modern,” western medicine, and the practice of acupuncture was considered to cast a pall of old-fashioned, non-scientific superstitiousness over the Chinese political image.

Scalp acupuncture primarily creates a temporary (one or two day) feeling of decreased anxiety and decreased tremor – similar to the feel-good sensation that you are experiencing. There is nothing wrong with feeling relaxed and less anxious. However, scalp acupuncture does not treat the underlying cause of PD. If it did, Chairman Mao Tse Tung would not have needed to endure his own debilitating case of PD. Scalp acupuncture merely makes the patient feel better for one or two days following the treatment. There is a concern, not proven, that because scalp acupuncture stimulates the *incorrectly* flowing Qi on the head, as well as relaxing the patient, it may actually speed the development of PD. A few patients who tried scalp acupuncture before coming to our clinic expressed the opinion that the scalp acupuncture, over a period of many months, actually worsened their PD. Objectively, this is impossible to evaluate, as PD is a constantly degenerating condition, and one cannot know how fast the condition would have deteriorated with or without the scalp acupuncture. As for the temporary good feeling and temporary cessation of tremor, those two things go together. Anything which reduces anxiety will temporarily reduce tremor, and so in this way, as a short term relaxant, scalp acupuncture continues to be used as a short-term treatment for PD symptoms.

Q. Janice, you are wrong, I’ve never had numbness in my feet from PD. I would have been able to tell if I were numb, because I’ve had frost bite once when I was a child, and I could feel it.

A. True, long-term numbness has no feeling. A person with deep, long-term numbness cannot feel that there is numbness, because there is no longer any awareness of the area. The pins and needles which occur in the recovery from frostbite, for example, are not the pain from cold and numbness, but the pain of recovering from numbness. You may be thinking of short-term numbness, such as the heaviness which occurs when your hand falls asleep, or some other short-term numbness which comes on relatively suddenly. This type of numbness can be differentiated in the brain from the normal sensation. But true numbness which develops over decades has no sensation, and there is no awareness of the numbness.

I have watched many people go through recovery and the return of sensation. They are usually amazed at being able actually to feel the inside of their shoes, they marvel at the feeling of fabric of their sock on the skin of the foot, and in so many ways they are able to realize that they were, in fact, numb, although they had no idea of it at the time. There are many patients who are aware that their legs are increasingly numb, that their legs are like wood. These patients often feel sporadic pain in the feet, or legs, but most of the time feel only heaviness. So they are certain that they have feeling, but that the feeling is one of heaviness. When true sensation and muscle use returns to the feet and legs, they are able to understand that what they had been feeling before was not true sensory nerve feeling.

Q. I’ve been experiencing pain in my feet at night in bed and a burning sensation in my feet and ankles. You had said they might get warm, but they are burning hot. This interferes with sleep which is marginal at best. I thought that having painful feet was a good sign, but I simply am not showing any signs of improvement.

A. But you *are* showing signs of improvement. If you are hoping for smoothness of movement and better sleep and needing less medication, you may still be six months away from

those preliminary “signs” of impending recovery. Please understand the enormity of what you are doing with these treatments. You are reversing an electrical pattern which has been in place for possibly (you did not state your age) forty years. At this point, you are beginning to have enough life flowing through your feet that the nerves are waking up. This is incredible, if you stop to consider all of the processes which must occur for this to happen. First, the blockage which was preventing electrical flow has been removed. Then, current has to make a new pathway through your foot. This is like trying to carve out a new river in a flat mesa, using a garden hose. However, the power of the body to right itself is so powerful that the currents will, in much less time than they took to degenerate, reform themselves anew. After these currents are flowing, their electrical pattern will cause the surrounding cells to divide and grow in such a way as to build a restored circulatory system. This is an enormous task, requiring good nutrition, rest, and the removal of the old, incorrectly patterned cells. After the circulation begins to be restored, the nerves in the area will slowly begin to function. At this point, you are still a long way away from diverting the flow of energy from the head where it has been creating the chaos in your substantia nigra. The flow of electrical current through your foot is still but a trickle of what it should, and will soon, be. But until the foot is so restored that 100% of the current can run through the feet instead of diverting, even partially, through the head, the Parkinson's disease electrical process will continue.

And yet, the feet will begin to feel pain. Every stubbed toe, every sprained tendon in the foot which was ignored because of the decades-old numbness in the feet will be discovered. Every insult which the feet have received during their long period of numbness will be found out by the recovering nerves. There may be some fantastic injuries, and you may begin feeling all of them at the same time, or they may be discovered by your foot nerves over a period of many months. At any rate, they will hurt. The pain signal from the feet to the brain will cause the body to set in motion the required healing activities. This is the very thing which, had it occurred decades earlier, might have prevented the PD from ever developing. So be patient, and abide or even rejoice in your new ability to experience the pain which exists in your foot.

This Question and Answer could easily apply, in addition to pains in the feet, to pains in the leg, thigh, hip, torso, face, neck, arm or any place on the body which had become numb.

MID-STAGE RECOVERY

Unexpected difficulties

Again, all of the following events may or may not occur. The order of appearance of these symptoms is not predictable. The duration is variable and depends on the patient's age, medications, years elapsed since diagnosis, physical condition, and degree of physical degeneration. The following symptoms in this section may appear alongside the early-stage symptoms. They may occur late in the process, or they may never occur at all. It is merely to help the recovering patient realize that he is not alone that information about these symptoms, along with suggestions as to their causes, has been included. Do not try to determine too closely what stage of recovery you are in by observing the order in which you have or do not have the following. Because the most throbbing question that all recovering patients have is: "How long will this take?," I answer here, "Much longer than you expect." Please remember, when it says in this book months, it actually means months.

How many times have I seen a patient who is chafing at the bit, who exclaims to me, "I'm just the same as I was a week ago! What's going on? When will these crazy symptoms ever go away?!"

I usually answer, "What did I say last week?"

To which the patient usually replies, "You said it would take months."

"So," I continue, "how long has it been?"

The patient, puzzled, says, "A week."

At which point I gently say (and I truly do this every single week with some people), "When I say months, I mean months, not a week."

"Oh."

Red Rash

At least ten percent of patients have experienced a rash or group of sores which breaks out on the foot, ankle, and, rarely, even as high up the leg as the groin. It appears as if there has been some fungal, bacterial or viral growth existing in these areas preceding the onset of treatment. Many people with Parkinson's disease have poor circulation in the feet and legs, and at least half of our patients have some amount of toenail fungus.

During treatment for Parkinson's disease most cases of toenail fungus slowly begin going away. After several months (or in some cases, years) of treatment, the new toenail growth slowly becomes visible, beginning at the cuticle. We assume this lessening of the fungus and the resumption of healthy toenail growth is due to increased circulation in the feet following the FSR and needling. With increased circulation comes an increase in blood flow and immune system function in the toes, which allows the body to perform its natural process of detecting and killing the fungus. Prior to treatment, while the feet had relatively poor circulation, the body may have been unable to detect the fungus, or may have been unable to combat it.

As for the rash, it can appear as a ring around the ankle, a saddle over the foot, or it may even appear in patches, several inches across, up the leg. It can have oozing sores, or it may be just itchy skin. We suspect that this is caused by the body suddenly being able to detect and fight the infectious agent which has been grazing happily off of tissues with poor circulation. The agent, previously living out its merry life as a free-ride passenger in the unsuspecting (because of poor circulation) foot or leg, now swings into action to save itself from the immune system. The

pathogen does two things: it becomes engaged in battle with the body's immune system, and it desperately tries to reproduce before being annihilated. The heat and itching in the area may be from the immune response creating inflammation. The desperate attempt at reproduction might account for the explosion of sores on the surface (fruiting bodies, if a fungus, or departing viruses or bacteria, if that's what it is).

Patients' MDs have examined these rashes and sores and announced variously, "It's an infection, use antibiotics;" "It's static dermatitis, use cortisone;" "It's from dry skin, use lotion;" and "It's a fungus, use any over-the-counter athlete's foot medication."

Patients who have used the anti-fungal preparations have had the best success. How long before it's gone? It appears to require from several months to over a year for the inflammation to recede.

If you are concerned about the red rash showing up on your foot, ankle, or leg, please, of course, have a dermatologist look into it. If you are trying to find a way to put a positive face on this itchy, bothersome annoyance, consider this: If there was an infectious agent lurking just under your skin, it is significant that your body is finally able to recognize the fact and summon up whatever forces it needs to battle it and conquer it. If nothing else, you can use this as a visible, tangible sign of the changes going on under your skin.

Weak muscles

Although it has already been mentioned that the muscles will become weak, patients are so alarmed by their increasing weakness that this section is included here to expand on that theme. Again, the hard muscles of which so many Parkinson's disease patients are so proud, imagining as they do that these rigid areas are "good, firm muscle," are actually diseased, non-functional distortions of healthy muscle tissue. This rigidity of these tissues is more akin to rigor mortis, the frozen immobility of dead tissue, than it is to healthy, flexed muscle. Please understand this. You will save yourself much heartache if you spend some time, before you even begin getting treatment, familiarizing yourself with the muscle problems in your body. Although the muscle problems may be present in the arms, chest, neck, and legs, it is easiest to feel in the legs. I will refer to the legs throughout this section, but please understand that this may occur in the arms as well.

Now. Feel the consistency of the muscles which run down the lateral (outside) of the leg with your hand. Note how hard the area is. Poke it with your fingers. Notice that it is stiff as a board, regardless of what your medication is doing. Notice that when you try to isolate and tense those muscles nothing happens. Those muscles do not work. This is different from the lack-of-dopamine induced inability to move. That, as you know, is a feeling in the brain that you just cannot bring yourself to command your body to move. But the muscle situation in this very specific area, along the lines of degradation, is unique. To prove to yourself that this area is different, try poking the muscles on the (medial) inside line running down the leg. See how these muscles have more feeling, and are more pliable? Good. You must understand that you do not have functional muscle along the outer leg, or you will be alarmed, depressed, and even despondent when these muscles begin to recover.

Here's what appears to be happening. Although it would be very wonderful if the muscle tissue in the legs could slowly come back to health upon being reawakened by the new electrical patterns which your acupuncturist is building in your legs, that is not the way it works. Do not imagine that your legs will go from rigid, distorted tissue, straight into vibrant, muscular tissue. Instead, here is what will happen. The rigidity will begin to go away. This means that the areas

along the leg will begin to soften up. This means that if you were previously using this hard area as a sort of splint or stick to brace against with your other muscles, it will no longer serve this function.

How many patients love to show off that they go up the stairs two at a time, as if this is somehow proof of their legs still being muscular! *This is not muscle strength.* This is taking advantage of the wood-like rigidity of the muscle tissue in the legs to push off against so that going up stairs becomes a push and hoist process, rather than a natural, quadriceps tensing activity which a healthy person uses to go up stairs.

When the diseased muscle tissue begins to break down, suddenly you will not be able to go up stairs in the old way. You might not be able to go up stairs at all. You might not be able to stand up from a chair, or from the toilet. You might have trouble performing any action which requires pushing against (your Parkinson's pattern) or flexing (the correct pattern) the quadriceps muscles. (Or the arm muscles, or the sides of the calves, or the thumb and forefinger grip, or the front of the shoulders, or any area which had begun to be rigid.) This will be alarming. If you are taking medication, you may find yourself doubling or tripling your medication, to no avail. That is because *this is not being caused by lack of dopamine.* This is being caused by your body not having any firm, healthy tissue in the area which it is trying to stimulate.

The next traumatic realization is that this area, long rigid, long numb, seems to have no relationship with your brain. It will seem as if this area is not responsive to brain signals. You will struggle to tense these areas, and nothing will happen. Your body has not actually used these deathly, rigid muscles in years, maybe decades. You will not actually have a way to access these muscles. You will imagine yourself to be very weak.

I cannot overemphasize enough how panicked most patients become when this occurs. They imagine that their body is falling apart. In fact, it is reassembling itself. What will happen is that slowly, the body will break down the worthless, rigid tissue in the affected areas. These areas will become softer and the rigid tissue smaller. Next, the body will slowly begin growing healthy muscle in these areas. Over time--- a long time--- the body will learn how to use these muscles again.

It is often at this stage that the patient demands to know just how long this is going to go on. There is no easy answer to that. Some recently diagnosed patients have gotten through this stage in several months, with the worst of it being over in several weeks. One patient who was diagnosed with PD over twenty years earlier, in his forties, was in the "too weak to move" stage for over thirteen months. It is partly for this reason that patients who are in care facilities or who can barely move as it is are not good candidates for this program. During this time you may need constant help in getting up off the side of the bed, getting dressed, feeding yourself, and using the bathroom. At this stage, even though you are taking plenty of medication, and are able to talk, move certain muscles and maintain posture, you will not have access to those muscle groups which are critical for raising the legs and arms.

The single best thing that you can do for yourself during this time is walk. Walk every day. Don't just walk around the house. Walk outside. Walk for as long as you can, every day. Walking will force the brain to recognize the patterning which you learned as a toddler. This in turn will stimulate the muscles which are necessary for improving your walking. This genuine stimulation of these muscles may be tiring, even exhausting. In this way you will come to realize that you were not, in fact, using these muscles when you thought you had such firm, proud muscles on the sides of your legs. Eventually, as your recovery progresses, your arms will begin to swing. Then you will notice that your arms ache. The motion of walking will propel

your arms to swing, just a bit. The muscles at the back of your arms, which have been functional all along, will be the muscles which you use, incorrectly, to form the arm swing. As you continue to recover, and the rigid muscles along the front of the arm first break down and then rebuild as healthy tissue, these budding young muscles will soon try to work as well. The arm swing, stimulated by much walking, will begin to incorporate the muscles along the front of the arm. These muscles pull the arm forward, just as the back of the arm muscles pull the arm backwards. You may not realize this, but during your years of developing Parkinson's disease, you were using the front muscles less and less, and relying on your back arm muscles to pull the arm back into a swing. The forward portion of your arm swing was actually just the reflexive swing which was caused by the back of arm muscles letting go. There was less and less true forward movement of your arms. Many people who sustained some degree of arm swing even as their PD increased, did so by using muscles along the sides of the arm. This creates the bent-arm, fists swinging towards the centerline of the body type of arm swing which develops when the body can no longer perform the true forward and backward motion of the arms.

Why I am I going into all this? Because when you begin to recover, and you begin to create new muscles in the arms, your arms will ache from walking. Just imagine, in walking for ten minutes you will unconsciously swing your arm in the new, correct way hundreds of times. This is like doing push ups on those frail, new budding muscles in your arms. You may be baffled that walking caused your arms to ache. In fact, it may take over a year before your arms have a reasonable amount of strength again, and you can walk for a considerable distance without getting pain in your arms. Some recovering patients have even found that the arm pain becomes the limiting factor during walks, rather than leg fatigue.

I cannot emphasize enough the importance of daily walks, to the maximum of your endurance, during this time when your body begins to feel like a blob of Jell-O. Please, walk.

Some patients want to know how they can tell the difference between not being able to move due to Parkinson's disease and not being able to move because of bad muscle breaking down, being replaced by new muscle. One of the easiest tests is to examine the quality of your movement. If it used to be the case that you could not turn over in bed because you were rigid, but now you cannot turn over in bed because you are limp, that is a good indication that you are recovering! Some patients describe the feeling of weakness which develops as "body turning into mush," "the life just drained out of my body" and "I'm more fluid, but I'm more weak." Please try to observe yourself carefully. If you find that you can no longer move because you have no rigidity in your body, do not despair. Celebrate! It is embarrassing, it is humiliating, and it is exhausting for your caregiver (depending on how advanced your condition was), but you are recovering. Give thanks.

Now I must also note that not everyone will be so weak as to need physical help with movement. I have had very young, newly diagnosed patients who are reluctant to begin with treatment because they fear being incapacitated. This is unreasonable. If you are still able to get around with minimal or no medication, you will not be needing physical assistance during recovery. The patients who will fare the worst are those patients whose bodies have degenerated the most. For example, if you are already in a condition where you need physical help to move during most of the day, even with medication, this stage may be so difficult for you that you must consider if you are better off *not* beginning this program, as you may be utterly unable to move for many months during this stage of weakness, and your caregivers may not be able to care for you, especially if your body is large. This is a real concern.

Swollen Ankles

This is actually a subset of the above condition. What occurs is this: the previous rigidity of muscles in the ankle area break down. Until the new, healthy muscle forms (Get walking!) the limp tissue around the ankle will not be able to contain the pressure from the lymph and blood in the area, and it will swell. Please, do not rush to take diuretics. Unless your MD says you should, for reasons of internal medicine indicating that you have a fluid/kidney problem, this ankle swelling is not a sign of excess fluids building up in the body. It is only a sign of lack of muscle pressure around the ankles due to the breakdown of previously rigid tissue. The swollen ankles will go away about the same time that the leg strength returns.

Social Smiling

“He can smile again, but he only smiles for others...never for me.” At about this time, you may notice that you are able to move a bit, when in a social situation. Unlike before, when social situations made you anxious or tense, and you felt worse, you may now find that your body creates just a pleasing, correct amount of adrenaline in those social situations. This little extra bit of oomph and motivation will create a pleasing situation. You will find that your new muscles, such as the ones used in smiling and getting up from chairs and swinging the arms actually work better when you are around others. This will infuriate your caregiver or spouse.

Caregivers have come to me in tears, and also in rage, telling me that, “After all these years of taking care of him, now that he can smile again, he only smiles for the neighbors, never for me! It has been so hard for me, having him look so dour, and now that he can smile (or get up out of a chair, or whatever), he only does it for others. I could handle the infirmity, but I am so hurt (or furious) at this, I’m ready to leave him.”

You both need to understand. The ability to perform these new jobs will be fleeting for many months, and it is not a question of will power. The extra adrenaline, which is produced by the body in a social situation, is needed in order to power you up to be able to perform some of your new tricks. This is why you will be able to show off to your doctor, your acupuncturist, or your friends, your new physical skills such as standing up or smiling. When the stress chemistry is not present, such as in the comfort of home with only a caregiver or spouse, it will not be physically possible to commit these same acts. Please, caregiver, do not attribute this to willful disregard. This is a very difficult time. In fact, for some caregivers, this is the most difficult time, because the recovery seems to be looming on the horizon, and questions abound as to the changing roles which might develop as the patient resumes healthier life. The seeming indifference to the feelings of the caregiver, as manifested by the “refusal to perform” for the caregiver, does not reflect the case. Please try to understand that stress, which includes social settings, creates a different chemistry, a chemistry which is crucial, in the early stages, to propel the wavering muscles into performing their new tricks. Please be patient.

Frequent Urination

You will notice a change in urination pattern. (Please note: You should also be aware of the importance of regular medical check-ups with regard to this area. A change in urinary patterns, especially an increase in nighttime urination, urinary retention due to incomplete voiding, or frequent urgency, all of which are discussed in the following, may be signs of other serious medical conditions, including prostate problems in, especially, older men and bladder infections, etc., in both women and men. Please seek medical attention in these cases to be sure that everything else is fine beyond the conditions described in the following.) Many people with

Parkinson's disease noticed a curious bladder propensity during the years far prior to their diagnosis. They found that it was not unusual to go for many hours, up to twelve hours or more, without needing to urinate. They usually credited themselves with tremendous bladder control, and didn't give much more thought to the phenomenon. As an example of this, the following quote is not at all atypical: "My spouse would ask me when I got home from work if I'd remembered to use the toilet all day. Half the time I realized that, in fact, no, I hadn't. I just assumed that I could hold it better than most." Another patient recalled that in his foxhole days in WWII he was able to stay in the foxhole for up to 36 hours at a stretch, holding his urine for this long, to the amazement of his fellow soldiers. The other side of this coin is that most people with Parkinson's disease, especially as the disease becomes more advanced, notice that there are days when it seems as if the bladder needs to be emptied very frequently, nearly every hour. Also, many people with advanced Parkinson's disease notice increased incontinence.

What is the reason for this strange bladder pattern? The answer is fairly simple. In someone with Parkinson's disease, the area in the low back receives a greatly reduced stimulation from Qi and is extremely poorly nourished, which leads to several of the symptoms of Parkinson's disease. First, and relating to the bladder, is that the reduction in energy in the low back reduces the vitality of the nerves in that area. The nerves which go to the bladder region, those which notify us of bladder urgency (known as stretch receptors) and also those which control the sphincter muscle at the bottom of the bladder, travel into the bladder region after emerging out of the spinal column, down at the low end of the spine. Secondly, the weakness in this area contributes to the low back pain and lumbar problems which cause such a high percentage of people with Parkinson's disease to have the lumbar vertebrae lamination surgery as their PD advances. Thirdly, this weakness contributes to the hunched posture. The hunched posture is formed not only by the tightening and rigidity of the muscles down the front of the body, but by the parallel weakening of the muscles down the back of the body. The combination of weak muscles down the back, and rigid tight muscles down the front makes for the increasingly bent back, neck and shoulders in Parkinson's disease.

But looking specifically at the bladder weakness, many people have asked why weakness in the bladder nerves would contribute to the ability to hold the bladder so well, for such long periods. It is because some of those nerves are signal-senders to the brain. Because the brain is not able to tell intuitively if the bladder is full or not, the brain relies on getting a definite signal from the stretch receptors, the full-bladder nerves. If that signal is weak, the brain will not get a firm message that there is a need to empty the bladder. During the years while the PD develops, the full-bladder signal nerves are not working very well. Consequently, the brain does not receive a strong signal. Often, even if a signal does come through, the signal is weak enough that it can be ignored. If this full-bladder nerve is among the nerves which are being effected by low energy in the small of the back, the person will not get very strong signals about bladder urgency. Through the years the bladder may even become enlarged due to holding such huge amounts of urine for long periods of time. This so called "strong bladder" is not something to be especially proud of; it is actually a case of poor nerve messaging.

The opposite can also occur. Every now and then, due to some low back irritability, there may be more sensation in the full-bladder nerves than usual. On these days, the person may find that extremely frequent trips to the toilet are necessary. The amount of urine is not large, but the brain is receiving, on these days, a much higher than usual number of signals from the agitated nerve, telling the brain that the bladder is full.

If the small of the back weakness effects the bladder sphincter nerve more than the bladder fullness nerve, there may be the opposite problem. There may be some incontinence as the sphincter muscle lets go now and then, randomly.

What happens during recovery? The nerves begin to function again. This sounds good, doesn't it? You shall see. Prior to recovery, most people with PD have relied on a feeling of pressure in the abdomen, rather than a signal from the stretch receptors in the bladder, to know when the bladder was full. During recovery, these stretch receptors begin to function. Suddenly, these nerves start sending signals to the brain. Now, in the past decades, the only time that these muscles sent a strong signal to the brain was when the bladder became so overextended that you felt you were going to explode if you didn't void your bladder. So what happens now when these nerves begin to send frequent signals to the brain? The brain assumes that there is an urgent need to urinate.

Let me illustrate the scenario. The bladder begins to expand a tiny bit due to the presence of urine. "Aha!" says the newly functional bladder stretch receptor, which is able to detect that the bladder is indeed beginning to stretch just a bit. This nerve, newly functional, sends a report to the brain. The brain, receiving a signal from this nerve, assumes that it is an emergency. After all, in the past, for decades, this nerve was only able to send a signal to the brain if the situation was dire, urgent. So the brain sends an emergency command to the body: "Go to the bathroom!" The person who is experiencing this will suddenly feel a desperate, panic-level need to urinate at once OR DIE! So, off to the bathroom, only to discover that there was less than a teaspoon of urine in the bladder. Half an hour later, this will happen again.

The Parkinson's brain, accustomed through years of training to associate a signal from the bladder with desperate urgency, will institute a panic, frantic need in the brain to urinate which will only be assuaged by emptying the bladder, every single time that a signal comes through from this fledgling nerve. Emptying that bladder will stop the panic signal. For a short time there will be no signal from the nerve, until the bladder has a few drops in it again. Then it will begin again. Just like a toddler who is learning to control bladder function, you will need to learn, over time, how to integrate these bladder signals with an appropriate brain response. Until then, your body will feel a state of emergency every time the bladder has the slightest bit of fluid in it.

Which leads us to:

Hell Stage

This seemingly cute name is the name given by people in recovery, not in jest, to that stage of recovery which combines the weakness in the muscles with the bladder urgency. What happens is this: for weeks, or more likely months, you will find that you cannot sleep more than twenty minutes at a stretch because of shrieking, intense bladder signals which can only be shut off by the act of emptying the bladder, no matter how minute the amount of urine. This is usually combined with an utter inability to get out of bed. The combination of weak muscles and sleep-time lack of adrenaline or bedtime low-levels of medication makes it impossible to get out of bed. And so the Hell Stage begins. Innocuously at first, you notice that you are waking up more often at night. The caregiver, however, notices that he/she is becoming exhausted. There is a hopeful assumption that this will only last a night or two. After a week, the first panicked phone call to the acupuncturist occurs. It is not unusual for the need to urinate to occur more than a dozen times per night.

The desperation of this stage would justify my writing an entire chapter, quoting from patients and caregivers who are reduced to tears. You may have been able to cope with all of the other indignities of PD and the fears and fatigue, but this new stage will be unlike anything you have ever known. After the first month, you will be pleading with your acupuncturist to give an estimate of how much longer this will go on. During this stage, peaceful, loving spouses and caregivers have been known to become violent. The utter exhaustion and fatigue, caused by spending all night hoisting your limp body out of bed, over to the bathroom, then back into bed, and then back to the bathroom again, can drive a caregiver around the bend.

To add to this, because of the frequent waking up due to the urgency, there will be a tendency to want to move about, reposition yourself on the bed, an attempt to turn over, and the struggle to get comfortable so that you can get back to sleep.

The most common request for private consultation from caregivers occurs when the patient is going through Hell Stage. During this time caregivers find that they benefit from support groups of others who are going through this. The best suggestions to come out of these support meetings have been:

1) Catheter. If you are a male, you can purchase an external catheter which means that you can void your bladder.

2) Diapers. These are second choice, because they need to be changed as soon as possible after urination to prevent sores and rash. After all, this stage may go for a long time, and a diaper rash, on top of everything else, will make everyone unhappy.

3) Compromise. Even though you want to move about, reposition yourself on the bed, attempt to turn over, and struggle to get comfortable so that you can get back to sleep, you must try to understand that the caregiver needs some sleep. So the choice becomes one of you getting some much needed rest or the caregiver getting some. This is a horrible, no-win situation. Try to spend a bit of time, maybe five minutes or so, before waking your caregiver. On the other hand, caregivers should realize that this person is miserable, possibly in pain and exhausted, and living in a body which has become like a foreign thing. It is a horrible time for both of you. Therefore, consider the next option.

4) Get help. It may be emotionally hard to do this. But remember, it is not forever. This stage will end. People who have gotten someone to come into the house to help with the night time attending have sworn that it is the only way to go. The helper can either stay in the house during the daytime, taking care of the you so that your caregiver can get some much-needed sleep, or the hired helper can come at nighttime to attend to your needs during the night. Even a helper who comes every other day will go a long way to prevent the caregiver coming to a breaking point.

5) Try sleeping pills **WITH YOUR DOCTOR'S ADVICE**. A sleeping table or relaxant may drug you into being able to sleep past the first few screaming bladder signals, giving you extra precious minutes of sleep. Benadryl, an over-the-counter medication which can help sleep, is usually considered to be safe to use in combination with most Parkinson's disease medications.

Please do take Hell Stage seriously. I have had to comfort an 85 year old woman who, for the first time in her nearly 70 years of married life, lashed out in anger, screaming at her helpless husband. Another gentle woman found herself shoving her immobile husband so hard, in anger at his inability to move, that he fell down, badly bruising his leg. I have heard of so many of these cases. There is such remorse, such anguish. The patient and caregiver both, very

often as they go through this, will decide that it is time for the patient to be committed to a home, or shelter, as the caregiver is no longer able to control emotions. This torment can be avoided by anticipating this situation, and getting help as soon as the situation arises.

Medication? The medication will not help. This is not a problem from lack of dopamine. This is a problem of weakness. If you increase the medication, you may actually worsen the situation, as most of the medications are brain stimulants, and actually create increased restlessness at bedtime. Patients who have increased their medication, thinking that this will give them nocturnal mobility, have been sadly surprised to learn that they get worse instead of better. In a few cases, specifically with Sinemet, the good feelings caused by a medication increase induced a sort of comfort and feeling of inner fortitude toward the problem, similar to the feelings of a mild dose of cocaine, which lasted for two weeks, and then the problem was back, as big as ever, and the additional problem of increased medication addiction was added to the mix. Please, do not try to get through this difficult time by overmedicating. Medication is for lack of dopamine. Do not create a larger addiction by using dopamine inappropriately.

The big question is, How Long Will This Last? I wish there was a formula. There is not. So I will offer up some numbers based on various patients. A newly diagnosed patient, no medication, age 76, took two months to get through this stage, and was nearly always able to get himself out of bed at night. Only twice did he need to spend the night downstairs on the sofa because he was not able to use his legs to go up the stairs to bed. Another patient, age 64, PD for over ten years, at the time of beginning treatment was taking (1) Sinemet CR 25/100, 4 mg Permax, and 300 mg Tasmar per day. Hell Stage lasted nine months. Another patient, age 77, PD for ten years, taking (2) Sinemet CR 50/200 (but who was nearly immobile, and chose not to increase the Sinemet for personal reasons though it meant he could barely move for the last eight years) was in this stage for eight months. Another patient age 68, PD for nearly 20 years, taking (3) Sinemet CR 50/200 plus 1.5 Sinemet (regular), 1.5 mg Mirapex, 3 mg Artane and 1 Paxil per day, was able to get through Hell Stage with relative ease. Although he was incontinent and the floor of the house was often sprinkled with urine, he was always able to get out of bed by himself and get to the bathroom as needed. Many patients who are younger, taking less medication, or who were more mobile at the beginning of their program than the above patients (whose amount of immobility may be guessed at by the level of medications they were taking), found that they were exhausted from needing to get up to urinate frequently at night, but that they were always able to get up, get to the bathroom, and get back to sleep. In fact, these patients, the ones who were able to move by themselves, albeit slowly and weakly, often said that they thought that the exhaustion helped, in the long run. Because they were tired, their bodies/brains more quickly learned to re-code the bladder signal from Urgent down to Mild so that they could get more sleep.

This stage will end someday. Patients erupt with joy, handshakes, and high fives when they walk in to the clinic, finally, after months of hell, and they can say “I slept through the night!” Hang in there.

Your Best Friends Will Tell You

An unfortunate corollary to the Hell Stage is the fact that at this point you will start looking quite haggard. Your friends and MD will certainly start telling you that you look terrible, and that you have never looked worse, and that you are absolutely degenerating, and that your Parkinson's disease is accelerating. There are several reasons for this. The first is that you are having facial expression. Previously you may have had a masked, expressionless face. This

mask is usually perceived as a grimace or scowl. Often people with a masked face are told “cheer up” or even more offensively “smile!” It’s not that the PD person wasn’t smiling, it’s just that the frozen face gives an expression of scowling disapproval. What happens during hell stage? The face has been quite expressive for some time. And now that you are not sleeping, and you ache, and you can’t get up from chairs, and especially because you are truly exhausted from not sleeping, your face looks haggard, weary and depressed. The face is no longer impassive, it is deeply expressive. The problem is, that expression is one of horrible fatigue and struggle. NO ONE wants to see this face. Everyone will insist that you look terrible. Very few people will be able to understand the inner meaning of the fact that you look lousy, and rejoice that you once again have a readable facial expression. Instead, the universal sentiment will be that you have taken a terrible nose-dive for the worse, because before you were always maintaining, and now you look just dreadful. I went to the MD’s office with a patient once. The patient was going through a very difficult time with her medication – she was now grossly over-medicated, and the MD refused to allow her to reduce her medication. The MD pointed out to me the concerned, haggard look on the patient’s face and said, “See, no facial expression! Your patient is getting worse.” Even though the patient then exhibited very lively facial expression in an attempt to show just what she could now do with her face, the MD insisted, “You are just showing off for the doctor. You don’t really have any facial expression.” There was no way that the MD would recognize that the previous condition, one of no expression whatsoever, was in fact more Parkinsonian than this new condition of a face which exhibited deep concern, fear, wry humor, and later that day, discussing the MDs reaction, radiant laughter.

Other signs which will make your friends tell you that you are getting worse: You will have such difficulty going up stairs. Most people with PD do well on stairs, but are not very fluid in their movements on the level. When your overall movements begin to be more fluid, your friends will only think that this is normal. They will not think that this constitutes and improvement. But when you can barely hoist yourself up the steps to the house, or get up from the sofa, they will cluck their collective tongues and tell you how much worse you are. The fact that you may have by now needed to reduce your meds by half because of dyskinesia and other signs that you could no longer tolerate the meds at the previous high levels will mean nothing to your friends. If you have gone from ten assorted PD pills a day down to none, and your friends see that you have difficulty using your quadriceps muscles to lift yourself even though you are now fluid on the flats, they will tell you how much worse you are.

One of my favorite MD stories comes from a patient whose MD tells her every appointment, as if it were a new symptom, that, “You’re cogwheeling now!” She has been cogwheeling from the beginning of her diagnosis. So when she reduced her medication, and was sleeping much better and feeling much better, her MD’s first pronouncement was, “That explains why you’re cogwheeling now.” This same MD, concerned that the patient had reduced her medication, told the patient that she was obviously getting much worse, because her voice was faint and raspy. When the patient told me about this, I showed her the initial intake form which I had done with her, on which was clearly recorded her opinion that her greatest concern about her PD was that her voice had become very soft and raspy. Now, over a year later, during which she had begun moving much more smoothly, had warm hands and feet, had improved small motor skills, could twist at the waist, had much improved facial expression, and had reduced her meds to one third of the previous level, her MD wanted her to increase her medication because of this “new” problem: her voice was becoming soft and raspy.

In other words, your friends and your MD will not recall your old problems. They will not understand that you are actually experiencing positive changes. They will attribute every problem you have to worsening Parkinson's disease, even if the new problems are the opposite of Parkinson's disease. Remember, most people are not really familiar with the symptoms. Any thing that looks "bad" will be perceived as worsening PD. Sometimes it is good to go back to the PD literature and review what the symptoms of PD actually are. It can help you to realize that whatever the new symptoms are, they certainly aren't PD. And that's all you really need to cling to.

This is actually a very, very difficult stage. This is the stage at which people who live alone will be reported by their friends as incompetent to care for themselves. Friends will not understand why you have decreased your dyskinesia-causing medication. They will scream at you to please just take your medication when they see that you are limp or weak. If you try to explain PD is about rigidity and intense energy trapped in an unresponsive body, and that PD looks like nearly the opposite of what you look like during hell stage (although patients in advanced condition will have both old PD symptoms and hell stage symptoms at the same time – REALLY APPEARING DREADFUL to an outside observer), or if you try to explain that the medication has side-effects which were becoming increasingly dangerous, they will ignore you. Even people with PD, who have presumably read the medication inserts (although, of course, this isn't always the case...), are amazed to learn, during recovery, that Sinemet, for example, can *cause* tremor, slow movement, and freezing. Your well-meaning friends will not be educated whatsoever as to the effects and side-effects of the medication. They will only want you to look better, and they may take strong steps, such as trying to have you committed to a full-time care facility, so that you can be forced to take high doses of medication against your will. This actually happens. I could not make this up.

The Headaches

About half of the people recovering from Parkinson's disease will experience one or more of The Headaches. I suspect that actually everyone experiences them, but they can be very fleeting, and if you are asleep at the time you may miss them. "Headaches" is actually a misnomer. They are a series of three passing vibratory sensations which occur in the head. But they are not "headaches" in the usual sense. If you are awake when they occur, you will know, deep in your bones, that you are now recovering. There is an unmistakable sensation in the entire body when that fast, internal shaking and vibrating comes to an abrupt halt. It is the more shocking because, since you have had this internal shaking for decades, you may have learned not to notice it. But it is there, that vibration caused by the electrical fire storm between the brain halves. When that vibration ceases, following the "headaches," there is a peace which fills the heart with joy.

I call these Headaches "first," "second" and "third" because that is the order in which I first learned of them. However, they do not necessarily occur in this order. Also, in rare instances one or more of them will occur a second time. If you never notice the Headaches, but wake up one morning and find that the internal vibrating is gone, and that your symptoms seemed to have changed overnight, or you just feel "different," don't worry about having the Headaches. You have probably slept through them, which shows you just how mild they can be!

Side-To-Side Headache

The first of the Headaches begins with a vibrating sensation. It is a very, very slow vibration, not the rapid, tremor-tempo vibration which is always lurking in the body. It is between 1 and 2Hz (1 or 2 vibrations/second). It begins behind the ear on the side opposite the side where your Parkinson's symptoms first appeared. The vibration slowly moves from the side of the head to the center of the brain. It vibrates there for a moment. It then continues to vibrate over towards the temple on the opposite side of the head from where it started. There is a quick shudder, and the vibration is gone. *So is your internal tremor.* The internal tremor never returns. (Tremor habits in your muscles may cause you still to experience trembling from habit, but the internal tremor which drove the process will be gone. The habit-driven tremor and other symptoms will continue to manifest, but they will be of steadily decreasing intensity, frequency and duration.) The whole thing may take less than a minute, although in one patient it took, or seemed to take, nearly twenty minutes.

Top-To-Bottom Headache

The second Headache feels like an extra-tight swim cap pulled down over the head. It is not a painful pressure, but it feels very strong, as if the head was contracting inwards, and the very center of the brain is bearing down on the spinal column. It may last moments or minutes. In some cases it is followed by a fleeting moment of extreme cold inside the head, after which the pressure and cold completely disappear, followed by a feeling of deep strength.

I will insert here a partial transcript of a tape recording made in my office by a patient who had just experienced the Second Headache four hours before coming to his appointment. He refused to talk to me until I produced the tape recorder. "You'll want to get this down," he said. I add as an aside that he had never heard of "The Headaches" before, and was only my second patient to experience a Headache. The first patient had the first Headache only. So this was my introduction to the second Headache.

In the middle of the night last night, I had an awesome experience, just awesome. ...The upshot of it is that some life form, or some piece of me, some part of me, died during the night. And it may have been the Parkinson's part.... I had the feeling that something was coming to an end, it was as though I were dying, but I was aware that I didn't think I was really dying... I wasn't getting ready for my own real death, but as though some part of me or something in me was dying. And it was a totally unique experience.

I went with it, breathing was fine, and whatever it was then moved to the point of dying, letting go... (long pause) And I still am not sure what are the best words to use. (eyes fill with tears) Time will get some perspective on that too. But it's as though something were lifted. And I gave it plenty of time to go, and respectfully said goodbye to it. And then when I was sure it was gone, realizing that would be the end of whatever that was, I got up on the side of the bed. (long pause) At that point, I was aware, more keenly than before, that I was actually alive, that it was not a death experience, that I wasn't getting ready to have a heart attack or die, but something was dead, something was gone, something was lifted and I had a strange experience of... lightness, and... smoothness (tears) ...those two words were real clear. And I knew at that point that I was not dying, that I was not dead, that I was continuing to live... I was clear that this was an experience about me, and the interesting part was that I felt free of tremor, and it was unbelievable. But I've made a career out of being open to believing the unbelievable, so wait and see, time will tell, but clearly this was some kind of important experience.

It was clear that I was tremor free, I had a sense of balance and solidness that was new, that I didn't really want to test, for fear that it wouldn't really test out. So I started gently testing it. Oh, there was also a sense of symmetry that hadn't been there before... So I kept testing it by putting my arms above my head, by putting them out in front (He gestured, with hands straight up, then out to the sides, then out in front and demonstrated the wrist movements.), looking for tremor, turning 'em, looking for cogwheel, not seeing anything, doing a bunch of touching, testing, touching the back of my head... and in the middle of this, I got up, twice, and tested my stability and balance, and ease of movement, and it was there!!!

*It was easy movement, it was as though I was without Parkinson's. ...Oh, then at one point, I said to myself, I wonder what my writing is like. So I have a pen, and a note paper right by the bed, right by where I was sitting, to the left of where I was sitting, so I got that, held the little telephone note pad in my hand, so it's not the steadiest thing, so I wrote something. What I wrote, interestingly enough, was "I am a renewing person. I am a renewing being" and I (pause) looked at it and it was (tears, again, chokes a few times) luh, luh, **large** (choke) **handwriting**. (Crying.) Not micrographia! And it was a little scrawly, but the I reminded myself that my handwriting had always been scrawly, but it was just naturally as big as it used to be! (gestures, thumb and forefinger showing an inch in height)....*

In further discussion at a subsequent session, after I learned about the three types of Headaches, I requested more detail as to the physiological sensations which he had felt that night, preceding the sensations of lightness and smoothness. He then described an experience very similar to what is detailed above for "Second Headache."

Although this type of headache is most often described as "a too tight swim cap," its main focal point is on the axis of the head which runs from the top of the head down through the center of the head and into the spine. Another patient had what sounded like a variation on this second type of headache: "*I did have one of the headaches once, I think, though it was not a vibration. I was sitting in the concert hall listening to a piano recital, and all of a sudden I turned my head and there was this deep piercing pain in the very center of my head. It went from the very top of my head down to my neck stem. I thought I pulled a muscle or something, but that wasn't really the feeling. It was like a big train running through my head, painful but didn't really hurt. The big shock went away in a few minutes, but the aftershock stayed for about 20 more.*"

Front-To-Back Headache

The third type of "headache" feels as if the frontal bone (forehead) is gently pulling away from the rest of the head, moving forward about a tenth of an inch, and just as the head feels very relaxed and light due to the decrease in internal pressure in the head, there is a sensation as if the front of the head is gently floating upwards, and pivoting so that the back of the head moves slightly down as the front of the head moves up. It is a very quick, non-dramatic sensation, followed by a faint sensation of increased relaxation in the head.

Again, not everyone notices these three headaches. And certainly not everyone describes them the same way. I have received descriptions ranging from "transcendent" to "kinda weird, I thought maybe it was a migraine coming on, but it went away so fast, so I guess not."

One patient actually experienced the Side-To-Side Headache in my office. In the following, the comments of the patient and her husband are in quotes, although I am paraphrasing from my memory, based on my notes taken during the session.

I had been massaging her upper arm when her hands flew to the sides of her face, covered her ears, and her mouth was wide open in a silent scream, eyes popped wide open. I asked her what was happening. No reply, "What is it?" I asked. "Are you O.K.?" No reply. "(Name)...can you hear me? Are you all right?" No reply. This went on for nearly a minute, which is a very, very long time. Then, she stopped, and with tremendous gravity and solemnity, turned to me and said, "Something just went through my head. I think I am getting better now."

Her voice was strangely loud. (She had previously had the Parkinson's faint voice, sometimes barely audible.)

Her husband had been silent, poised on the couch, staring.

"The shaking is gone," she announced, slowly and clearly.

What happened? "Something vibrated through my head. It went from lower left to top right, through my brain, I thought I was screaming, I didn't know what it was. It was very slow vibration, not tremor. I think now I am going to get better. My body is stronger now. I feel good," she announced. Statement of fact.

(She had never said that she felt anything but miserable, up until this moment. This woman had been in constant pain and distress from various symptoms ever since I had started seeing her. This was certainly news!)

"It was crazy! I thought I was going crazy! It went through my head, this big vibration!!"

I wished I could have gotten it on tape. I cannot remember her exact words now, but she went on and on, how good she was feeling, testing her arms, legs, and moving her head from side to side.

She got off the treatment table and grabbed her husband by the shoulders, saying, "I feel good! Do you hear me!!" She laughed. "I feel GOOD!!!" She beamed at me with her new smile. Two months ago her face had been an expressionless mask. Wow! I had just been present at a miracle. I had been present at a turning point in recovery. It was incredible. I had heard about this, by now. But this time I had seen it. She hadn't been told to expect a headache (The earliest pioneer patients didn't have this book to read; they were the ones writing it!) but her experience was like the others in every aspect, even down to the direction of the vibration, and the location point of the beginning and end of the vibration.

The word headache is a misnomer. One person described the sensation as "similar to when I was pregnant and I could feel the baby moving around inside. I've been feeling my brain moving around inside my head. It doesn't hurt, it's, well, it's just sort of things all moving around."

Again, not everyone has these "headaches," at least not that they know of. Very few people are aware of having all three. But if you should suddenly find yourself feeling still inside, as if the internal vibration has suddenly, instantly ended, or if you feel strangely stronger, or lighter, you have probably passed through one of these three "strange things that happen."

Finally, because I don't know where else to include it, I will mention here that one patient who had completely recovered from every symptom except a left hand tremor, but who had felt the internal tremor cease some time earlier, recently had a symptom which seems akin to the vibrating headache. For over a month now, just as she was falling asleep, she has felt a slow, rumbling vibration which seemed to move from her sternum (the bone down the center of the chest), across her left chest wall, over her left shoulder, and down to her left hand. It was a unique sensation, she did not have words to describe it, and struggled for quite a while trying to

explain it to me. She also said that it was possible that it occurred in the sternum, chest, shoulder and hand all at once, but that there was a sense of it being directional, towards the hand, so that she could not tell if it was actually moving from point to point, or happening over the entire area at once. Her description of the low speed, shuddering vibration is similar to the descriptions of the side-to-side headache. It may or may not be a coincidence that her hand tremor is finally showing signs of decreasing.

Recovery Dyskinesia

Another very strange aspect of recovery is the unique type of dyskinesia (incorrect movements of the muscles) which occurs. It is important to learn to distinguish the recovery dyskinesia from the other forms of dyskinesia one may encounter, those related to the use of artificial dopamine and to the body's natural response to stress. So many people, both patients and doctors, fail to discriminate between adrenaline-based dyskinesia and medication-caused (dopamine) dyskinesia. Although this medication type of dyskinesia is a relatively new twist in the history of Parkinson's disease, very few doctors or patients are around anymore who remember the old days of non-medicated Parkinson's. You must be able to understand the difference between dyskinesia and tremor if you are going to be able to evaluate your progress during treatment. Really to understand Parkinsonian dyskinesia, it would be good to do a quick review of the symptoms of Parkinson's disease.

Historically, before the development of Parkinson's disease medication, idiopathic Parkinson's disease was a syndrome characterized by muscle rigidity and poverty of movement. People with Parkinson's disease moved more and more slowly over the years, as their Parkinson's disease advanced. In some cases, but not all, this slowness of movement would be combined with a resting tremor in the hands or feet. This tremor would, now and then, *under stress*, be enlarged into an exaggerated tremor, but in general, the trend was towards slowness. As the condition continued to worsen, people with this syndrome became more and more rigid, and finally, they could not move. Except under conditions of extreme urgency, they were frozen, motionless. Finally, there would be no movement at all. Ever.

Consider this paraphrase of a description of a man with late stage Parkinson's, before the days of dopamine medication. This is taken from my memory (hence the paraphrasing) of reading a description of a famous photographer of the 40's in a newspaper article retrospective:

Towards the end it was so strange. He was very depressed. He had no facial expression, and he wouldn't talk. But he wanted to move, he always wanted to move if he could. So he would walk, in tiny, tiny steps, in a straight line, until he came to the wall. He would stand there, then, indefinitely, until someone came and turned him around. Then he would walk to the other wall. He did that all day. He could only go in a straight line, so he would walk again until he came to the next wall. Eventually, the time came when he couldn't even move his feet.

What is dyskinesia?

Dyskinesia literally means "wrong movement" and refers to any movement which is not "correct." In the case of Parkinson's disease, dyskinesia is the name given to uncontrolled, involuntary movements of the arms, legs, hands, feet, or face. Although the word "dyskinesia" literally applies to any form of wrong movement, the word "dyskinesia" has acquired a distinct and separate meaning when applied to PD symptoms. Parkinson's disease "wrong movements"

are divided into two types: tremor and dyskinesia. Differentiating between the two types becomes important during recovery. In this overview of PD symptoms the words "tremor" and "dyskinesia" have the following meanings:

Tremor is vibratory, powerless movement which occurs when the body is relaxed.

Dyskinesia is muscular, spasming movement. It can be aggravated by stress. It often manifests as an exaggerated, more muscular form of the tremor.

For a lengthier description, consider this:

Tremor

Tremor is a rhythmic, vibrating motion. Parkinson's disease tremor is also called "resting tremor." It occurs when the body is awake and relaxed. It usually stops during sleep. In Parkinson's disease, tremor most often appears in the hand, arm, leg or foot. What does the tremor look like in these areas?

In the hand, tremor takes many forms. When it occurs between the thumb and index finger it is called "pill rolling." Less common is the fourth (ring) finger tremor, or the five finger tremor in which the straightened fingers make fluttery, quick vibrating movements. Sometimes there is tremoring in the arm, but because of the weight of the arm, these movements are harder to see. Very often, tremoring in the arm is a feeling, more than a real motion, although in some cases true tremor (as opposed to dyskinesia) can cause the entire arm to vibrate.

In the foot, tremoring is a steady, quick, small vibration. Because the foot and leg are so much bigger than the hand and arm, these motions will tend to be a little larger in the lower extremities, but they are still fairly small, very rhythmic, and vibratory. Foot tremor often occurs when one leg is crossed over the other. The foot which is crossing over, suspended over the knee and hanging down unsupported, will make quick, vibrating motions. Tremor of the foot can also occur any time that weight is off the foot. Leg tremoring is also a quick vibrating motion. When standing, a leg tremor can cause the leg to bounce up and down off the floor, just a bit. It can resemble the foot-tapping of an impatient person.

Tremoring can also occur in the chin and neck. It is a small, vibratory, trembling motion. Neck tremor can sometimes cause the entire head to vibrate.

Dyskinesia

Dyskinesia movements are large, muscular movements. They can be steady and rhythmic, or irregular and unpredictable. The movements can be jerky or smooth and flowing. They are not under conscious control. They are involuntary movements. The movements occur in muscles which would ordinarily, in a healthy person, be voluntary muscles. These are the muscles which allow walking, waving, dancing, facial expressions, etc.---all of the activities which require conscious or semi-conscious thought. Dyskinesia looks like muscular activity. There is some power behind it.

Many people with Parkinson's disease refer to any uncontrolled movement as "tremor." This is not accurate. For example, one patient told me: "Last night I had to give a speech, so of course my tremor was making my arm bounce all over the place. The tremor was totally out of control..." That wild-arm-bouncing was not tremor. It was dyskinesia.

Ordinarily, during general conversation about Parkinson's disease, the distinction between tremor and dyskinesia does not matter. But during recovery it helps tremendously if

you know the difference. Your doctor will be extremely interested in changes in your tremor and the nature of your dyskinesia episodes. If you say tremor when you are talking about dyskinesia, it will cause confusion and misunderstanding. So start taking note of your movements and using the correct terms.

And to make it even trickier, there are three kinds of dyskinesia! They are adrenaline dyskinesia, medication-induced dyskinesia, and recovery dyskinesia. Before discussing these three, let's first review the causes of Parkinsonian dyskinesia.

The person with Parkinson's disease has a decades-old injury in the foot. This creates two situations. First, any significant injury causes a brief slowdown in dopamine production. The foot injury never heals, therefore in Parkinson's disease the dopamine slowdown becomes permanent. Second, the injury creates an electrical blockage which, after decades, becomes impassable. This prevents normal current flow through two of the many electrical paths that run over the surface of the body. Due to lack of electrical flow the tissues in these two areas, including muscles, nerves and blood vessels, slowly degrade. The path of damage is here referred to as a "line of degradation." Let's look at these two areas.

The first area of damage is in the line of degradation on the leg. The degradation effects all the body tissues (nerves, blood vessels, ligaments, tendons and muscles) in a line, about two inches wide, which extends from the top of the foot to the neck. (See figure 1.)

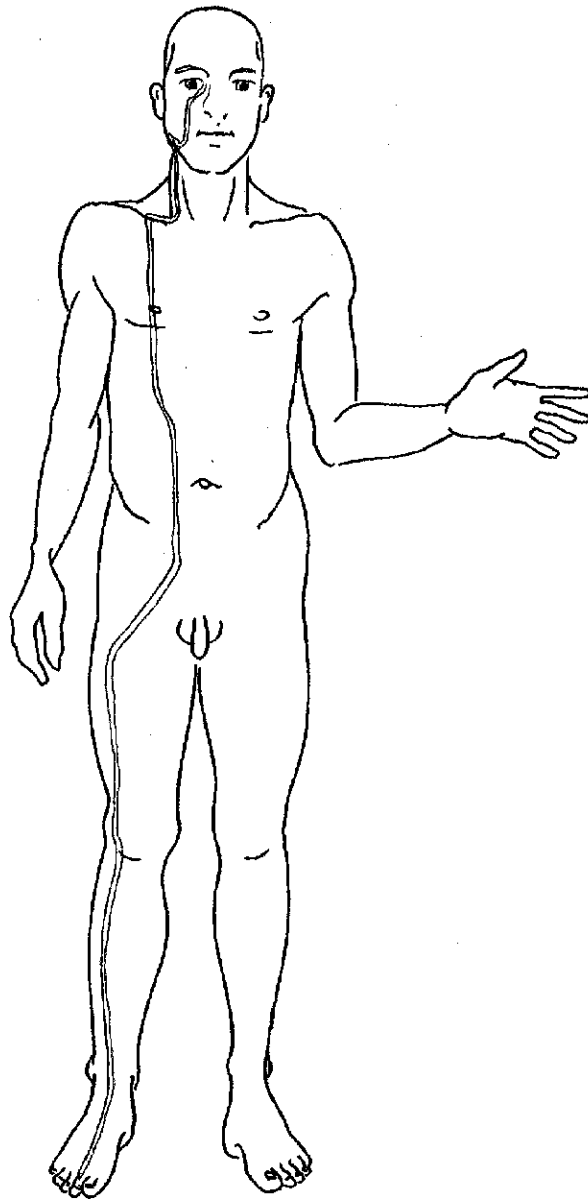


Figure 1

The line runs from the inner canthus of the eye over to the lower eyelid. From there it flows down the front of the face to the jawline, and then back to the corner of the jaw. It then travels down the front side of the neck, across the collar bone, and then travels down the chest along the mammary line. Midway down the chest it moves closer to the midline, and continues down this line to the pubic bone. The channel moves laterally and diagonally over to the side of the leg, and then runs down the leg to the front of the ankle. It runs across the top of the foot to the web margin between the 2nd and 3rd toes, and ends on the lateral side of the 2nd toe.

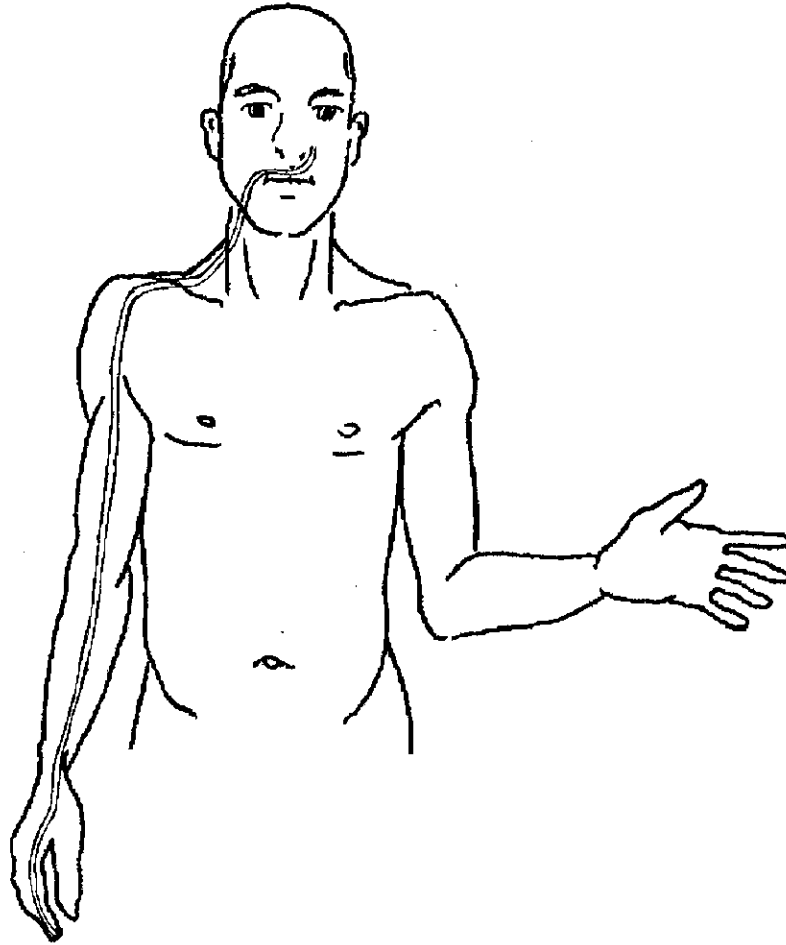


Figure 2

The other area of damage is in the line of degradation on the arm. This line is about one inch wide, and begins on the side of the forefinger and travels up the forearm, passing over the lateral, or radial, side (also known as the "thumb side") of the elbow crease. From here it continues up to the point where the arm joins the body at the front of the shoulder, about three inches above the front end of the armpit crease. From there it runs up the neck and upper jaw and crosses over philtrum below the nose to the other side of the face. This line is referred to in Asian medicine as the Large Intestine channel. (See figure 2.)

Figure 1 and Figure 2 show the two areas of the body in which tissues have been damaged by electrical malfunction. These are also the areas which are most likely to tremor and be rigid. These areas are very weak and rarely stimulated. The sensory, motor and proprioceptor nerves to these areas barely function. The various Parkinson's disease medications do not stimulate these areas. The body has almost no communication with the areas along lines of degradation.

Now let's look at the other cause of dyskinesia, the dopamine reduction problem. Dopamine reduction is an attempt by the midbrain to make the body slow down. It is easiest to understand this process if you consider the case of a wounded animal.

A Natural History Interlude

An animal that is badly injured will drag itself away to a safe place and then become nearly motionless. It will be as still as possible to prevent itself from being noticed by predators. It will lie quietly while its injured body heals. Breathing will slow, and the animal will not eat or be involved with other animals as it lays low. However, the animal will remain utterly alert. If an emergency arises it will be able to flee. In fact, using adrenaline, the "fight or flight" hormone, an injured animal or human can perform impossible feats of movement and strength. (Adrenaline is the common name. The more technical name is epinephrine.) But if there is no emergency, the healing mode, or lowered-dopamine mode, prevails. If the animal can find a safe place and can rest, the brain of the injured animal will slow dopamine production and the animal will be able to remain very still, seemingly lifeless but utterly alert, until the injury is sufficiently healed. Motionless but alert? Cannot move except in emergencies? Sound familiar? End of Interlude.

When you have idiopathic Parkinson's disease your brain is in the "injured animal" state. The problem is, with PD, the injury never goes away. The injury sits there in the foot for a lifetime, while the brain purposely slows the dopamine production. Finally the midbrain cells which produce dopamine restructure themselves so that the dopamine-producing structures are dismantled. As dopamine levels in the brain decrease, the healthy muscles in the body become less responsive to conscious and unconscious control. The brain remains alert, but the body is trying to achieve a state of motionlessness.

Remember, this has nothing to do with the areas along the line of degradation. Those muscles and nerves are virtually inaccessible, due to electrical malfunctions caused by the injury itself. Those areas have been sealing themselves off from the rest of the body for years. The healthy muscles have been compensating for the "missing and damaged" ones for years.

But as dopamine levels decrease, the healthy muscles which require dopamine are also less usable. They can no longer do their job of compensating for the damaged ones. When dopamine decreases in the brain become significant enough that healthy muscle movement becomes slow and less responsive (bradykinesia), the healthy muscles can no longer control, restrain, and compensate for the degraded areas. The symptoms of Parkinson's disease can then begin to appear.

Using dopamine medication does not actually restore function to the damaged areas. What medicinal dopamine does is allow the other muscles of the body to continue their function of compensating for these weak areas. The body is trying to perform an overall "shut down" because it perceives that there is an injury that needs healing. It does this by decreasing dopamine production. Medicinal dopamine restores dopamine levels, enabling the healthy muscles to continue their job of compensation. Medicinal dopamine does not cure the actual injury, or restore the degraded tissues.

In summary, there are two problems in Parkinson's disease: 1) degradation of muscle, nerves, and circulation along two narrow, specific lines in the body, and 2) dopamine reduction causing decreasing responsiveness in healthy muscles. The different types of dyskinesia are caused by the interplay of healthy muscle and damaged muscle, a hormone, adrenaline, and a neurotransmitter, dopamine.

The Three types of Dyskinesia

Adrenaline-based Dyskinesia

The first type of dyskinesia is produced by situations which create a sense of anxiety or fear. In the book *The Shaking Palsy* by James Parkinson (dated 1817), he notes that even a person with advanced Parkinson's disease can move quickly and smoothly in times of emergency. This is most likely due to the internal body chemistry which is produced in an emergency. In an emergency the body releases adrenaline. Adrenaline is sometimes referred to as the "fight or flight" molecule, the chemical of emergency.

Even in the early stages of Parkinson's a patient may experience dyskinesia. This is the dyskinesia which occurs when adrenaline has been produced in the body in response to a stressful situation. In this case, adrenaline goes to all muscles, *even the damaged ones*. Adrenaline can bypass the nervous system and go directly to the muscles. Adrenaline takes the place of dopamine. Think of adrenaline as a form of super-dopamine. This is the hormone which causes dyskinesia even in the early stages of Parkinson's disease, even before a person begins taking medication. How does adrenaline affect the damaged area, though, if those areas are not in contact with the brain?

Ordinarily, the nerves of the tissues which are on the line of degradation no longer get switched on or off because in addition to being damaged, these nerves have been turned off in the brain. Even if dopamine is present in the brain it cannot get through to this damaged area. But when adrenaline takes over, the situation is altered. Adrenaline can bypass the brain switches and go directly to the muscles, whether they are damaged or not. This is how a person with a broken leg can run away from danger, even though under normal circumstances he would not be able to walk. In a person with Parkinson's disease this means that those damaged areas along the arm and leg get a jolt of "action" chemistry. These areas, ordinarily turned "off" at all times due to damage, will, under the influence of adrenaline, receive the same jolt as all the other muscles in the body.

(Eventually, in cases of very late stage Parkinson's, the body shuts down the movement mechanisms so completely that even adrenaline cannot get through. But this occurs slowly, gradually, over years, and is only apparent in very, very late stage Parkinson's disease.)

The majority of the muscles in the body of a Parkinson's disease sufferer are in pretty good shape, and under conscious control. These healthy muscles, even in the presence of adrenaline, can be controlled by the brain and conscious decisions can be made as to whether or not to use these adrenaline-enhanced muscles. However, the weak muscles along the lines of degradation are not under conscious control. They no longer connect to the brain. They are no longer coordinated, and the nerves which used to govern them consciously are dormant. So when these damaged areas receive a jolt of adrenaline, Whoa, Nelly! They flap and jump. They bounce and spasm. They are not healthy tissues. They are severely damaged tissues, damaged from years of incorrect electrical flow, and they cannot be controlled consciously like the other healthy muscles. When these muscles are flooded with adrenaline they pump back and forth in a very predictable set of motions. These motions, which look like variations on a salute, are caused by the frantic flexing and pumping of those muscles which underlie the lines of degradation show in fig. 2, page 40.

Adrenaline is a wonderful thing to have flooding your body if the stress inducing situation is one where flight is required, such as "The house is on fire! Run!" In this case the body will use the adrenaline to override the "go-to-sleep-because-you-are injured" signal in the brain, and will institute an adrenaline rush. This will allow the muscles of the body to move quickly and smoothly to cope with the emergency. The healthy muscles will compensate for the weak ones, controlling them, and the net effect is that the body can move smoothly until the emergency is over, moving even better than you could have normally done.

However, in our modern world, stress is more often found in situations where frantic running is unsuitable. Stress can occur in the car, or while addressing a meeting. In these situations, adrenaline is still produced by the body. The heart beat increases, blood flow to the muscles picks up, and the muscles are primed to respond to the slightest command. And the modern person, sitting in a car or speaking from a dais, orders his or her muscles to be perfectly still, in spite of the stress. The body may be primed for a primitive fight or flight response but the modern social situations which cause stress most often call for absence of movement or restrained movement. Instead of the body firing off a muscle response, the modern person must hold that energy inside. The healthy muscles, responding to conscious control, are able to hold tight.

But what happens to those weak, damaged areas, with damaged nerves and poor coordination, which are no longer under conscious control? The adrenaline hits those areas too! Those muscles start firing off. Back and forth, up and down, those muscles contract and relax spastically with all of their limited strength. The other nearby muscles tense up in an hopeless effort to control the adrenaline-charged, spasming muscles. But those "weak" muscles are not under conscious control, and they jerk and spasm with all the rude, animal strength they can muster. This animal strength is much more powerful than the conscious strength of the healthy muscle, and so dyskinesia occurs. This is adrenaline-based dyskinesia. The arm movements typically take one of two forms. The most common motion of adrenaline dyskinesia is "the salute." The arm goes up and down as if the index finger is trying to tap the outer edge of the eyebrow. The next most common form is the "pledge of allegiance," in which the arm flails back and forth across the chest.

Let's look again at that quote earlier in this chapter: "Last night I had to give a speech, so of course my tremor was making my arm bounce all over the place. The tremor was totally out of control..." His arm was saluting up and down, up and down. Was that tremor? No! It was adrenaline dyskinesia.

A Non-medicated Combination of Shakes

A person who has Parkinson's disease and is not yet taking medication will sometimes have both tremor and adrenaline dyskinesia occurring at the same time. This combination of movements is often noticeable at meals. The mild, resting tremor can make it difficult to perform the simple actions of eating and drinking. A filled water glass lifted up by a trembling hand can splash and spill. A trembling hand trying to hold a fork loaded with rice will likely send rice flying everywhere. This causes stress. The stress causes adrenaline to kick in. This causes dyskinesia, the larger, bouncing movements. It is hard to tell sometimes when the tremor leaves off and the dyskinesia sets in, in a situation like this. This can also occur during public speaking, or any situation where the body is trying to be relatively calm and controlled, but stress is also present. In situations like eating or public speaking, the tremor itself creates the stress in what might ordinarily be a peaceful situation. When stress is due to the tremor, causing

dyskinesia to combine with tremor, there may be quite a bit of uncontrolled movement going on anywhere along the lines of degradation as well as some vibratory hand tremor, leg tremor, and head bobbing. Most of this movement will cease, however, when the stress is reduced. Then the body can revert back to the relatively calm resting tremor.

After many years, as the Parkinson's disease progresses, and if the patient does not take medication, these symptoms will change. The dyskinesia will decrease, and rigidity and immobility will become more established. Larger and larger levels of stress are required to trigger either controlled movement or dyskinesia. Tremor may cease. Eventually, even the presence of adrenaline will not be able to stimulate the body into movement. Fortunately, the onset of this stage is now greatly delayed by the availability of medication.

Medication-based Dyskinesia

With the discovery of L-Dopa, the most common Parkinson's disease medication, a new form of dyskinesia entered the picture. When the body receives too much dopamine, a response can be that muscles jerk or spasm. This can be caused by dopamine overdose. More often it occurs in Parkinson's patients when the patient has been taking dopamine for several years. Over the years the midbrain of the Parkinson's patient continues its struggle to shut down the muscles. When a patient defies the body by taking pharmaceutical dopamine, the body fights back. It just works even harder to stop its own dopamine production. If pill-form dopamine is being forced into the body, the body will accelerate its shutting down of dopamine by altering even more cells in the substantia nigra area of the brain and creating chemical and neurological resistance to dopamine. (This is not the place to go into it, but as far as your brain chemistry is concerned, too much dopamine is much, much more dangerous than not enough.) After several years of this, there is so little dopamine being processed in the midbrain and the brain's resistance to dopamine is so great that the patient must increase the dopamine dose. So a pattern begins which results in a situation in which, finally, pretty large doses of dopamine are required to achieve effectiveness. But that is a problem, because when the doses get larger they can begin to have an unpleasant side-effect, that of dopamine dyskinesia. This is also referred to in this writing as medication dyskinesia. Dopamine dyskinesia is the erratic, uncontrolled movement of muscles, but it is different from adrenaline dyskinesia in that it occurs when there is too much dopamine in the body. When the nerves which regulate the muscles get slammed with so much dopamine, the muscles begin to move. In a healthy person, the regulation of dopamine is very exact. The body produces just enough dopamine to do the movement it needs. The body works quickly to break down any excess. But when the body is suddenly hit with a large amount of dopamine from a pill, the body cannot moderate the effect. The muscles get over-stimulated and they begin to jerk and move on their own. This is dopamine dyskinesia.

The historical, pre-medication *rigidity* version of Parkinson's disease referred to at the beginning of this section is very different from the late-stage Parkinson's which you see today. If you observe a group of people with Parkinson's disease today, what you will see will be the very opposite of rigidity. You may be expecting to see a room full of very still people, with the stillness broken only by tremor, or a bit of nervous, adrenaline dyskinesia. But surprise! You will see twitching and bouncing. You will see spasming, flailing, and jerking. This will be in addition to the tremoring and the trembling, and the sudden moments of complete immobility. If you only know about Parkinson's from the medical description, you will be baffled. Where is the rigidity? Where is the small, tiny movement?

This excess of movement which is observable in modern Parkinson's disease is due to the fact that most people with Parkinson's disease are taking medication. Most of the movement which you are seeing is medication-induced (dopamine) dyskinesia. It is combined, in these modern times, with the dyskinesia which comes from stress. In fact, the dopamine dyskinesia can cause enough stress to trigger the adrenaline dyskinesia. Dopamine dyskinesia combined with adrenaline dyskinesia! Double dyskinesia! Wild, crazy movement!

This is very different from mere bouncing, "salute" movements along the damaged tissue lines which was described in the section on adrenaline dyskinesia. This dopamine dyskinesia can be taking place anywhere in the body. Often there is hand flapping, where the whole hand flaps open and shut. Or the arms, legs or neck move in spastic, jerking movements to the sides, the back of the body, up in the air, any which way. These are movements which use the healthy muscles, as opposed to the damaged ones. These are not Parkinson's damaged muscles which are trying, struggling to find movement. Dopamine dyskinesia is healthy, functional muscle which is being over-stimulated by medication so that it moves back and forth without conscious control. Many people consider the dopamine dyskinesia to be the hardest part of their Parkinson's to bear. But in fact, it is not a part of their Parkinson's. The wild, disordered movement, often considered even by modern doctors to be the worst part of Parkinson's disease, is not a part of Parkinson's disease, but rather *it is dopamine dyskinesia caused by the medications for Parkinson's disease.*

Why does this dyskinesia occur? At high dopamine dose levels, there is only a small difference between "just enough medication to achieve results" and "oops, too much medication, there's dyskinesia now!" This narrow target zone of "not too much, not too little" dopamine is referred to by doctors as a narrow "window." As dopamine need increases, over the years, and the window gets smaller and smaller, it becomes harder to get dosing just right. Over the course of a day, a patient who is using a high dose of dopamine will have the following scenario. The patient takes a pill. It takes a while for the medicine to kick in, and until then, no relief is achieved. The body is rigid. Then, as the medication begins to get into the bloodstream and up to the brain, the body can move smoothly for a moment, but not quite smoothly enough. But then, as the dopamine from that pill continues to be absorbed into the bloodstream, Wham! Suddenly, there is too much dopamine, and the body goes into dopamine-caused spasming, or dyskinesia. Eventually the dopamine from that dose breaks down, the dyskinesia slows down, but shortly after that, the body is rigid again. It's then time to take another pill, and begin the cycle all over again.

Why not cut back on the dose, you might say? Dopamine has a very short half-life, which means that it does not stay active in the blood for very long before it breaks down. A certain level of dopamine must be delivered to the brain before it is enough to be significant. It is very hard to get just enough dopamine to the brain without getting too much, since the medication is constantly being broken down in the body, and must therefore be taken every few hours. The newer pills, which release a steady stream of dopamine over a longer period of time, help to reduce the incidence of dopamine dyskinesia. But the main thing to bear in mind here, as you are recovering from Parkinson's disease, is that your dopamine dyskinesia is not the same as your Parkinson's disease. Remember this. Parkinson's causes rigidity and poverty of movement. Your medication causes your dopamine dyskinesia.

Parkinson's disease causes rigidity and poverty of movement. It causes trembling and tremor. *It causes dyskinesia only in times of stress*, for instance when a fight or flight response is stimulated and yet the large movements of fight or flight are repressed, such as in stressful,

modern-day social situations. And even adrenaline-based dyskinesia eventually ceases; in very late stage Parkinson's disease even the adrenaline movement is no longer possible, or may manifest only as a small flapping of the hand in times of stress. But don't confuse your medication symptoms with your Parkinson's disease: **Parkinson's disease is a disease of rigidity and absence of movement.** If you keep reminding yourself of this fact, you will be able to rejoice when your body begins going through the spontaneous movements of recovery during periods of relaxation. If you forget this fact, you will panic when your damaged body areas begin to recover. You will imagine that your dyskinesia is increasing.

In discussions of their Parkinson's disease, people often talk about their "Parkinson's tremor." Very often, what they are actually talking about is their medication-induced dyskinesia. In fact, even most neurologists have not bothered to discriminate between tremor, adrenaline dyskinesia, and dopamine dyskinesia. Why should they? There was nothing to be done about most of it anyway, so it didn't really matter what it was called. But now that you are in recovery, these differences do matter. So study your body, observe your movements, and when you describe your motions to your doctor during your weekly visits, be sure to *differentiate between your occurrences of "tremor," "stress-induced (adrenaline) dyskinesia," and "medication (dopamine) dyskinesia."*

Why is this so important? Why all the song and dance about movement? Because Parkinson's disease is about movement, or lack of movement. During the recovery your body will begin exploring the use of muscles which have long been unused. You will begin to experience Recovery Dyskinesia, also called Relaxed-State Dyskinesia.

Recovery Dyskinesia

Now that you have a good understanding of the motions which Parkinson's disease causes in your body, you may start paying more attention to your movements. This is good, because at some point in your recovery, you *will have* a new set of movements.

During recovery the damaged areas of your body will regrow. Blood vessels, nerve cells, muscle cells, substantia nigra cells, and even the brain cells which coordinate movement will regrow. When this healing gets to a certain stage, the long-disused muscles will begin to be able to move. They will begin to have warmth, then sensitivity and awareness of their location, and then strength. But coordination is still a long way away.

Imagine a new-born baby. The arms and legs and facial muscles are all in place and healthy, but they are not coordinated. There is no control over them. Watch a new baby as it grimaces, or smacks itself in the face with an arm. It seems cute, doesn't it? This is what is going to happen to you. During recovery from Parkinson's disease, every person, in my experience, has experienced some sort of uncontrolled movements. It will commence just as you think you are beginning to get better. You will notice many of the positive changes, such as increased warmth and sensation and less dyskinesia. Just when you are starting to feel pretty good about your recovery, you will get surprised by the strange movements of your body. Remember the image of the baby. The baby is not alarmed by these movements. If you are informed about what is going on, you will not be alarmed either.

These movements, called recovery dyskinesia, may occur at any time, *especially when you are peacefully resting.* The movements are not caused by adrenaline. They are *not* related to your medicinal dopamine levels. Patients who have never taken Parkinson's disease medications have also experienced recovery dyskinesia. This type of dyskinesia is caused by

the brain beginning to explore the connections and coordination of muscle groups long dormant. Even though you may imagine that you have some degree of coordination, remember: you were only using your intact muscles to perform your various activities. Your muscles which were located along the line of degradation were no longer in use. Your healthy muscles were compensating for your dormant, unhealthy muscles. Now that your body is restoring these muscles, it will need to relearn how to use them. If the Parkinson's disease was fairly advanced, you will be nearly starting from scratch. You will be like the newborn baby.

When a baby swings its arms around or jerks its legs rhythmically, it seems fairly harmless. When a 150 pound adult does the same thing, it can be alarming, to say the least. But if you are prepared for these spontaneous movements, you may be bemused by them, and even inspired, for they tell you that you are entering a new stage in your recovery.

During your recovery, you may have a few mild events of dyskinesia from various muscle groups, or you may have one set of muscles which exert themselves strenuously. Each person's recovery is unique. Your dyskinesia symptoms will effectively draw you a picture of where recovery is occurring. It will be a dramatic demonstration of just which muscles were dormant in your particular case. It will help you to understand why you have the unique symptoms which defined your own Parkinson's disease. In the following section, I will offer a few generalizations about recovery dyskinesia. I will then explain the ways in which this dyskinesia appears in the various muscle groups. *No one will have all of these symptoms.*

Recovery dyskinesia may begin abruptly. The muscle group in question will begin moving on its own. You may experience a strong sensation of being out of control. You are. Just let it go. The movement is usually a steady, rhythmic, tightening and relaxing of the muscles. The sentiment heard over and over was well expressed by one patient, who persisted in calling these dyskinetic movements by the wrong term: *"My tremor doesn't go as often, but when it does, wow! It's much more intense. And it's when I wouldn't expect it. And it doesn't seem to have anything to do with my medication. And gentle tremor never used to make me tired, but this is almost like muscles are involved or something. It tires me out."* Also, the movements will seem vaguely strange, not quite like the familiar tremors and twitchings to which you've become accustomed. *"For years my twitches and tremors used to jerk the muscles in a certain direction,"* observed one patient at this stage, *"and now all the jerks are going in the opposite direction. For example, my fingers used to jerk and twitch towards the little finger side of my hand. Now, all of a sudden, the fingers are jerking and twitching towards the thumb."* If you find yourself expressing these sentiments, you are experiencing relaxed-state, recovery dyskinesia. You are beginning to recover from Parkinson's disease.

"My tremor (or various movement symptoms) occurs less often, but it's much stronger when it does occur."

That is the phrase that your acupuncturist is waiting to hear. A variant of this is: *"My side effects of my medication are changing, getting worse; I'm doing strange new motions which I've never done before..."*

If possible, just sit back and enjoy the sensation of having a limb suddenly start pumping back and forth by itself. It will be utterly effortless. An observer might say, "Why on earth are you doing that?!" Just explain that you are regaining use of your muscles, and there's nothing you can do about it, and try to relax and enjoy it. Each episode only lasts for about twenty minutes. The episodes may be once an hour or once a day. They may last for a week, but it is more likely that they will come and go over a period of months. If panic sets in, it is good to look

at a clock, and remind yourself, "This will only go for about twenty minutes." In a strange sort of way, it can actually feel good. If you pay close attention to the movement and realize that this part of your body has been dormant for so long but now it is coming back to you, you can see in this dyskinesia a cause for celebration, a welcoming back of that body part. The best way to deal with this dyskinesia, in fact, is to embrace it. When the movements begin, go along with them. Rather than resisting, encourage your body to move in the motions which it is trying to make. Mimic the movements, and even exaggerate them. If your arm is pumping up and down, throw your whole body into it. Really pump that arm up and down with vigor and intent. It will cause the dyskinesia to end sooner, and it will help the recovery process to go more quickly. Trying to resist will be an exercise in futility and frustration. Playing along with it, encouraging it, will accelerate the healing.

Patients in the early days of research in Parkinson's recovery, not knowing what on earth was going on, sometimes got in the car and drove to the hospital. By the time they arrived at the hospital twenty minutes later, the symptoms would have ceased. The patients would go home, and two hours later, the strange, uncontrollable thrashing would start up again! It was certainly puzzling for the first few research volunteers. Be grateful for their experience and the knowledge gained from their recoveries. When your own recovery dyskinesia begins, just keep doing your regular work if you are on the job, or sit back in a chair and watch your limbs jerk if you are relaxing at home. It will alarm any and all who are watching.

But knowing that this dyskinesia is the greatest harbinger of recovery from Parkinson's disease, you will be wanting to jump for joy. This is a wonderful stage in the recovery process. This stage means that you have turned the corner. From this point on your recovery will accelerate. There can be no backsliding after this. Your body will be driven, after this stage, to complete the recovery process. So, though it will be emotionally trying, especially when it happens in public, try to put a smile on your face and anticipate what it will mean to be free of Parkinson's disease.

In general, the younger and stronger the patient, the stronger the dyskinesia. A forty five year-old may have powerful, wrenching dyskinesia. This person may be finished with the recovery dyskinesia process in a mere month or two. A sixty five year-old will have dyskinesia which is gentler, and which continues over a much longer period.

Recovery dyskinesia is not related to your Parkinson's medication. In fact, by the time you begin having the recovery dyskinesia, you will have noticed a change in your relationship to your medication. The following patient quote illustrates this: *"The timing of my meds doesn't seem to matter very much anymore. I used to know when to take my meds, because my symptoms would begin to act up. Now, I only take my medication because my watch tells me I should. I don't actually have symptoms if I forget a pill. Sometimes I completely forget a dose, and it doesn't seem to make a difference."* Please note: this does *not* mean it is time to change your medication levels. You are still in recovery. Work with your neurologist on this. I merely mention the medication to point out to you that your body is beginning to be able to cope and compensate for varying degrees of medication in the body. This recovery dyskinesia is not being caused by the medication. Therefore, don't imagine that changing your medication levels will alter the fact that you must go through the process of relearning to use these muscles.

NOTE : This dyskinesia will usually occur while you are *peacefully resting*. Also note, if you let yourself get anxious due to the new dyskinesia, adrenaline will kick in, and the

movements will become greatly amplified. Do not be afraid to begin this therapy because you are afraid to suddenly have dyskinesia at work. (Unless you have a job as a mattress tester.)

Here is a brief listing of some of the various body parts and the type of dyskinesia which *may* be experienced during recovery. *No one will have all of these symptoms.* People who are elderly or quite weak may scarcely notice that they are having symptoms at all.

Try to keep your sense of humor when this begins. The pioneer patients who first experienced this type of dyskinesia nick-named it "Slamming," as in, *"The body change stuff is kinda mild up until the Slamming starts...but once you start Slamming, then you really know you're changing"* and *"I started arm Slamming this week. Wooooo. It's a lot more intense than the face Slamming."*

Face

The facial muscles may begin to spasm. This will cause grimacing expressions. The cheek which used to sag lifelessly will be pulled up tightly towards the eye. The eyelid which was sagging down may begin to twitch. The corners of the mouth will be jerked upwards. This usually occurs on only one side of the face, and that is usually the side of the face which was the first to show symptoms. Usually this side of the face will experience dyskinesia until the side is recovered. Only then will the other side of the face begin its grimacing. This can be a bit embarrassing if you must be out and about in public. Then again, it is no more embarrassing than falling face down in public, as you might do in middle stage Parkinson's disease! Try to keep your perspective. Again, it will only last about twenty minutes at a stretch. It can be exhausting if it occurs every hour, around the clock. Get plenty of sleep. It may only last for a few days. If your Parkinson's disease was fairly advanced, it may occur every hour of the day for several weeks, after which it will occur in decreasing frequency, intensity and duration over a period of another month.

Vision

Don't run out and get your vision checked. Your eyes will begin making subtle changes. The muscles which move the lower focus muscles of the eyes have been increasingly rigid over the years. As you begin to recover, these muscles will alternate between loosening up and being flaccid, and tightening up with new vigor. This means that there will be times which may last for up to twenty minutes at a time where your vision will be much sharper than it has been in years.

A patient reported *"I need to remove my glasses, sometimes, my vision is so good. Yesterday I saw a hawk in a treetop three houses away without my glasses!"*

There will also be times when it seems as if your eyes won't focus quite as well as they used to. This can be very disconcerting, especially if the vision was, just moments ago, more crisp than it had been in years. The eye muscles will take a fairly long time to reach recovery equilibrium. The muscles may not spasm or relax at the same time, so you will notice that one eye is doing just fine and the other eye is either too good or not really good enough. No one has had problems which were severe enough to prevent driving, and vision is not particularly blurred, it is just "not quite right," or "too good," for brief periods of time. It has been, in all cases so far, more of a curiosity than a danger, but it is certainly pointless to have an eye exam and replace your glasses during this stage. It may take nearly two years before the eyes are working at a consistent level of focus muscle tension.

Neck

If you had been prone to tightening of the throat muscles causing either a hoarse, weak voice, or "choking/thirsty" events, you may have some throat muscle dyskinesia during recovery. It may feel as if those choking bouts are coming every few minutes at first, but if you pay close attention, you will notice that they are actually different than they used to be. The old muscle spasming was severe, and the throat would feel sore afterwards for quite a while. During recovery, you will notice that these choking feelings come more and more frequently, but they are gentler and gentler. *"I started having these choking things in my throat,"* said the patient. *" I would get so thirsty, so I started keeping a glass of water by my bed. Then they got milder over the last few weeks. Now when it happens it feels like I'm wearing a turtleneck. Doesn't last very long anymore, either."* At some point, you will realize just the slightest sensation of tension in the neck now and then, but nothing resembling the old hoarseness or choking. And then, one day, you will notice that you just never do that choking any more, or else your friends will begin to remark on how much louder your voice is.

A Wonderful Tip! When the choking begins, you can perform acupressure on yourself. There are three points to rub. (see fig. 3) Use your index or middle finger and massage the following points gently (they will be tender) for three seconds each. Repeat the three points until the spasm is gone.

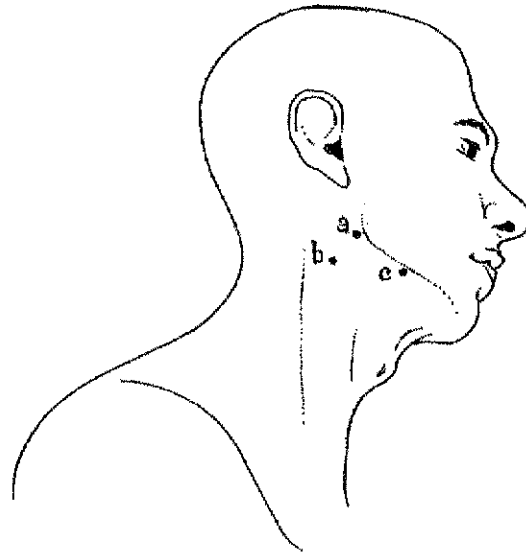


Figure 3

The three points are:

- a. SI 17, just behind the upright portion of the jaw bone, just above the corner of the jaw. Come in behind the bone, pointing your finger towards the front of the face.
- b. TB 17, just below the lowest point of the earlobe, in the side of the neck. There is a depression in between the muscles which you can just get your finger into.
- c. Near ST 5, just under the jawbone, midway from the corner of the jaw to the front of the jaw. You want to rub under the jawbone, to the inside or "medial" side (towards the center of the body) of the jawbone in the soft tissue under the chin. Don't rub on the bone itself. There is a salivary gland there, tucked along the medial edge of the jawbone. The motion you make with your finger is as if you are milking the salivary gland to cause it to produce saliva.

Here's how these points work. When you repeatedly stimulate these points in order, it causes the throat to relax and the salivary gland to produce saliva. This in turn makes your brain and throat think that you are getting ready to eat food. This causes the throat to relax even more than usual to make way for the incoming food. This is a normal response to food. By tricking your throat into thinking that food is coming down, it will stop spasming and get ready to be open as wide as possible. Neat, huh? Do a dry run, before the choking begins. Isn't that fun?

Shoulders and arms

The shoulder/arm dyskinesia can be quite startling. The entire arm may jerk up and down as if saluting. You may slap yourself in the head or face. Your arm may jerk back and forth across your chest. This creates a "Me Tarzan, you Jane" sort of effect. Sometimes, both arms go at once, alternating. The intensity of the blows to the chest varies considerably. A healthy young person can actually end up with a bruise or two from pounding on their chest or face.

Remember, the healthier and more vigorous the dyskinesia, the sooner it will be over. A bruise or two is a small price to pay to leave your Parkinson's disease behind. This dyskinesia will occur in decreasing frequency, duration, and intensity over a variable period of time. The variables include age and level of Parkinson's symptoms.

If you had been having arm and shoulder dyskinesia as a side effect of your medication, it may have been the type where your arm is suddenly pulled backwards, behind your back, with the fist clenched shut. This new dyskinesia will be just the opposite! The arm will be swinging towards the front of the body instead of the back. As you make careful observation of the direction of the muscle movement, it will be easy to discriminate between the old medication-induced dyskinesia pattern and the startling, new, recovery movements.

Hands

The hands may have jerking motions. Observe them closely. It may seem as if the tremor has suddenly gotten much worse, and is now involving bigger muscles, and the tremor is more tiring than it used to be. To determine that it is in fact recovery movement, and not Parkinsonian tremor, note the direction of the tremor. Most often, Parkinsonian hand tremors are pill rolling or wrist vibrating. If there were the larger dyskinesia movements of the hand, especially the dopamine dyskinesia, it was probably a flapping motion in which the fingers flap shut onto the palm of the hand, and the fingers are pulled towards the little finger side (ulnar side) of the wrist. Sometimes even the wrist is pulled over to that side. During recovery, the motion will be just the opposite. The fingers will start flapping towards the thumb. Also, if the tremor used to be a pill rolling motion, in which the thumb was constantly springing away from the index finger, it may now change, during recovery, to a steady rhythmic motion in which the index finger pulls towards the thumb, and then relaxes away from the thumb. This new motion will seem more fluid, more circular, as if the fingers are describing a circle, rather than the old motion of staccato jerkiness.

If the hand motion was one of flapping shut, it may become one of flapping open, where the relatively extended period is one in which the fingers straight stick out.

Chest

If the chest muscles have become slightly rigid over the years, making the "hunched posture" often seen with Parkinson's disease, there may be some dyskinesia in these muscles. It will feel as if there is a heavy weight on the chest. Some patients have compared it to asthma. The contraction and spasming of the muscles over the chest will make it slightly difficult to breathe. Walking up hills may be very difficult for a week or two. Patients in recovery have experimented with breathing techniques to help get through this stage. They have found that "labor breathing" works well. Labor breathing means lots of very short, quick breaths. Do not try to struggle against the spasm and strain to draw in a deep breath. You just will not be able to. Instead, take dozens of short fast breaths as if you had just run a sprinting race. Breathe the way an overheated dog does, in quick, short pants. The sensation of being short of breath will pass, usually within a few minutes. This type of dyskinesia rarely lasts more than ten minutes at a stretch, at the most, though it may occur on and off for months.

Breathing problems

Although many patients find that the recovery dyskinesia which occurs in the chest muscles is a mild deterrent to breathing, others seem to have a very difficult time with it. For so

many years the muscles of the chest have been rigid, like rock. These rigid muscles are a large contributor to the hunched posture which is characteristic of Parkinson's disease. These very large muscles which run down the front of the chest have become useless, and locked into an increasingly tight and hard band which was pulling the chest smaller and smaller, making the posture hunched and limiting the ability to take a deep breath. When those muscles begin to recover, they will do two things: first, they will become relaxed, as the old, rigid pattern begins to break down and be replaced by muscles which can actually relax and tighten correctly. Before the muscles can behave correctly, they often go through a stage where the muscles spasm out of control for a while. Second, they will begin to practice flexing, as they slowly resume some muscle tone and vigor. During this second stage, while the muscles are just relearning how to function, they will not be smooth and responsive to the subconscious brain commands which normally regulate breathing.

The relaxed stage usually precedes the muscles tightening stage by a few months. During this stage the chest might just feel very relaxed and open. The muscles of the chest, practicing at flexing their new-found ability to expand and contract, are not yet very skilled at making the graceful, subconscious movements which should accompany breathing. So at times they become utterly relaxed. This causes the chest cavity to become very large. At these times there is so much air in the lungs that a person might not need to breathe very rapidly at all. Just the opposite. Nearly a minute may go by, and then suddenly, when the urge to breathe does come, it may be startling and even frightening to realize that there has been no inhalation for such a seemingly long time. *“I was taking a shower, and then I breathed in, and I panicked, because I realized I hadn't been breathing! It's as if I didn't need to breathe! I was afraid I had forgotten how to breathe, so I kept reminding myself for the next few minutes 'breathe!'”*

Don't worry. You will remember to breathe. It is not that you have forgotten how to breathe, it is that the lung cavity is so enlarged that your air supply is greatly increased. This is disconcerting, but not painful or dangerous. The reason that you are not breathing frequently is that you do not need to. Your body will breathe just as often as it needs to provide you with fresh air. You are not “forgetting” how to breathe. You are breathing less frequently because the expansion of your chest cavity is giving you so much oxygen that you don't need to breathe as often.

What is more alarming is when the opposite occurs during the second stage of chest muscle recovery. When the opposite occurs, namely the tightening up of those muscles which have been rigid for so many years, it feels very bad indeed. Patients have shared the following: *“It felt like an elephant was sitting on my chest.” ; “I thought I was having a heart attack.”; “I became absolutely rigid and could barely breathe. I was taking big, struggling breaths to try to get air into my chest, and I thought I was going to die.” ; and “It's so frightening, it seems as if you're going to not get enough air, and so you take big, gulping breaths, and that doesn't do any good, and it's exhausting, so then you take gasping little breaths, and sometimes it lasts for hours.”*

These patients have had severe difficulty in taking a deep breath. The new muscles which are growing in the front of the chest wall cannot relax very easily or smoothly. They are like the hand muscles of a new born baby who has just gripped mommy's finger in his tiny hand, and he can't let go. The newly restored muscles of the chest wall are doing the same thing. They are saying, “Whee! Look at this! We can flex our chest muscles! How strong we are!” And they can't loosen up very well.

That playful muscle flexing causes you, the patient to feel as if you cannot breathe. Many patients have gotten to this stage in the recovery and become understandably alarmed. Several patients have, at this stage, gone to the doctor for a complete check up. When they describe the symptoms to the doctor they are typically given a chest x-ray, a heart test (EKG), an oxygen check, a treadmill test, and various tests to determine if the body is in fact receiving enough oxygen. Every patient who has gone through this battery of tests has been relieved to be assured that the body is doing just fine, and that there is plenty of oxygen getting to the tissues, even during the attacks of what feels like labored breathing. However, that does not make the sensation of compression of the chest wall any less alarming. Even though the medical tests assure you that everything is fine, it still feels as if you can't open your chest and breathe easily, because you can't. In fact, you can breathe as much as is necessary. The diaphragm muscle is still working just fine. You ARE getting oxygen, and plenty of it. Many of the other muscles of the chest are working just fine. They are working to assure that you can get all the air that you need. It only feels as if you can't get enough air because those muscles which run down the front of the chest, which should ordinarily be moving along with the rest of the group, are defiantly remaining clenched, locked in place as if someone is gripping you around the chest. The normal, human reaction to this is to try to expand the chest outward, to loosen the binding sensation. And that's when the trouble starts. This spasming is much, much stronger than you are. It is completely out of conscious control. You can struggle all you want, trying to pull in huge, gasping breaths, and you won't be able to get any increase in the chest capacity. This is when the fear factor sets in.

Most patients, when they first begin to experience this, struggle mightily against the pressure, exhausting themselves and terrifying their loved ones. They usually reach for their Parkinson's disease medications, wrongly thinking that this is some new, bizarre manifestation of the Parkinson's disease, and, not knowing any better, they start tossing back medications such as Sinemet in a desperate attempt to get some control back. This will NOT work. One patient insisted that if she took a small (regular, yellow colored) Sinemet, the breathing would eventually go back to normal. She began to graph the incidence of chest spasming against the intake of Sinemet over a period of weeks. She found that the medication actually made the spasming last longer. This makes sense, because most Parkinson's disease medications are stimulants. When you add a strong stimulant to a muscle which is vigorously spasming, it will be able to work all that much harder, and spasm even better! The chest spasming had in fact stopped, eventually, after she began taking the extra Sinemet. But she was able to conclude from the charts that she made that the periods of difficult breathing ended more quickly when she did NOT take the extra Sinemet. The difficult breathing WILL stop. It appears that it will stop faster if no extra medication is taken. Feel free to chart it for yourself and see if the breathing problems last longer at each episode if you take extra medication or not.

The best thing to do, based on the reports of all the patients who have dealt with this, is to do a short, quick, panting type of breathing. This does not put any pressure on the muscles in the front of the chest. It guarantees plenty of oxygen. It is easy to do, because it uses a completely different set of muscles, muscles which are not involved in the spasming. If you do the short, quick panting breath it will bypass those new muscles, those muscles which are having a field day by compressing themselves, exploring their new capabilities, and instead draw on those muscles which are perfectly functional, so that the necessary air can continue to flow easily into the lungs. .

Although it will seem logical to think that you don't have enough air during this time, in fact, you have plenty of oxygen. Some patients think, at first, that it would be best to lie down and not do anything strenuous, because there is not enough oxygen. That's not the case at all. In fact, it doesn't matter if you lie down, go for a walk, take a nap, or go skiing. The muscle spasming will go on completely regardless of whatever you choose to be doing. It will go on its merry way regardless of what meds you are taking. It seems, based on patient reports, that the spasming, and in fact most of the symptoms of recovery, will occur in their own sweet time, and there doesn't seem to be much that one can do to speed them along or slow them down. Most patients, when they finally get a grip on the fact that there is nothing to be done but grin and bear it, just get along with their daily, busy life, and reconcile themselves to breathing like a woman in labor (pant! pant! pant!) and go ahead with their normal life. It will seem strange at first, walking around breathing like an overheated dog, but in fact, it is the most painless and easiest way to deal with the spasming of the chest muscles.

How long will this go on? Hard to say. The first time it occurs will probably be in the evening, when you are relaxed and winding down, maybe staring at the TV at the end of a long day or maybe even after you've gone to bed. The body usually tries to do this sort of playful experimentation with new muscle groups when the body is relaxed. The first time is the most alarming. This is the time that you begin to think in terms of heart attack and seizure! The second time that it occurs you may say to yourself, "That's funny, this happened a week ago..." Soon, it may be a daily occurrence, it may be weekly. It may happen once a month. It may last for twenty minutes or three hours. It may happen on and off during a day so that you have two hours of rapid breathing followed by two hours of rest, and then back to the heavy breathing again.

Some patients have found that, contrary to all intuition, it actually feels better to get out and walk around. Stimulating exercise can decrease the symptoms. Remember, the body is doing this when it thinks you are relaxed. If you are actually busy and using your body vigorously, such as during a nice brisk walk, the body will turn off the recovery games and resume its normal mode of operations. This is surprising to caregivers and friends, who are concerned that the patient should be staying in bed, conserving breath. In fact, this is not the case at all. There is actually plenty of oxygen. There is plenty of air moving in and out of the body. The only problem is that the muscles of the chest are stone rigid in spasm, and so it feels as if you can't expand your chest in the usual way. Once you overcome the panic associated with this feeling, you can relax and behave in your normal fashion, as long as you pant like crazy. *"I've started going for long walks whenever the rapid breathing sets in. It's funny, it doesn't make me breathe any harder, in fact I think it actually makes it stop sooner."*

For some reason, going up stairs and climbing hills seems to be the most difficult thing to do while the chest is tightened up. Walking on level ground actually seems to decrease the breathing problem.

How long will this go on? That depends. Three months seems to be the longest that anyone has had intense breathing dyskinesia. Some patients have only had it for a matter of weeks. Some have only experienced the mild chest discomfort which is outlined in the section just above, entitled *Chest* dyskinesia. The most important things to remember are:

- 1) You will not suffocate.
- 2) If you go to the emergency room, they will not know what to think, once they determine that you are not having a heart attack, and in fact your oxygen level is normal. They will decide that

you are having some sort of emotional trauma. Most likely they will be utterly unfamiliar with the symptoms of Parkinson's disease, and especially with the recovery symptoms.

3) Increasing your medication will not help. Increasing the medication may intensify the strength and duration of the episode.

4) Short quick breaths are much, much easier on the body than deep, struggling breaths, which won't work anyway.

5) Your caregiver, friends, or spouse will be very, very alarmed every time the rapid breathing starts. If you can explain what is going on you can help relieve some of the concern.

If worst comes to worst, and you are certain that you will suffocate, remember this cheerful fact: If you actually do start to have an oxygen shortage, and you get light-headed, and go so far as to pass out, the moment you pass out your body will relax and the muscles will all go limp, including the tight muscles over the chest. So then you won't have any chest compression for a while and it will be easy to breathe! It is reassuring to know that the body has this back-up mechanism to prevent a tightening of the lung muscles from causing a serious lack of oxygen. But this has NEVER occurred in any patient who is going through this. In fact, once you become used to the sensation, you will realize that you do in fact have plenty of air.

6) If you are at all concerned that you may be having a problem with your heart or your lungs, SEE YOUR DOCTOR. If nothing else, it will set your mind at ease. If you do want to have a complete physical, at this stage, as many of my patients have, do so. It will also help to reassure your loved ones that you really are OK.

Abdomen

The muscles in the abdomen may spasm or contract a bit. This will make you suddenly feel as if you are pulling your stomach in. This sensation may create a feeling of urgency, as if your bladder is full, or else digestive pain, as if the abdomen is bloated.

Buttocks

This is fairly rare, but it can happen. The muscles of the buttocks begin to tense up and then relax. It is usually painless and tension-free, but it feels "funny." The muscles alternate tensing on one side and then the other. *"My butt started going back and forth, sort of dancing, all by itself. It didn't hurt or anything, but it was so funny! Maybe my butt muscles will get round again! I used to have a nice round butt, but over the years it's become perfectly flat. Maybe it's flat from the Parkinson's? At any rate, the muscles of my butt are coming back, and I never even knew they were gone."*

Legs

Spasming may occur in the legs. This becomes most apparent at night, though it may also occur in the daytime. Many people report "restless legs" or "flailing legs" but for most patients the new movement is easy to differentiate from the traditional "restless legs" because the motion is much more steady and repetitive. Although most of the recovery dyskinesias only last up to twenty minutes at a stretch, the twitching of the legs during the night may go on for hours. I suspect this is because during the day the legs are being used for support, and the legs cannot really relax and get down to the business of exploring their new nerve connections. However, when you lie down for a good night's sleep, and the strain is taken off the legs, they may go into a free-for-all of kicking and jerking. *"My legs took turns 'taking big steps,' as if I were marching, when I laid down for bed. Left! Right! Left! Right!"*

When the legs begin their dyskinesia, you may feel the urge to repress the movement. After all, you need your sleep! As a patient reported, "*I try to stop them from moving, I even take extra dopamine, I try telling my legs 'stop it!' I believe in mind over matter, but I just can't get them to stop.*" I like to remind patients at this point what is really meant by "mind over matter." Mind over matter does not mean denial. Your legs need to grow and heal, discovering their "new" sensations. To deny them this opportunity is to be fighting with yourself. The true meaning of mind over matter, in this case, is this: use your mind to support your legs in their recovery. Mentally send energy to your legs. Visualize the area of the leg which is shown in the diagram (fig. 1, pg. 33) as being the injured area. Focusing on that area, imagine you can send light and energy into your legs, first the upper leg, then the lower leg, then the foot. Then begin over again with the upper leg. Send energy, visualize light going to the muscles, and tense the muscles. First tense the upper leg, then the lower leg, then the foot. Then repeat. Focus especially on the areas of the leg and foot which are the injured areas. Do this for as long as you can bear. This is truly mind over matter. If you wish to use your mind to assist in your recovery, be honest with your mind. Do not deny that your body was sick. Use your mind to accelerate the healing, to conquer the illness. This is the correct use of "mind over matter."

Some patients have reported that increasing their bedtime dose of Sinemet helps to stop the leg movements. This is because the Sinemet provides extra stimulation to all the muscles, including the healthy leg muscles. When these muscles get more stimulation, thanks to the Sinemet, they can help restrain the muscles which are in recovery. It is not a good idea to increase your medication to mask and deaden the symptoms of recovery. Please discuss medications with your neurologist, and consider reading *Recovery from Parkinson's – The Medication Handbook (available soon)*.

Ordinarily, at bedtime, the strong, healthy leg muscles would be beginning to relax. This relaxation of the healthy muscles at bedtime is the reason that the recovering muscles finally get their chance to "cut loose." So Sinemet can increase the controlling power of the healthy muscles.

HOWEVER, others have found that they can better control their restless legs by *decreasing* their evening Sinemet, or *omitting* the bedtime dose altogether! Work with your neurologist for the best way to proceed.

Sometimes, towards the end of recovery, you will feel the urge to lie in bed at night and "flap the feet." Many people with Parkinson's disease, when they reach this stage, suddenly have memories of long ago childhood years, when they used to lie in bed and "flap the feet" back and forth. Do you know why you used to flap your feet? Your body knew that it was injured. This was your body's way of trying to dislodge the stuck section in your foot. It felt so good to flap the feet, as your body tried to shake loose the stuck, twisted fascia in the center of the foot. It never succeeded, of course. And through the years, that area became numb, "disowned" by the rest of the body, until finally the urge to flap was forgotten. Now, the body wants to flap again, to feel the sensation in the foot, and rejoice in the freedom of movement and the correct flow of energy through the restored foot bones. Go ahead and flap!

The Back

Ah. The back. You *will* have dyskinesia in the back, especially the low spine. Every person has this. It seems to be unavoidable. During Parkinson's disease, sometimes a hunched posture develops. This is not due just to the tightening of the muscles down the front of the body. During the development of Parkinson's disease, the muscles of the back, along the spine,

are also changing. They are becoming weak. As the chest muscles pull in tightly, and the muscles of the back loosen up and spread wide, they combine to create the hunched posture. And during recovery, the back muscles will begin to tighten, which will cause low back pain. Unlike the other forms of recovery dyskinesia, the back pain will not come and go every twenty minutes but will be nearly constant. Though it may ease up when you are standing, the pain will be very strong when you are sitting or leaning forward, such as when washing dishes. It will last for months. It may be a nagging dull ache, but it may be a strong, pulling back pain. It will feel just impossible for you to bend and stretch. Patients report: *"I feel so old, I can't do my yoga because my back hurts all the time"; "I hurt driving the car, I hurt sitting in my desk at work"; "What can I do about this back pain? I don't think it's ever going to go away"; and "Everything else is better, but I still have this d--- back pain."*

The back pain is going to be with you for a while. Patients have found various things that help. Hot tubs, Epsom salt baths at bedtime, over-the-counter pain relievers and prescription level anti-inflammatory drugs are just some of the solutions which patients have come up with. Do whatever it takes to ease the back pain. This is no time to be a martyr. The back pain will last for a very long time. But it *will* end. The shortest duration of back pain, in my limited experience, was nearly a month. That was in a patient who had just been diagnosed, and only had Parkinsonian symptoms on one side of her body. Her low back pain was mild and was only on the one side of the back. Most patients, especially patients whose Parkinson's has become bilateral (on both sides of the body) will have back pain on both sides at the same time. The longest duration of back pain, so far in my experience, is five months.

The back pain does go away. Again, experiment with it. Visualize energy going into your back. Try to consciously tighten and relax the muscles of your low back. The sooner the muscles are recovered, the sooner the back pain will go away. During this time of low back pain, your posture is also beginning to change. It may be imperceptible to you, but your entire body weight is shifting back to where it should be. Muscles which were not doing their job are beginning to buckle down and get to work. Other muscles, having been doing work which was not rightfully theirs, are beginning to relax and yield to the new muscles. The entire body is going through a tremendous postural change, even if you had never noticed any postural irregularities. In fact, most people with Parkinson's disease pride themselves on their upright posture. Many had a perfect "military bearing" before the Parkinson's disease set in. But even so, they have been maintaining that posture by "splinting" the healthy muscles to do the work of the dormant ones. So understand that your low back is doing a tremendous job, supporting you during this change. When the back pain goes away, it will be as if it was never there, like a fleeting bad dream. But you will feel more balanced and posturally more vigorous than you have felt in years.

Summary

To summarize the recovery- dyskinesia, it will occur in various parts of the body, probably not in each one mentioned here. It will be strongest at the beginning. Over a period of time the episodes of dyskinesia in any given muscle group will decrease in frequency, duration and intensity. Although some people experience both sides of the body spasming at the same time, the dyskinesia, or spasms, will generally begin on the side of the body which first had the Parkinson's disease symptoms. It may then move to the other side, after the first side is nearly

healed. The exception seems to be the back. Most people have both sides of the back in spasm for months.

During the time of recovery dyskinesia, the other symptoms of Parkinson's disease will still be following that pattern that was explained in the Early Stages portion of this handbook. In other words, old symptoms may be changing, new ones may be showing up. For example, if your tremor was a low level, constant tremor, it may now be very rare, nearly forgotten. If it was intermittent, it may now be constant. The opposite side of your body may suddenly seem much worse off than before, even as the "bad side" seems to be recovering. Or both sides may seem to get suddenly worse at the same time. But there may be motion in the area which, when it occurs, is quite robust. Or perhaps, if you were plagued with strong dopamine dyskinesia, you may find that you are better able to control those symptoms, but your rigidity has increased. You may suddenly find yourself unable to move your feet forward, as if your feet were stuck to the floor. This is alarming, and you will feel for certain that you are getting worse and not better. When you are beset with doubts, do an honest appraisal. Are your feet healthier looking than they have been in years? Do you have more sensation in your hands? Can you dress yourself more easily? Have friends noticed that you are smiling more? Try to keep a mental checklist going so that you can decide whether you are really worse off than ever, or if you might actually be having signs of improvement and decline happening at the same time. If this combination of good and bad is what's happening, hang in there.

This is a very difficult time. One patient's swings were extreme. *"My symptoms used to be pretty predictable. I would fall down about a dozen times a week, but I could always get around with the walker. But last week my body suddenly went completely rigid. I couldn't move for over 100 minutes. That's never happened to me, ever. It was horrible. Also, some days I'm unable to turn, and I just walk in a straight line until I get stuck in the corner. Or I can't lift my feet off the floor, I can't take the smallest steps. This is horrible! I'm terrified of what's coming. And yet, the day before the freezing-up day, I was able to go jogging for 15 minutes. And the following day I was able to go jogging as well. When I do feel good, I feel really, really great. I don't need my walker, and I can go days without falling down. But when it's bad, boy, I get scared.*

"Some days my whole body will just stiffen up, and the next day I'll feel better than I have in years. At first it would take about five days for the stiffness phase to let go and the relax phase to kick in. Now I can swing back and forth from stiff to relaxed in about three hours. It used to scare me. Now I'm learning that the stiffness is a harbinger of a looming decrease in medication, and ever-increasing recovery, so it's kind of fun..."

Keep these stories in mind, and see if your case is similar. Are the "bad" days getting considerably worse, and are there a few good things happening at the same time? When in doubt, remember: Change Is Good. If, on the other hand, you feel you are definitely not making progress, or you feel that there have been no changes in over a month, or that the progress which you have made is disappearing, please speak with your acupuncturist. There are several variations on Parkinson's disease. Although most cases of Parkinson's disease can be improved by working on the electrical channels which run over the feet, there are other cases which require additional areas of the body to be treated. If there has been a history of injury in the hip joint, tail bone, mid-spine, shoulder or side of the head, there may be obstructions in these areas which are confounding the case. These other areas can all be treated. Your acupuncturist has written instructions which discuss the symptomatic signs which should alert the practitioner to the need to treat additional areas. The instructions include information on exactly how to treat these other

areas. Often when these other stumbling blocks are treated, the stalled recovery falls neatly into place. So be aware, be positive, and communicate with your acupuncturist.

Questions from Patients

Q. This past week I have been awakened in the early morning by cramps in my calves. This could be as a result of missing my daily walk a few times. I got in a good walk yesterday, and had no cramp this morning.

A. Maybe. Then again, many people have cramps in their legs, especially the backs of the legs, as the legs begin to recover. But you present a wonderful point, which is that daily walking is absolutely wonderful, and one of the best things you can do for yourself. Walk outdoors, a considerable distance, every day!

Q. Last week I had a horrible week. My dyskinesia was suddenly horrific, incredible, unlike anything I'd ever experienced. I saw my MD, and she had me admitted to the hospital, and they made me cut my medication in half. I was much better within twelve hours after they reduced the medication, and now my MD says that I must not have ever had Parkinson's disease, because if I had had it, I wouldn't ever be able to reduce my medication. She wants me to stop it altogether, but when I tried that, I could hardly move. Now she is sending me in for a battery of tests to determine what I *really* have. I'm pretty certain that she suspects that I've just been neurotic, and that I never had Parkinson's disease. What do you think? What should I do?

A. I think that you are recovering. This MD's response, her insistence that you were misdiagnosed, simply because you are recovering, is very common. Remember, by definition, Parkinson's disease is incurable. Therefore, if you recover, you obviously never had Parkinson's disease. You will not be able to easily change your MD's opinion, if the MDs I have met have been any indication. It is always wrong to generalize, but the MDs I have met and worked with tend to either be supportive, or at least curious, or else absolutely hysterically committed to their own understanding of Parkinson's disease.

As for your medication needs and sudden overdose, I suspect there were some warning signs that you were getting more Sinemet than you needed as your recovery progressed. Please, in future, work very closely with your MD (you may need to change MD), your acupuncturist, and your own sense of what is right, so that you do not find yourself either overdosed or underdosed.

During recovery you must walk the razor's edge, always opting for less dopamine, rather than too much, but never sacrificing safety or comfort. You will be walking that line for a year or more. Although the need to reduce medication may not begin for the first six months or so of your treatment with these techniques, be ready for when that time does come, and when that time does come, go carefully. Keep a diary of what time you take each pill, what your symptoms were, and when. No MD or advisor can know exactly what is going on as well as you can, so keep good notes.

Q. I think you are wrong when you say that the muscles have degenerated, because when my medication kicks in, I can move just fine.

A. Yes. Observe carefully the texture of the muscles along the lines indicated on page 33 and 34. Note the steely, immobile texture of this muscle when it is prodded and poked. It is especially evident on the side of the leg. Now, note what happens to this muscle when your

medication is working. No change. So how are you able to move so easily when the medication is working? Easy. The medication imparts to the working muscles, the majority of muscles, powerful energy. These muscles “splint”, or divide up amongst themselves the jobs which would normally be done by those muscle groups which no longer work. This creates the illusion that everything is just fine, when, in fact, the healthy muscle is taking on extra tasks which would most efficiently have been done by the non-working muscle.

A good way to observe this is to rotate the hands or feet and see the jerky, “cogwheeling” motion at the wrists and ankles. This motion, which should be fluid and even, requires each muscle group, in turn, to do a very specific job of rotating a particular segment of the joint. When the attempt at rotation comes to a brief stop, it is because it has come to the spot where the injured muscle should begin to work. It takes a moment for the brain command of “rotate the foot” to bypass of the non-functional group and for the next muscle group to pick up where the rotation left off. In this way you can isolate the specific muscle groups and see for yourself that although you can move nicely, you are only using certain muscle groups, and not the full complement.

LATE STAGE

Decrease in Adrenaline

“So What?”

An exciting change, and one which seems utterly impossible to most people with Parkinson’s, is the change which occurs when your natural dopamine levels are so high, and the distress signal to your brain has been stopped because the injury in the foot is completely healed. This change is: your adrenaline levels will decrease. Why should this be so fascinating, you ask? Because when your adrenaline levels drop back to a normal level, instead of being on Red Alert all day long, you will suddenly become a fairly calm, patient person. You will actually find yourself saying, with regards to some appointment or other function, “So what if we get there a bit late?” This is such a remarkable thing, coming from a Parkinson’s disease patient, that we now consider it as conclusive proof that the patient is nearing the late stages of recovery. You will suddenly notice that you are able to sit and watch the birds in the park, or stare at the patterns formed by the limbs of a tree.

One patient was asked by her adult daughter *“Is there something wrong? You’re sitting on the sofa...just sitting there”*

“No, I’m fine, why shouldn’t I be sitting on the sofa?”

“Well, it’s just that I’ve never seen you do it.”

You may find yourself being less compulsive about punctuality and responsibilities in general. You will find yourself saying, “Oh, so what...” about petty subjects which always seemed to be of crucial importance. In the words of one patient, *“So what if I get there late? I mean, it’s not like the end of the world or anything, I mean, who really cares? I can’t believe how I’ve spent my whole life really worrying about doing everything on time and doing it perfectly. All of a sudden I see how stupid that all was. I mean, if things don’t get done, so what? It’s not like most of the things we do every day are really a big deal...”*

To the mildly curious reader, the above quote will not seem especially spectacular. To someone who has spent a lifetime dealing with Parkinson’s disease, either as a patient or a

spouse, or even a friend, the above quote will be utterly unbelievable. And yet, it will happen. We now call it the So What stage, and it is a glorious time.

Panic Attacks

Following sharply on the heels of the So What stage, usually only a few months later, will come the Panic Attack. This occurs when the person has to perform a new task. By this I mean a non-emergency, insignificant chore or something inconsequential but which has never been done before. In general, people with Parkinson's disease have always prided themselves on their ability to learn quickly, act quickly, and to be efficient without regard to the emotional cost. In the words of one patient, *“If the going got tough, I used to just work harder, faster, and smarter. I never accepted failure.”*

What these people had no way of knowing was that their ability to perform so well, to learn faster, work harder, and achieve farther was not in fact coming from any inherent superiority of mind or body. Although people with PD like to imagine that they are more clever or efficient than most people, in fact, they are nothing of the sort. Where they differ from most people is that, due to being injured, and due to decrease in dopamine, they have increased levels of adrenaline at all times. Being injured causes an adrenaline increase and the concomitant decrease in dopamine, causing the body to be unable to be roused unless there is some sort of urgency in the task at hand, and creates a mental approach to everything in life in which all situations must be urgent. If they are not, they cannot be done. Therefore, these two facts, the injury and the decrease in dopamine, contribute to the Parkinson's disease person becoming more and more reliant on adrenaline over the decades.

How does brain function change under the influence of adrenaline? It becomes much more efficient. The sides of the brain are not tapped into as deeply, and the midbrain and frontal lobe are dominant. Feelings, artistic sentiment and convoluted logic are thrust aside in the urgency of the moment, and the brain fires off as quickly as possible, assimilating everything and making snap decisions in fantastically accelerated tempo, because adrenaline is the chemistry for emergency. How does it affect one's life to have lived it with adrenaline as the dominant neurotransmitter, instead of dopamine?

Unbeknownst to everyone, the future PD patient learned his childhood schoolwork and processed his emotions using adrenaline, when all the other children used both sides of the brain. Most people with PD were secretly infuriated with the other children in class by the time they reached high school, because the other children were so slow, so stupid, so thoughtful. A person with PD gets out of bed in the morning using adrenaline instead of dopamine. He brushes his teeth with adrenaline. He eats his food and meditates using adrenaline! The neurotransmitter which should only be used in rare occasions such as deathly danger or rage is used for daily maintenance! No wonder those with PD are considered “intense,” if not domineering, driven, brilliant, and a dozen other adjectives, both complimentary and negative at once, which fit gracefully over the personality of people with Parkinson's. No wonder these people stay so busy. How can you sit around gazing at the art on the walls when your internal brain is trembling and your blood is coursing with adrenaline! And so the qualities on which those with PD pride themselves, crediting Mind over Matter – the mantra of the PD person, with their seeming successes in the world, are actually parts of their disease process. Curiously, people with PD hate to hear this. They insist, often right up to the end, that their achievements and intelligence come from their superior ability to focus, to address issues and to work harder than anyone else. They do NOT want to hear that these qualities, so highly rewarded by a results-driven society,

are actually coming from their illness, and not their greatness. It is a wonderful time when, with eyes wide open, and new awareness of the beauty and joy to be gotten in stillness and inner peace, these patients begin to have a reduction in adrenaline, and a healthy level of dopamine.

One patient explained it this way: *“When I compose music, I’m not in such a hurry now. Before, I used to need to have the entire idea all mapped out, and I would rush to set down every note. Now, I mosey, I muse on things, I explore ideas. My work comes more slowly, but it’s so much more fun! I feel as if my logic circuits and my emotions are both able to express themselves more, and the crazy need for speed and completion has fallen away. It’s wonderful!”*

So why did I mention panic attacks way back there in the beginning of this little section? The other side of being able to relax, as the adrenaline levels subside, is that your body will no longer produce adrenaline unless it actually needs it. A person with PD has used adrenaline his entire adult life, and possibly even most of his childhood, to make every single decision. Decisions such as where to go for dinner, which freeway exit to take, which sprinkler head to buy--- these decisions were all made with adrenaline. The brain only knows how to process decision making through the brain sequence which uses adrenaline. What happens when there is not adrenaline coursing through the brain and blood all day, every day? A time will come when a decision must be made using dopamine. It will be a dull, ridiculously small decision. After all, if there is an emergency, the adrenaline will be there. But what happens if there is no emergency? *The brain will not know what to do.*

What will happen? The easiest way to explain it is to cite some examples from real life. I could not make these up, they are too precious.

From a PD spouse: *“Jordan refused to go to the new restaurant this weekend because he’s never been there! What the heck is that all about? We try a new restaurant every weekend, and he refused to get in the car because ‘How will we know where to park? How will we be able to find the front door? How will we know what to eat?’ It was crazy. He just couldn’t fathom going to a new place, and he got so terrified, just thinking about it, that he was nearly in tears.”*

From a brilliant scientist: *“I had just gotten another kitten, and it was dinner time. I opened the can of kitty food, and suddenly realized that I didn’t know how the new kitty would want to be called for its dinner. I panicked. I tried to think of what to do. I realized that I couldn’t think of how to think. I started trying to scour my brain for some idea of how to go about figuring out how to feed the kitty. There was nothing there, inside my head. It was a black hole. I got desperate, there was nothing in my brain, I was searching everywhere in my head for some way to figure out how to figure out what I needed to do, and I got more and more lost. Twenty minutes later, as I was standing in the living room screaming out loud--- thank goodness the neighbors didn’t hear me!--- yelling at the top of my lungs, ‘Help me! Help me! I need help!’, the tears were streaming down my face. I suddenly stopped and said out loud, “Hey! This must be the panic attack stage!”*

A quote from a very competent businesswoman: *“I was installing some new computer software. I couldn’t figure out quite what to do. I tried to think about what to do next, and I found that I couldn’t. I literally could not think about what to do next. Not that I couldn’t decide, but I couldn’t think. It was as if I had no way to process what needed to be done. My brain started spinning in circles. I was digging in my brain, searching for the way to make the flash of insight appear, and instead of insight, there was literally nothing there. It was as if there was no known thought process. I felt as if the way that I had always processed thinking was not accessible. I was stuck in my own brain with no way out, no way to figure out how to get out, no way to go about thinking about how to think! I found myself screaming hysterically for my*

husband to ‘Hurry, hurry, I’m dying! Help me! Help me! AAAAAAAAAAAAA!’ I was sobbing for nearly half an hour, it was so terrifying. And it was triggered by some stupid software installation!”

From a very strong horse trainer: *“I have been handling horses my entire life. When they act up, I punch them in the chest. If they kick me, I punch ’em. They may be surprised at first, but they learn real quick, if they’re fair, I’m fair. I’ve calmed more ponies than anyone in this county. They just need fairness and steadiness. But last week, I was working with a new horse. We’d just picked her up, and I was about to lead her into the trailer, when I suddenly stopped dead in my tracks and asked my partner what to do. She said, ‘Put the horse in the trailer and let’s go.’ But I said, ‘How can I put her in the trailer?’ And my partner said, ‘Huh? What?’ So I tried to explain, I’d never worked this particular horse before, so I didn’t know what to do with her, she wasn’t a horse that I’ve ever done before. So my partner said, ‘Are you crazy? Pull on the lead and get the horse in the trailer, what are you talking about?’ And I started crying, and I said I couldn’t because I wouldn’t know what to do. I tried to figure out how to put this horse in the trailer, but I didn’t know this horse, it was a new horse, I didn’t know what she wanted or how she would respond, and suddenly it occurred to me that she might not want to go in the trailer, or she might fight the trailer, and I didn’t know what to do if that happened, and I couldn’t figure out how to start, or what to do, or anything, and I just started sobbing. My partner told me to get in the cab, I must be sick, and she put the horse in the trailer and we drove home.”*

And finally, from an experienced driver: *“I was driving in a new town, and I missed the freeway exit. I got off at the next exit, and instead of driving over the bridge and getting back on the freeway to go back the other way, I pulled the car over to the side of the road and I started flipping out. I was sobbing, absolutely bawling like a baby. I’m forty seven, I’ve been driving most of my life. But I suddenly didn’t know what I was doing, why I was doing it, or something, I can’t describe it, it’s as if I didn’t know anything, and there was no way to figure anything out. I sat there and called home to my wife, three thousand miles away, and asked her what to do. I was completely nuts. She told me to get back on the freeway going the other way, and then take the right exit. Which sounded like good advice, so I did it. But I tell you, I could not have thought of it myself in a million years, not right then.“*

What do these stories of panic attacks all have in common? They all involve some situation which is not an emergency. They all involve the person having to perform some task which is new in some way. And in every case, because there is a new factor in the situation, and this means that some thought processing must be done, the brain tries to figure out what to do, and it cannot. It cannot process a new thought because the long-term behavior of this person is to process all new information using adrenaline. When there is no longer adrenaline, which is the correct situation in a non-emergency condition, there is no established pattern in the brain for learning a new task and performing the simple decision making which must accompany a new task.

My favorite story, because it is so simple, involved a situation in which the patient’s family was getting new rugs installed. The patient and his wife needed to move the items off the bookshelf and set them in the kitchen so the carpet people could then move the bookcase, move the sofa, and install the carpet.

“So I asked Remie to help me take the things off the bookshelf and put them in the kitchen, and he just stood there. So I told him to shake a leg, we had to empty the shelves in twenty minutes. And he took a step closer to the shelves, and then just stood there. So I got mad.

I said, 'I don't intend to do this all by myself, you need to pull your weight around here, buddy,' and I saw that a tear was starting to roll down his cheek. So I told him to stop being a lazy bum and what on earth was the matter, and finally, he choked out, 'Where should I put the things that are on the shelf?'

'Put them in the kitchen.'

'Where in the kitchen?'

'On the counter.'

'Where on the counter?'

'I don't care, put them on the table.'

'Where on the table?' And now I was really mad, and turned to see what the heck he was playing at, and I realized that he was in a state of absolute terror. He was frozen in fear, he was completely unable to move his arms, legs, or mouth. He couldn't even talk, tears were streaming down his face. He really didn't know what to do. I realized that he might be having a panic attack, like you'd mentioned, and then I realized that, in fact, he never had taken the things off the bookshelf before and stacked them in the kitchen. So I suppose it was a new thing. Whatever it was, he just couldn't figure out how to do it.'

The wonderful thing is, after the first or second panic attack, you will realize what it is and you will stop yourself in a matter of seconds as you feel it come on. You are not stupid, after all. You are just experiencing the same thing that a five year old experiences the first time the teacher calls on him in class and he is forced to think a bit in an area which is new to him. Most of those children freeze up the first few times. A few of them cry. You probably never did. You thought fast and on your feet and you probably wondered why everyone else was so slow. So now it is finally your turn to learn to do integrated, slow brain thinking for the first time, and you are an adult, a competent, successful adult. So it will seem a little funny. And it will be wonderful. Everyone has mastered the ability to process new information without adrenaline, and it takes only one or two panic attacks before the brain starts, very quickly, learning to integrate the old methods of learning with the new neurochemistry.

Do not worry. If it is an actual emergency situation, your body will give you an instant jolt of adrenaline and everything will be fine, just like old times. The panic attacks will only happen during the most innocuous situations. You will only have a few of them. After that, you will realize that your thought processes have become much richer, and that decisions are much more fun, more pleasant and peaceful. You will still be able to think quickly, but you will find that your decisions will be enriched, when appropriate, by thoughts of similar situations, memories that tickle your fancy, or goals and values which, in the past, you had been too hurried to consider.

Arm Pain

As the weakened, dormant muscles along the arm begin to regrow the arm will begin swinging again. Also, you will unconsciously begin using these muscles to lift and carry things. Because these muscles will be frail and weak for the first few hundred thousand times they are flexed, you will notice arm pain along this line. When you first begin to swing the arms again you will actually be using muscles at the back of the arm. The swing will consist of a backwards movement, and when the backward pulling muscles let go the arm will fall passively towards the front of the body. This is not a true arm swing, but only half an arm swing. It occurs when the

electrical signaling is restored enough so that the body tries to initiate an arm swing, but the actual muscle for the forward part of the swing is not yet in place. As arm muscle regrows, the arm will begin making small genuine movements towards the front part of the swing, not just follow-through from the backwards half of the swing. Over the course of a year or more the forward swing will get larger and larger.

The muscles in the arm will hurt. Because you will be using them, and they are very weak. This becomes most noticeable when you walk. When your arms begin swinging naturally, they will perform a swing for every single footstep. If you walk a quarter of a mile, your arms will swing hundreds of times. If you walk this far, swinging your arms, those new muscles, pumping back and forth for the first time in years will feel as if you have just done hundreds of push-ups. You may find that the limiting factor in how far you can walk in your daily exercise is not leg strength or dopamine, but arm pain. After a thousand arm swings or so, the pain in the arms will be quite strong. So walk every day, and push yourself a bit each day. After a year or so the arms will be strong again, and you will enjoy noticing that your arms once again have a normal shape, especially in the upper arm.

Also, when you lift or carry objects by bringing your arm up to the bent position using these muscles, the muscles will ache, for the same reason. They are young and fragile. You will notice that this pain is not in the joints, it is actually in the muscle. Also, you will notice that if you hold your arm more towards the center of your body, or further out towards the side, thereby using other muscle groups, there is no pain. Go slowly, don't use weights for the first few months of new-muscle pain. Chances are, when you use the weights, you will merely be splinting other muscles, training yourself to use your arms incorrectly. Be patient. Walk. Swing the arms and let the muscles redevelop naturally.

Vain about Veins

You may notice that your blood vessels are starting to bulge in your hands and feet. Men don't seem to care about this. Women sometimes get very concerned. Please try to keep in mind that most people with PD have insufficient veins in the extremities. (How do they explain *that* with their dopamine theory?) People with PD often develop an irregular pattern of veins in the feet in which the blood vessels do not fan out over the feet, running from every toe up to the ankle. Instead, a looped pattern develops across the saddle of the dorsum of the foot, and although some veins may run from the third and fourth toe up to the loop, there are almost no veins running up from the second and big toes. Also, the entire vein system is very small and inadequate. The vein system lies under the smooth surface of the foot skin instead of bulging making bumps under the skin. Sometimes the blood vessels are so faint in the feet that they are hard to see. There is often purple, splotchy coloration in the medial (inner) ankle area from inadequate circulation. Although most men do not mind a bit when this disease pattern begins to change and the blood vessels increase in size, many women get concerned when the blood vessels enlarge and become more visible. *“My feet are getting so ugly! You can see the veins! Horrible! I used to be so proud of my feet and hands because the blood vessels didn't show. How can I get rid of them?”* It is sometimes a struggle to convince these women that those “graceful and smooth” feet were graceful and smooth because of their disease process, and not from any inherent femininity. On the other hand, most women (again, men don't seem to even notice) are pleased when the splotchy, purpley-grey area around the medial ankles becomes healthy and pink again.

Sleep

Beyond fatigue, beyond tiredness, most recovering patients in late stage recovery find themselves wanting to sleep for days, weeks, months. Towards the end of your recovery you may feel that you will never, ever, have energy again. Patients report: *"I find myself picking and choosing just exactly how much I have to do to get through the day, rationing my energy"; "I can't wait for the weekend so I can sleep. I can sleep like the dead"; and "Every time I sit down to read, I fall asleep."*

In the beginning, the ability to sleep soundly was a blessed relief after many years of restless nights from Parkinson's disease. Now, after months of sound sleeping, and no seeming end in sight, patients can begin to get panicked. *"Will I ever have energy again? This is no way to live..."* This may last for months.

This fatigue is a good sign. In the early stage of recovery you could sleep better because the electrical schisms causing the Parkinson's disease were becoming reduced. The relief made it possible to sleep. The late stage sleep is quite different. This exhaustion is present because your body is working night and day to grow new cells. It is growing new muscles, new nerves, new blood vessels, and most significantly of all, to those who have been taught that Parkinson's disease is "caused" by absence of substantia nigra cells, the cells of the midbrain are re-differentiating back to a healthy state. The substantia nigra cells are restoring themselves. This is hard, exhausting work. This sort of growth work is similar to that which occurs in childhood, when the need for sleep is very strong. This type of growth is very tiring to the body. You need to sleep. It will end.

(As an aside, a very few people have just the opposite. They find that they are quite sleepless. The changes in their body and the dyskinesia keep them awake for hours. This may indicate another common imbalance in your body. Tell your acupuncturist.)

More about sleep

The above section on tiredness and sleep was included in the first edition of the *Patient's Handbook*. However, nearly every patient, when going through this stage of extreme fatigue, protested that they had not been warned of the severity of this stage. Therefore I have written the following enhancement to the above information. I've included some quotes, and I've written about the fatigue in more detail. And yet, somehow, because of the very nature of Parkinson's disease, and the driven, relentless nature of most people who have it, I am certain that there is nothing I could write which would prevent that most common cry of the recovering Parkinson's patient: "Of course I read about it, but I didn't think that it would happen to *ME!*"

"I'm so tired. I've never felt anything like this before in my life."

The profound need for rest which occurs in the late stage of recovery is so overwhelming that most patients become alarmed. Also, please understand that while some patients will experience a fatigue so extreme that they will be unable to rouse themselves (the Deep Sleep), others will merely be so weak as to be unable to move. This was discussed in the section on muscle weakness. The discriminating patient will recognize that there is actually a continuum, a sliding scale, with deep fatigue (the weakness) at one end and the Deep Sleep (inability to rouse oneself even if awake) at the other. Some patients will have both. Some will only have weakness. Others will not notice the weakness so much as the Deep Sleep. In fact, there is no cut and dried distinction between the two symptoms, and because most people experience some symptoms of

both, I am including in this section remarks and comments on the entire issue of Inability To Move. One of the first symptoms to occur is the encroaching weakness. At first it may just appear in the legs, especially the quadriceps muscles. This will create an inability to get up out of chairs, get up off the toilet, or mount stairs. As this continues the legs will get increasingly weak and the arms will begin to weaken as well, to the point where one won't be able to lift a coffee mug to the lips.

What is causing this profound weakness? Again, although this may be review for my readers at this point, this material having been included in a previous section, I will jot it down again. I find that I need to repeat this information to my otherwise very intelligent patients over and over, before they begin to understand that it is normal, and that it is hard to live with. It appears that this weakness begins when the muscles which were rigid and wooden begin to break down. You may notice that certain parts of your body were very stiff and board like. I've actually had patients brag to me that "in spite of the Parkinson's disease" their legs were still firm and muscular, when in fact, those "muscles" were areas of wooden rigidity. The rigidity lent an apparent stiffness to the limbs which was misconstrued as "strength." It was not strength, it was rigidity, equivalent to having canes or stiffeners inside your legs. Your other, functional muscles used these rigid sticks to push off of so that you could mount stairs easier by using your functional muscles at the back and medial sides of the legs to push against the absent but rigid dead-muscle tissue in the lateral leg. When the circulatory system brings new blood and nerves into this area during recovery, the brain will once again try to use these worthless areas. At the same time, the body will begin breaking down this worthless tissue preparatory to replacing it. The combination of trying to use the correct musculature, which hasn't been used in decades, together with the breakdown of the rigid tissue into flaccid, baby-new tissue, creates a situation where the patient suddenly has no strength whatsoever when trying to do accustomed tasks. This is devastating, and the patient assumes that they are much worse. They are not worse. This stage must be traversed prior to complete recovery. If one could apply some perspective to this, it should be cause for rejoicing, because clearly significant changes are underway. However, the driven personality of the typical PD patient is not easily assuaged by the words "This is just a part of the recovery." This is not just due to impatience. This is also due to the years of feeling that Mind Over Matter could conquer anything, and now, weak as a kitten, the patient cannot even move! The utter indignity!

(me) *"Don't you remember reading in the book that you would go through a stage where you would get weak?"*

(patient) *"Yes, but I assumed that wouldn't happen to me, just the other guys."*

Hint to the astute reader – why do you think I have included this quote so many times?

This stage can last for a few weeks or a few years, depending on age, medication levels, and severity of symptoms. Many people have found that daily walks and even going to the local stroke recovery center are some of the best ways slowly and steadily (two concepts that most PD sufferers detest) to restore the body to health.

The weakness will be extreme, at some point. Patients have reported having to sleep downstairs in the living room because they couldn't go up the stairs for more than a week to get to bed. This is real. It will happen. It is a good thing. It means that your body is rebuilding, CORRECTLY, the damaged areas. Hang in there!

For some people it will seem more like fatigue than weakness. Or their caregivers will begin to accuse them of laziness. However it manifests, it can be detected by the practitioner by careful examination of the muscles along the lateral side of the leg. When this area begins to make the transition from stick-like or wooden, to soft and flaccid, it means that energy is once again traveling through this area, bringing with it the necessary components for eventual health.

Many patients are so used to condemning every motor difficulty as stiffness that they don't bother to discriminate between rigidity and inability to move from weakness. Please observe yourself carefully. If you can be rolled over in bed with more ease, but you can't go up the stairs, this is a decrease in stiffness and an increase in weakness. Learn to discriminate what you are actually feeling. Don't assume it's the PD. It may be the recovery. **INCREASING YOUR MEDICATION WILL NOT HELP IF IT IS RECOVERY SYMPTOMS YOU ARE EXPERIENCING.** If anything, the increased meds will make you worse. Also, don't forget that you may actually be needing fewer meds at this stage, and that *being overmedicated can cause freezing and inability to move.* The results of overmedication can be strikingly similar to the results of under-medication. Don't believe it? Check the insert that you receive with your medication. All of the most common medications for Parkinson's disease can *cause* immobility and temporary inability to move. You must learn to be observant. Again, because most patients refuse to believe this at first, second, and third hearings, **BEING OVERMEDICATED CAN CAUSE FREEZING.**

As an aside, and although I have avoided discussion of the medication to a great extent, I must make a few mentions of the special problems which arise during Hell Stage and Deep Sleep time for those patients who are taking medication. It seems that patients who have never taken the meds understand more easily that they will not be able to bestir themselves in the morning, or that they will run into difficulties doing tasks which require the use of the new muscles, such as getting up from chairs and climbing stairs. These nonmedicated patients just grit their teeth and accept this humiliating phase for what it is, a glorious time when the PD is going away. People who have grown accustomed to reaching for the pills when they have any problem at all with movement will not be able to understand what is going on.

The following case study demonstrates this problem. Adie was doing quite well and had reduced her medication considerably. She had made the reduction in medication because she increasingly was having facial grimacing, hand clenching, and movement freezing, all symptoms of overmedication. Consequently, she had been slowly, over half a year, decreasing her medication ever so slightly, as needed, so that she was always at a medication level where she had movement but no dyskinesia such as the grimacing and clenching. She would be doing just fine at the lower medication level for a month or so, and then, slowly, as her own, native dopamine levels, that dopamine produced in her own brain, slowly increased, the symptoms of overmedication would reappear, and she would make another, very small reduction in the meds.

Then, over the course of a few weeks, she began having the following complaints: she couldn't get up in the morning, her medication didn't work in the morning, her medication didn't work as well as it used to, she couldn't roll over in bed - even though she was becoming more supple at the waist, she didn't have the power to move herself. She was getting up all night to use the bathroom and her sleep was terrible, even though she had always been a pretty good sleeper. And her meds no longer worked, especially in the morning.

The most important thing is the comfort and safety of the patient. Adie's MD had given her pretty much carte blanche to determine her own medication levels, so Adie decided to increase her medications back up to a higher level. What happened? Terrible dyskinesia. Her face was spasming and grimacing, her hands were spasming. She felt terrible. She was clearly overmedicated. And she still couldn't move in the morning, and she just wanted to sleep all the time. It took her several months to admit finally that she was taking plenty of medication, in fact, that she was taking far too much. She was taking so much medication that she was dyskinetic even as she was dropping off to sleep in my office. The problem was not lack of dopamine in her body. The problem was that she was recovering. During recovery, your body will try to make you be still, it will cause you to be limp and sleepy, and you will not have any adrenaline. No amount of dopamine in the world will be sufficient to create vigor and movement in your body when you are going through this stage of recovery. All that you will do by increasing your dopamine to the point where you are having dyskinesia and freezing spells is create more of an addiction to the dopamine which will make more difficult the eventual weaning from the medication. (Also known as Offs, or periods of utter rigidity during phases when your medication should be working, this phenomenon is caused by overmedication, not under-medication.)

Please, never forget, safety and comfort are crucial while going through this stage. I have had several patients announce that, since they can't move anyway, they will just stop taking their medication, since it isn't working. These patients have a very difficult time until they realize that the medication was in fact doing much good during those times of day and during those activities when the recovery symptoms were not as severe. It is just as unnecessary to be under-medicated, and suffer the depression and rigidity of dopamine deficiency as it is to make yourself dyskinetic and frozen with overmedication while trying fruitlessly to combat the fatigue and sleepiness of recovery. Work with your MD to create a safe program of sensible, gradual recovery. Do not play games with your medication.

Enough of the medication scenario. Back to the details of this very difficult stage of recovery:

Later on, after the muscles have already been weak for quite a while, and when the brain itself goes into the serious reconstruction stage, the muscular "fatigue" will be replaced by mental fatigue, and the person will want to sleep extraordinary amounts. Please do not be alarmed by this, it is a passing, necessary stage.

Everyone wants to know in advance "How long will it last?" and "How bad will it be...give me the details."

First, let me point out that not every patient has the ultra-extreme levels of fatigue. Every patient is different. One patient wanted to sleep around the clock, but she was done with the deep sleep stage in a mere 5 weeks. Another only slipped into the deep sleep for two hours every morning, but it lasted for six months. Everyone is different. Also, some patients, reading the descriptions in this book, have wondered whether it was worth it to recover from Parkinson's because the recovery sounds so difficult. Let me state here that every one who has recovered says that it is absolutely worth it. In the words of one person: *"I wanted to die. Now I want to live. I'm not saying it was easy going through this process, but I want to live again. I'm glad to be alive. I didn't think I'd ever say that again."*

So what is the deep sleep, and how does it differ from the weakness and fatigue? The Deep Sleep comes in the later stages of recovery. It occurs most often between 7:00 a.m. and 9:00 a.m., although some people have experienced it at every imaginable hour of the day, and for a few people it has been around the clock. Most often it occurs in specific two hour intervals, the same interval being the Deep Sleep time for weeks or months. After a few months of this, however, the patient may switch over so that a different two hour interval is the Deep Sleep time. The two hour intervals correspond roughly to the time of day which is indicated in Asian medicine as being the time in which electrical activity is most active in a certain channel. The hours of 7:00 a.m. to 9:00 a.m. are indicated as the time of day when the Stomach channel, the channel most affected in Parkinson's disease, is running at its highest electrical strength. Repair work which must occur in the Stomach channel will occur during this time interval. Because other channels may have collateral damage in Parkinson's disease, other channel times may also be affected by the deep, recovery sleep. Although the exact chemistry behind it is not known, I'm offering here one patient's explanation, as it makes as much sense as anyone else's so far. *"It seems as if my whole life I've had a slave master, and didn't realize it. It was this relentless, restless, driving thing that made me stay busy, work hard, and caused my moods. Turns out it was the Parkinson's. Looking back, it was as if I was running on adrenaline while the rest of the world was running on dopamine. The adrenaline is what made it easy for me to be the one who bounded out of bed early in the morning, it was what gave me the intensity that made me so 'successful' in the eyes of the world, and the adrenaline is also what made me edgy and a self-control freak. I needed to be in control because if I wasn't, I might explode. I was pretty intense. Possibly it was because my body couldn't rely on dopamine, my body used adrenaline to do the simple stuff like drive the car, sing to the kids, all the usual activities of daily life. Stuff that normal people used dopamine for, I was using adrenaline, even though adrenaline should only be used in emergencies. My whole life was an emergency, from a chemical point of view. And the adrenaline worked, to some extent, giving me the drive that kept me going. But it was also the thing that made me so intense, made me feel the need to burn the candle at both ends.*

"And what happened, at some point during the recovery, it seems like suddenly, the slave master died. The adrenaline went away. For the first time in my life, I was calm, I could sit peacefully, I didn't need to be in the middle of something. If someone startled me, I didn't jump out of my chair and holler. As my body began making its own dopamine, it's as if the body got the signal that it didn't need adrenaline any more, because the dopamine was back. And for a few months it was as if I had both, a little dopamine, a little adrenaline. But then, suddenly, the adrenaline was down for the count. It was as if that constant adrenaline surge just took a vacation. Suddenly, I didn't care so much if I was late to things. I didn't care anymore if a task didn't get done on time. For the first time in my life, I didn't really care if I wasn't in control. It felt really good, but that's when the sleep thing started.

"I would sleep through the night, sleeping so well, much better than I used to, no restlessness at all. And then, around six o'clock in the morning, I would wake up, just like I used to, but I couldn't move. It wasn't that my limbs wouldn't move from the Parkinson's. I couldn't move my eyelids, my lips, my toes, my tongue. And it was the EXACT OPPOSITE of Parkinson's disease. I wasn't rigid, I was limp. My body felt utterly relaxed, and like pudding. It didn't feel bad. It wasn't like Parkinson's disease, where I'd feel agitated, and struggle in my brain to move but I'd be stiff. It was just the opposite. I couldn't move, I didn't want to move, and my entire body felt like mush, as if I had no bones, only squishy putty. And I'd lay there like that, utterly unable to move, until eight thirty in the morning. And then, as if it had never happened, I

would be able to move normally. I was not taking any medication. The rest of the day I was completely better, to look at me. I hadn't tremored in over five months. My hands and feet were warm, I moved quickly and easily, I could turn over in bed easily, I could turn my head to look behind me while driving, my face had full range of expression, I had been feeling completely better in every way, and then, wham. The deep sleep hit me.

“During these hours of laying motionless, in semi-conscious sleep, it was as if something in me had died; it was the death of the slavemaster. The driving thing which had pursued me my whole life had died, and in its place was Nothing. The strange thing was, this strange sleep state, in which I felt drugged, or altered in my mind, only lasted for a few hours every morning. As soon as nine o'clock rolled around, I could instantly move perfectly normally. Every day I would wonder what had been going on with me that I couldn't move, and since I was able to move normally by mid-morning, I would assume that the strange fatigue had passed, and that I would be normal from then on. I would go to bed feeling normal. I would be able to roll from side to side with perfect ease during the night. Then the next morning at six thirty, there it was again. Lying in bed, completely limp, not able to move. It lasted from the last week of September to the middle of the following February. It's gone now, and strangely, so is the hyperactive self-driving impulse that had ruled my life for so long. I'm still very busy and get a lot done, but it's because I want to do it, not because I must do it.”

Compare this with the description of another patient who had Parkinson's disease: *“I have energy, plenty of energy. It's just that I somehow can't get it to go to my legs. I really work hard at it. I can exhaust myself trying to get that energy to my legs, but nothing happens.”*

Comparing these two description, in the first case, the recovery patient had NO energy, and was in an enforced state between wake and sleep, in the second case, the Parkinson's disease case, there was mental energy and drive, but no physical results from it. The underlying feeling, the deep down inside motivator feeling of the deep sleep and fatigue is very different from the driving force of Parkinson's disease. Evaluate yourself honestly to decide what is going on in your own case.

Next, I will repeat the principle, because it is one with which most westerners are not familiar, but according to the very ancient Principle of Midnight/Midday, this morning deep sleep may possibly be related to the variations in electrical currents which travel through the body. Every electrical channel has surges in current during the day. The electrical channel which is most involved in the development of Parkinson's disease, the one which runs from the eyelids down to the toes, is also the channel which receives the highest electrical charge from 7 to 9 in the morning. The body does most of the reconstruction of healthy tissues along this channel during those hours when the currents are running at the highest levels. The arm channel which is most affected by Parkinson's disease is most electrically active from 5 to 7 in the morning. It seems likely that a person recovering from Parkinson's disease will need to expect a greater need for sleep during the hours when these zones of the body are doing their repair work.

The sleep which occurs during the deep sleep stage is very different from the normal sleep which most people experience during the night. It is much more like the profound sleep which occurs after a person has been very sick with a high fever. That post-fever sleep is extremely deep, and the person recovering from a raging fever will often sleep motionless for hours at a stretch, and won't want to move a muscle, but will just lay in bed, even after waking, enjoying the sensation of limpness and slow recovery. This Parkinson's disease recovery deep sleep is very like that deep sleep which one experiences after an illness. The only difference is that it will last for weeks, maybe even months. This should not come as a surprise. Most flus

and fevers only last for a few days, or even a few hours. But the cell destruction which has been occurring in Parkinson's disease has been going on for decades. It should not be a surprise that it will take more than a few days of rest to restore tissues that have been breaking down for forty years or more. In fact, the amazing thing is that the recovery is as fast as it is. It is incredible, if you think about it, that the body can recover in a few years from the degradation which has occurred over a lifetime. The recovery from Parkinson's disease is a miracle of recovery, not an event to despair of. And yet the most dominant emotion of patients who are going through this stage is absolute despair.

Most people with Parkinson's disease are very active, very driven people, and they have spent a lifetime priding themselves on their ability to achieve. For these people, the feelings of mushy sleepiness are a curse, a humiliation, a source of deep guilt. Where most people who are recovering from an illness feel absolutely fine about propping themselves up in bed with a good magazine and the TV remote, most people with Parkinson's disease are devastated by their temporary state of sluggishness.

"I'm ashamed of myself" is the single most common emotion expressed during this phase of recovery. But everyone has a unique way of putting it. Here are quotes from an assortment of patients who were going through the deep fatigue stage of recovery:

"I can't go on like this! I'm sleeping all the time! I've got things to do! I've got papers to write, a life to live! I'm already seventy three, I don't have a day to waste, and here I am sleeping my life away!"

"This is ridiculous, I plan my day around getting as much sleep as possible, I'm avoiding my friends, I'm canceling my commitments, I try to avoid anything that isn't eating or sleeping. I can't stand it. It's been like this for five weeks. What's the point? I can't take much more of this."

"What's going on with me? I can't move. It's not rigidity anymore, it's much, much worse, it's a torpidity, I don't feel like doing anything."

"I feel as if my life is ebbing away, I'm lifeless. The life is being sucked out of my body."

"I'm so weak. I can't move, I don't want to move, and I'm worse than I ever was before. Before I could always force myself to move, but now I can't even hold up my own head. I just want to sleep, but I force myself to get up, but I'm ashamed of myself, I'm not able to do anything. I don't want to do anything. We'd planned a vacation for later this month, we'd planned it months ago, and now I'd just rather stay home. My wife can go alone. I don't care. I can't do anything."

"I feel drugged. I'm conscious, but I can't move. It's not the old rigidity problem, it's completely worse than that. I feel as if I've been drugged."

"My Sinemet doesn't work anymore. It always used to kick in after about an hour, in the mornings, but now, I wake up at six in the morning, I take double my usual dose, and nothing happens. I just lay there in bed, not moving. And finally, after about four hours, I guess the meds kick in or something, because then I'm able to move, and the meds work just fine for the rest of the day, but the meds don't work in the morning anymore."

"I was all set to go out the door to a luncheon, I had the casserole in my hands, and then I just realized I couldn't. I just wanted to go to bed. I was so ashamed of myself, I cried and cried, and put the casserole back in the kitchen and went back to bed. I've never done that in my life. I feel like I'm letting people down. I've always been the one that everyone depended on."

Even if I was sick with the flu, I never went to bed, I was a fighter. And now, I can't even get out the door. I'm so ashamed of myself..."

There is much confusion around how to deal with this deep sleep. Many people increase their medication, hoping, fruitlessly, that extra meds will get rid of the fatigue. This can be a dangerous mistake. Some people who have gotten off the meds altogether have resumed taking the meds again, mistaking the deep sleep and fatigue for a symptom of Parkinson's disease. The meds do not help this condition. The meds are designed to replace missing dopamine. This has nothing to do with dopamine. It has to do with your body recovering. For example, the two patients of mine who have insisted on resumption of taking Sinemet (L-dopa) again to combat the sleepiness after they no longer needed it, having as they did no PD symptoms whatsoever, developed the horrible gasping breathing and the whole body twitching which can be side-effects of overdosing on Sinemet. After stopping the Sinemet these frightening side effects continued to linger indefinitely.

Many people insist that the deep sleep is a sign that the Parkinson's disease is getting worse. This is wrong thinking. The deep sleep is not a symptom of worsening Parkinson's disease. Remember what Parkinson's disease is all about: Parkinson's disease is characterized by restlessness and frustrated desire to get movement out of a rigid body. This profound weakness and need for sleep is just the opposite. The body is very still, not restless. The body is not rigid. It is weak and limp. There is no struggle to move from within a resisting body. There is not enough oomph to have any struggle whatsoever. It is profound limpness, weakness, lifelessness, calmness, and peacefulness. If it weren't for the guilt which most people obsess about, this would be a very peaceful stage of the recovery, as the person slowly learns how to live in a body which is no longer driven and obsessed with precision, control and production. During the process of recovery you will be turning into what seems like a different person. One person moaned, *"I'm turning into someone else, I'm not me anymore!"* His son countered, *"No, you're not. You're turning into yourself, finally, after all these years. Your true self is emerging, and that's the person who you've really wanted to be. The other person, the one that's going away, was your sick self."*

But this sense of loss is very strong. One person who had always prided herself on working at least two full time jobs at a time, realizing that she was slowly leaving behind her compulsions to achieve, put it this way: *"I'm really depressed about this; I'm turning into the people I hate, I'm turning into a normal person..."* She had always valued herself because she was able to do so much more than others. As she came to realize that her recovery meant that she would become more peaceful, calm and less obsessive, she was saddened by her loss. She found herself crying over her "lost personality" and superiority. She explained, *"I've always hated underachievers, people who didn't push themselves..."* Because many recovering patients were concerned about the long range effect of what seemed to be a major personality change, I sought out a patient who had recovered over a year earlier. I asked her how she felt she was different, and did she feel that she was still able to be the person that she wanted to be, and was she glad that she had gone through the treatment. She described her change in terms of her job lecturing at University.

"I'm decidedly different. Before, when I taught a class, I was always a very good lecturer, and I was ambitious and I wanted the very best for my students. Therefore, I insisted that they learn the material in the way that I knew was the best possible way. I would only present material in the way that I was sure was the most efficient and most productive. If they

didn't understand the material the first time, I would explain it again, the same way as before, over and over until they finally got it or never did get it, as the case may be, in which case I felt that the student was inferior to those students who did grasp it quickly.

"Now, I am still very ambitious, and I want the best for my students. But I've changed so much. Suddenly, I understand that what is the best and most efficient way of learning the material, from my point of view, may not be the best way for everyone. This year, if a student doesn't understand the lecture, if he asks a question, I'll think of a different way to present the same material. I try to work with the student to find a way to get the material across. It's no longer so important that it be done MY way, what matters more now is that the largest number of students get the material, whatever it takes. I no longer care if students learn in the exact same way I do.

"I used to want the students to achieve according to my idea of what was the best way to learn. Now I want the students to learn in whatever way will enable the student to get the information. I'm no longer such a control freak about everyone needing to learn in the exact same way that I do. It's a big change for me, and I realize that I've become a much better teacher. More of my students are ending up with an understanding of the material, even if they don't learn in the same way that I do.

"...Am I glad that I've recovered? Yes. Of course. (laughing) But there was a while there, for two months when I would go to bed at eight in the evening and could barely struggle out of bed at ten the next morning, I was wondering if it was worth it. I didn't know what was happening to me. I thought that maybe I would never have energy again. I do, of course, but it was pretty frightening and depressing at the time.

"I do still get just as much done. In fact, I think I get more done. Before, I was very compulsive about doing my work, but before I could sit down and write a paper I would have to clean my office, vacuum the floor, get rid of any possible distractions. And then I would power through my work. But what I'm finding now is that I'm so much calmer, that I can work even if the surroundings are a bit scattered and cluttered, and the result is that it's actually easier for me to get down to business and get things done, because every single thing in my environment doesn't need to be so perfect anymore. So I'm actually doing more, and I think I'm actually producing better work. I wouldn't have believed it a year ago. I thought I was the most efficient, productive person in the world. I guess I still have the desire to do my work and do it well, but I've gotten rid of the over-achiever, super-driven compulsiveness. Emotionally, I'm having a much more enjoyable life. I think I'm a nicer person. (laugh) And of course, it's great not having all those weird symptoms..."

This is a difficult time to get through. In fact, because this time of great weakness and inability to perform at previous levels of high efficiency and productivity effects the ego, the very core of a person, this stage of recovery may actually be the most difficult. It is one thing to see the body going through changes. It is another, much more alarming thing to find that one is no longer in control of one's prided qualities.

My favorite quote from a person (non-medicated) describing what it felt like to go through this was *"I felt sort of drugged and dreamy. But I just kept telling myself, I don't know what the H... this is all about, but it sure as H... isn't Parkinson's. And that's good enough for me."*

A morning will come when you realize that you aren't planning your day around your fatigue. Or you suddenly realize, one day, that you feel energy coming from within your body, rather than from your mind overriding your reluctant body. It will be fairly sudden. One day

you will realize that energy and sleep just aren't issues any more. It will seem strange that you were ever so fatigued.

The Speed Up

Next, your movements may have been slow and deliberate for years. But right along, your brain was telling your body "Go as fast as you can." After recovery, you may find yourself suddenly moving faster than you intended.

One aspect of speeding concerns speech. If speech has been difficult for you, you may have gotten into the habit of ejecting a fast stream of words during those brief intervals while your throat was relaxed enough so that you could get some sound out. After your throat muscles resume normal tone, and your voice consistently comes out loud and clear, you will probably still use the fast speech pattern that you developed during Parkinson's. *"People used to say 'what?' all the time because my voice was too soft. Now my voice is loud, and they still say 'what?' all the time. Now they complain that they can't understand me because I'm too fast. I just can't win."* You will need to concentrate on slowing down your speech pattern. You cannot realize how difficult it is to understand someone whose words are just gushing out. It will take a conscious effort to slow down the speech. The reward is worth it. You will be able to communicate easily once again.

Another patient experienced the following: *"I would always hold vegetables with my left hand, and 'chop chop' with the knife with my right hand. I would slowly move my left hand away as the knife approached from the right. Last week I started chopping vegetables, and my right hand went so fast, it was so effortless, it was wonderful, and 'wham!', I sliced the tip of my left index finger. The next day, same thing, only I sliced the tip off my left middle finger. My husband said I couldn't use the kitchen knife again until I had relearned to coordinate my right and left. Now that my right hand could suddenly move at full speed again, he was afraid I would cut off all my fingers on my left..."*

So be careful! And have fun with your new energy.

Medication

(A book is underway which provides more detail on the medication issues. The following, short section is a generalized, quick overview of thoughts to keep in mind when recovering from Parkinson's disease if your illness included medication.)

During your recovery, you may be wanting to consider making changes in your medication. Now is the time to have your acupuncturist and neurologist get together with you and come up with a sensible, cautious plan for dealing with your medication. Do not make drastic changes.

Do not make sudden changes. I have gotten calls from around the country from people who have found themselves in the hospital after cutting back their medication precipitously, and without a doctor's advice. Some even did it *with* their doctor's advice. Any doctor who says to you, "If you don't think you need your medication any more, just quit taking it," is NOT familiar with the potential dangers of suddenly stopping the medication. Remember, even if a person who did not have Parkinson's disease had been taking these medications for years, they would

have developed an addiction to them. You are in that position now. You may not have Parkinson's but you have an addiction to very powerful, motor-stimulate and emotion-affecting medication. Don't take chances. Work with your neurologist. Others have successfully, slowly, sensibly weaned themselves from their medication. Even though the book on medication is not yet in print, your acupuncturist has access to the case histories of these pioneers through the Parkinson's Recovery Project. Your neurologist may work with you, using the experiences of these pioneer patients as a guide.

Many people imagine that once they have weaned themselves from the medications, they are cured. It is nice to think that after the rigidity is gone, and the posture is restored, and the arms and legs are swinging gracefully, that the book is closed on the Parkinson's disease. In a sense, it is. However, the symptoms of recovery may continue for many months.

Some patients are especially dismayed to find that even after all of their Parkinson's symptoms are gone, and they no longer need their medication, the recovery dyskinesia is still active. Remember, it took decades for your muscles to break down and become rigid with Parkinson's. It will take months for them to be restored. Even after you are completely free of your medication, or even if you were not yet taking any medication, you will have recovery dyskinesia for months. Some people, finding that they are undergoing episodes of uncontrolled physical movements, resume taking their medications. This never helps. In fact, it can worsen the intensity of the dyskinesia.

Remember: Parkinson's disease is a disorder of rigidity and lack of movement. The Parkinson's medications help create movement. If your Parkinson's symptoms of stiffness and rigidity are gone, but you are having excess movement, it makes no sense to take medication which will cause more movement.

The reason that there is confusion over this issue is that sometimes the medication does help to reduce tremor. Well, you might think, isn't tremor a form of movement? Don't the drugs suppress the trembling movement? Aha! No! Well then, what is the process by which a movement-creating drug seems to suppress movement? Seems like a contradiction, doesn't it? It is not. Remember, tremor is occurring in areas which are degraded and no longer under conscious control. The reasons that movement-inducing drugs can suppress tremor are that 1) the drugs give movement and strength *to the muscles which are not yet degraded*, and these muscles in turn use their strength and movement (from the medication) to suppress the tremor, and 2) many of these drugs have a psychoactive component which makes the patient more impervious to the anxieties which can trigger tremor. The drugs are not literally suppressing tremor. The drugs are either giving movement to healthy muscles and these muscles in turn suppress tremor by overpowering it or they are creating a condition of confidence in the brain which enables the body to ignore anxiety and tremor-producing tensions. Remember when your tremor was new and you could stop it easily by just willing it to stop? You were using your still-active muscles to control the section over which you had no control. The medication enables you to do that again as it imparts energy to otherwise motionless muscles. So it appears that the drugs are suppressing tremor. In fact, the drugs are giving movement to the muscles which are not in the line of degradation. The drugs create movement and a false feeling of confidence. They do not suppress movement. In some cases, there can be a suppression of movement which lasts for a few days while the medication builds up in the body, and then, suddenly the medication-induced dyskinesia will appear. Some people, thinking that the medication has

already gotten too weak to work, increase the meds again at this point, and receive a few days of good feelings while the drugs build up to still higher levels in the body, and then, several days later, even more vicious dyskinesia appears. There is no end to this cycle.

In the case of recovery movement, all the degraded muscles are becoming healthy, and the movement-inducing medication affects all of the muscles, including the recovering ones. When the movement medication hits those muscles which are recovering, those muscles move. These muscles aren't yet under very good conscious control. So they move erratically. They were already moving erratically, in the recovery dyskinesia. When you add movement-inducing medication on top of the spontaneous movements of the recovery dyskinesia, you can get REALLY big movements, severe breathing problems, whole body twitching or ticking.

Some patients, out of years of conditioning, reach for the Sinemet as soon as there is any sort of uncontrolled movement. Then there is the panicked call to the doctor because "*The medication doesn't work any more, nothing works, I've never had movement like this!*" Right. You never have. Because now you are having a body which is spontaneously exploding in movement, whether or not you are using any medication. If you add movement-inducing medication to the system, the movements will increase.

Remember: Parkinson's disease is a disorder characterized by poverty of movement and rigidity.

So if you are having spontaneous movement, and new muscles are working, and you are moving easily and smoothly, *you are not suffering from Parkinson's*. You are dealing with recovery. Sorry to be so repetitive here, but this period is very difficult to get through, emotionally. You have been through years of increasing stiffness, and possibly dyskinesia, and now, after months of therapy, you have an entirely new problem, which is a new set of uncontrolled movements. But realize what this means. You may not be sure what's going on from minute to minute with these new muscles, but you can be sure of this: **It certainly isn't Parkinson's!** This thought is what keeps everyone going during the weeks of unpredictable movement. Also, remember: this stage will end. And once it does, you have your body back. And all the muscles work again. And your body obeys you again. And you don't have Parkinson's disease.

During the weeks or months of recovery dyskinesia, with or without medications, enjoy the new movements. Do not try to fight them. If your muscles want to explore a new pumping motion, go with it. Exaggerate the movement. Help yourself out. Do not try to resist these movements. The more you encourage these new movements, the faster the recovery will go. Slowly, over time, you will realize that the episodes of recovery dyskinesia are less frequent, less strong, and of shorter duration. Then they will be only a memory. It will have been so bizarre, so fleeting. You may wish you had taken a video of yourself.

Tremor

The tremor, if you ever had one, will be the last PD symptom to cease. The tremor may remain for a year or more after all the other symptoms are gone, and long beyond the time when meds are no longer needed for safety, movement, and comfort (other than the discomfort and irritation of the tremor, of course). The tremor is more likely to slowly ease off if you are no longer taking medication, at this late stage. If possible, do not take meds just for tremor, except in times of desperation. The body needs to eliminate the internal tremor before the visible tremor will be gone. The internal tremor will end during the vibrating headaches described

earlier. And then, over months or *years*, after all other symptoms are gone, the tremor will slowly decrease until it is finally gone. Tremor is the last symptom to go away. *Tremor is the last symptom to go away.* Guess why I wrote the above three times?

“I must be getting worse, all my other symptoms are gone, I no longer need the meds, but the tremor is still there and it’s been months since everything else went away. I guess I’m never going to recover...”

Reappearance of old habits

“Before I was diagnosed with PD, for years and years I used to play with my fingers, thrumming them back and forth against each other whenever I got nervous. In the years just before I was diagnosed, I did notice that I tremored a bit now and then, instead of thrumming, but it didn’t worry me until it became full-time tremor. Now, lately, even though I still have tremor a lot of the time, I notice that once in a while it stops, and just last week, I noticed that I was thrumming my fingers against each other again. That’s just what I used to do! I hadn’t done that in years. I’ve been waiting for the tremor to just stop one day and never come again, but I’m starting to realize that it will never do that. It is a process, this recovery. I’m going to tremor slightly, imperceptibly less and less each month, and slowly substitute old patterns, and eventually, some day, I will realize it’s been a long time since I tremored, and I will never know exactly when it happened. I really wish there was an easy way to know when the PD is gone, for certain, but I have to admit, there was never really a specific day when I could say that it started, either. It grew on me slowly, and now it’s slowly going away.”

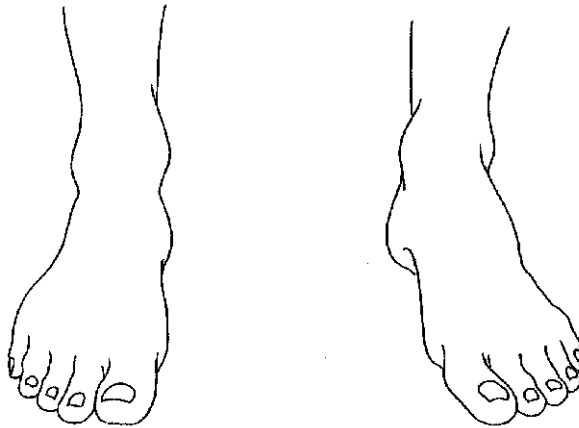
“Jim has recently started standing with one hip out, a bit jaunty, just like he used to do ten years ago when I met him, and now he’s making these little faces where he puts one eyebrow up higher than the other and one side of his mouth goes up and the other goes down. I haven’t seen that in ten years, at least. It’s exactly what he used to do all the time. It’s uncanny.”

“I used to always do this stupid thing where I would stick my tongue out to the side when I played violin. I hadn’t done that tongue business in maybe thirty years, and of course, I hadn’t played violin, really played, for over ten years, but lately, I’ve noticed since I can play again, that I’m suddenly sticking my tongue out to the side when I play, just as I did when I was a teenager! It still looks stupid, of course. ”

“Bill used to jut his chin out when he was thinking about something. He hasn’t done that since he was in his thirties. It’s been over twenty years since I’ve seen him do that, and lately, he’s jutting out his chin, and making all these old faces exactly like he did twenty years ago. It’s really crazy, after two decades of no facial expression, his face is moving just the way it did when we were young...”

Lastly, It's BACK!

The symptoms of Parkinson's disease made some strong movement habits in your body. They will not be completely gone for a long time. They will reappear, a tremor here, a spasm there, for the next year or so. These symptoms will occur with decreasing frequency, intensity, and duration. Every patient who has had major improvements has also had panicked moments during which it appears as if the symptoms are returning. Try not to panic when you find yourself trembling for 3 seconds, or even three weeks, after months of tremor-free bliss. I will close with this patient's very graphic description: *"I hadn't had any symptoms since March. Not one. And then, April 20th, I was waking up in bed in the morning, and my left hand, which never had tremor at all, suddenly tremored, a pill-roller, for about 4 seconds. I went into a complete panic. In all the time I had Parkinson's, I never panicked. I always stayed focused on what I had to do, how to deal with life one day at a time. I got depressed, I got frustrated, but I never felt raw terror. But here, I hadn't had any symptoms for over a month, I had energy, I had coordination, I lifted my legs while walking, my arms were swinging again, I was no longer tired, even the back spasming was long gone. I was totally recovered. But when my hand did that 4 seconds of tremor I just flipped out. 'It's BACK!' I was frantic. 'I'll never recover! It's back again! I knew it wouldn't stay away, I'll have it forever, it will never be gone!' Frankly, I was hysterical. That tremor never returned. Over three months later, in late July, I had two spasms of dyskinesia at the thumb/index finger junction of the left hand. I nearly flew into the same panic, but caught myself. I've had no symptoms since then, but I know that every time my body acts up, from now on, I'm going to notice it. Once you've had Parkinson's disease, you never completely forget what it was like to lose control of your body. It is the most humbling experience... In a strange way, now that it's gone, I am glad that I had the experience. I learned so much. I've changed. I'm a different person now. I'm more patient. I think I'm more compassionate. But I wouldn't wish it on anyone else. Ever. I'm glad it can be treated. May this disease go the way of smallpox. May we see the end of this illness, for all time."*



Disclaimer

A legal-minded friend has pointed out to us that we should modify statements such as "the circulation is improving" or "nerves begin to function again." In fact, we have **not** done autopsy work to measure the exact amount of restoration of various body tissues, and therefore should not really state specifically that they are recovering. What we should probably say, before every single sentence, is, "It appears as if..."

For example, "*It appears as if* the circulatory system is improving."

So, when you are reading through this handbook, read every sentence to mean "It appears as if..." and understand that no biopsies and/or technical measurements have been made to support these statements.

However, we stand by these statements, using the principle "If it looks like a duck, walks like a duck, and sounds like a duck, it's probably a duck."

The corollary is: If you're moving easily, your tremor is gone, you don't take meds, and no one can tell, not even you, that you ever had Parkinson's disease, maybe you no longer have Parkinson's disease.

And don't forget, for the next five years or so, while this work is in its infancy, if you tell someone, "I used to have Parkinson's disease," they won't believe you.

Absolute best wishes, and keep in touch!

- J W-H

Parkinson's Recovery Project Mission Statement

The Parkinson's Recovery Project has three primary objectives:

1) *Dissemination of information regarding Parkinson's disease treatments which use techniques of Asian Medicine.*

2) *Research of the most efficient treatment plans.*

3) *Establishment of a database of patient information.* Myriad factors influence the recovery rate and recovery symptoms. Age, symptoms, medication, duration of illness all affect the prognosis. In order to be able to offer new patients a reasonable prognosis, based on patients with a similar history, we are compiling a database. Hopefully all medical practitioners who participate in this program will be willing to submit brief outlines of their cases, using a standardized patient intake form, indicating number of treatments, frequency of treatment, and interesting developments which may be of general interest.

The Information Sharing Program

The Parkinson's Disease Treatment Center will provide free written materials to practitioners which includes the following: a handbook for the practitioner which includes new TCM theory on the cause of Parkinson's disease, treatment plans, instructions in the required techniques, a handbook for the patient on what to expect during the course of treatment, a Parkinson's-specific intake form, a consent form and a disclaimer.

Participating members must meet the following conditions:

- 1) must be a licensed or certified acupuncturist.
- 2) must agree to recruit at least four patients diagnosed with Parkinson's disease by an MD.
- 3) must treat these four patients for free.
- 4) copy privileges for the *Patient's Handbook* may be granted by the Parkinson's Recovery Project, but practitioners must never charge a fee for copies of the written materials provided by the Project.

After a practitioner has two of the four free patients asymptomatic and no longer requiring any Parkinson's disease medication for at least one month, as confirmed in a certified letter by the treating neurologist or primary care provider, that practitioner will be certified by the Parkinson's Recovery Project. The practitioner's name will be entered into a Certified Practitioner database, and that name will be made available to interested parties.

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The Parkinson's Recovery Project is incorporated in the state of California as a non-profit corporation.

