

## The Medical Mystery Called PARKINSONS DISEASE

Parkinsons Disease was originally called “shaking palsy” when Doctor James Parkinson named the phenomenon in 1817. If only the disease were as simple as that name! Once identified, this degenerative, progressive disease – with no remission and no cure – continues to baffle medical personnel. Parkinsons Disease symptoms vary from PERSON to PERSON, and can include any number or combination of the following:

- \* resting tremor
- \* freezing in place
- \* short, shuffling steps
- \* one side of body hurts
- \* voice gets very soft
- \* unexplained sadness
- \* feeling tired, fatigued
- \* rapid or stuttering speech
- \* flexed or stooped posture
- \* dragging one leg
- \* constipation
- \* difficulty speaking
- \* difficulty breathing
- \* facial masking
- \* slow movement
- \* lack of spontaneous blinking
- \* muscle rigidity
- \* poor balance
- \* handwriting gets smaller
- \* feeling depressed
- \* feet stick to floor
- \* excess of saliva
- \* abnormal arm movement
- \* stress increases symptoms
- \* bladder problems
- \* difficulty swallowing
- \* difficulty walking
- \* dizzy when standing up

Many of the above symptoms mimic symptoms of other diseases. Because they do not appear in the same number or order in each individual, Parkinsons Disease [PD] is a challenge to diagnose. Once considered an “older person’s” disease, almost half of new PD patients today are only twenty to fifty years old. It is easy to see why it takes time and attention to diagnose this “medical mystery.”

The PD journey for the patient begins when a number of the symptoms appear and interfere with their activities of daily living and even threaten their ability to remain in the workforce. For example, dressing, grooming, walking, writing, and/or speaking abilities may become difficult or almost impossible. Depending on the symptoms, most people try to hide them from family, friends and employers and many don’t seek immediate medical care due to fear. Or, as is often the case, they seek assistance from medical personnel for specific symptoms, unaware of the connection.

People suffering from PD symptoms often see medical specialists regarding their perplexing pains and losses. For example, if your jaw locks, it makes sense to see your Dentist, who can deem the cause to be Temporal Mandibular Joint [TMJ], and provide a prescription for strong muscle relaxers. If your ankle [on the same side] causes extreme, unexplainable pain, you may see an

Orthopedist, who could provide pain medication, an immobilizing splint and/or order physical therapy. If your elbow [on the same side] starts to hurt for no apparent reason, you may see a sports injury specialist, who makes the call of "tennis elbow" and orders appropriate treatment. It is easy to see how many "pieces of the puzzle" could be out there in the isolated medical community with no one person aware of the total picture. If you walk slower and write smaller, it is easy to attribute that to natural aging or arthritis. For many new patients, the lack of information and awareness of Parkinsons Disease actually slows down the diagnosis and treatment process. Finally, when the situation becomes unbearable, a visit to the Family Physician usually results in a referral to a Neurologist.

Neurologists are highly trained medical doctors who carefully examine and observe the patient exhibiting any number or variety of symptoms. They know immediately that the patient cannot be given an instant diagnosis, as the symptoms presented could be caused by any of several diseases. Possibilities include, but are not limited to: brain tumor, brain mass, muscular dystrophy, multiple sclerosis, ALS, stroke and Parkinsons Disease. Through a series of brain x-rays and scans, the Neurologist can eliminate the first five possibilities, all of which show up in the diagnostic films. If the symptoms persist and no other diagnosis can explain them, Parkinsons Disease is usually the verdict. Your Neurologist will usually try a simple medication experiment: if taking the prescription levadopa/carbo-levadopa [Sinemet] slows down or stops your symptoms - bingo! – PD is confirmed.

### **The IMPACT of Parkinsons...what does it mean for me?**

Almost 86% of our population knows someone with PD, yet most of us don't seem to have a clue about what the disease is or what it does to those who suffer from it. Many newly diagnosed PD patients know only that "it makes you shake and there's no cure". Just knowing that PD cannot be cured throws most people into instant depression. It is the L-A-C-K of knowledge that creates fear. What most newly diagnosed PD patients don't know is: Parkinsons Disease can, in most cases, be treated to give them a long and full life!

Once identified, Parkinsons Disease has to be reckoned with. Living with any chronic condition means change. Living with PD means change in lifestyle, experiencing loss and grief, taking new medications, finding new ways to eat [diet/nutrition], learning safe exercise, adapting to offset inabilities [dressing, grooming, typing etc.], changes in the family environment and the working environment. In other words, nothing will ever be the same again. The GOOD NEWS is...changes in how you live are not necessarily a bad thing! Nobody chooses to have Parkinsons Disease. The choice we have is how we will handle it! Fortunately, literature on Parkinsons Disease is readily available from PD foundations and at all Main and Branch libraries in Amador and Calaveras

Counties. New PD patients with internet access can immediately find reputable foundation sites to direct them to patient, family and caregiver information and forums. [Please see the internet listings on the last page.] It's time to get educated and empowered! We need to "make the most of it" and get on with life. Certainly adaptations will need to be made in many areas, including safe exercise, balance and coordination enhancement, mobility issues and techniques to prevent or alleviate speech, swallowing, chewing challenges. Perhaps we need to be more open in our communications, practice memory builders, improve our handwriting and/or use special household tools to adapt our activities of daily living.

And while we are in the adaptation mode, don't forget to include your favorite pastimes, hobbies and the travels you want to make. See...change is not always bad!

### **What ELSE presenting symptoms could be:**

- \* Brain Tumor Stroke Brain Mass
- \* Muscular Dystrophy Multiple Sclerosis Lou Gerhig's {ALS}
- \* Parkinson Syndrome / Parkinsonism / Parkinsons Plus

### **What does PARKINSONS PLUS mean?**

Parkinsonism or Parkinsons Plus refer to a person who has symptoms that look like Parkinsons Disease. These symptoms may include all of the same motor and non-motor manifestations of Parkinsons Disease and can include:

#### **Motor Symptoms:**

Tremor, stiffness [muscle rigidity], slowness [bradykinesia], soft voice [hypophonia], shuffling steps [may have festination – chasing your center of gravity with short steps], freezing or start hesitation, small handwriting [micrographia], and loss of facial expression [masked face].

#### **Non-motor Symptoms:**

Memory problems, thinking problems, fatigue, mood disturbances [depression, anxiety, mania, obsessive/compulsive] sexual dysfunction, constipation and others.

### **Does Parkinsons Plus respond to the same medications?**

Parkinsonism usually does NOT respond well to dopamine or other medications which are utilized in treating Parkinsons Disease.

## Is Parkinsons Plus just one disease?

There are several Parkinsonism Syndromes which have distinctive characteristics. Some examples include:

- \* LEWY BODY DISEASE  
Parkinsons symptoms plus hallucinations and thinking problems
- \* CORTICOBASAL DEGENERATION  
Parkinsons symptoms with problems with skilled movements [apraxia] and a misbehaving limb [alien limb]
- \* MULTIPLE SYSTEM ATROPHY  
Cerebellar Type: Parkinsons symptoms plus problems walking and with coordination [Olivoponocerebellar degeneration]  
Autonomic Type: Parkinsons symptoms plus problems with autonomic dysfunction [ear'y erectile or sexual dysfunction, dizziness when standing up, problems with digestion and constipation [Shy-Drager syndrome]
- \* STRIATONIGRAL DEGENERATION TYPE: Severe Parkinson symptoms unresponsive to dopamine
- \* PROGRESSIVE SUPRANUCLEAR PALSY  
Severe Parkinsons symptoms plus early falling and problems moving the eyes, particularly up and down
- \* VASCULAR PARKINSONISM  
Shuffling feet caused by small strokes with or without Parkinsons symptoms.

Parkinsonism syndromes seldom are responsive to Parkinsons medications and frequently progress rapidly, resulting in early death.

Parkinsons Medications ~ what is still working and what is on the horizon  
Most Parkinson symptoms are attributable to the lack of dopamine within the striatum of the brain. Therefore, the majority of antiparkinson medications are intended to temporarily replenish, mimic or enhance dopamine. Drugs that alter dopamine levels are called dopaminergic drugs, and are taken to alleviate muscle rigidity, improve speed and coordination of movement and lessen tremors.

Levodopa and dopamine agonists are the first line treatment for PD. Both drugs increase dopamine levels in the brain, but they do so differently:  
Levodopa: Levodopa, given in combination with carbidopa [blocks dopa-decarboxylase outside the brain, allowing more levodopa to enter the brain and dramatically decreases the occurrence of nausea, vomiting, loss of appetite, rapid heart rate and lowered blood oressure upon rising from a seated position to standing] is converted by brain cells to dopamine. Brand names include Sinemet and Stalevo.

Dopamine Agonists: Do NOT have to be converted into dopamine, mimic dopamine and act directly on the dopamine receptors in the brain. Brand names include Mirapex, Requip, Parlodel and Permax. Agonists have recently made news headlines as they seem to bring out the obsessive-compulsive element of PD, as demonstrated by excessive gambling, sexual activity etc. Other medications are utilized, usually in combination with dopamine and/or dopamine agonists, to control Parkinson's symptoms. Many new medications are being developed and are in clinical trials. Your Neurologist and/or your Movement Disorder Specialist will be able to keep you informed of alternative treatment medications. Be certain to keep notes of how you are feeling and moving each time medications are adjusted.

Medicines and meals...why does it matter when you eat?

Most of us are accustomed to taking our medications with meals – in fact a huge number of prescriptions are written that way. Unlike other medications, what you eat and when you eat can alter the effects of levodopa in the brain! Since levodopa must pass through the stomach into the intestine before it travels to the brain, it is important to have an empty stomach when PD medications are taken. Foods with high protein content – even a glass of milk – can interfere with the absorption of levodopa.

New dietary habits need to be developed in order to allow the medications to work to the highest advantage. Many PD patients take their medications at least an HOUR BEFORE MEALS or at least AN HOUR AFTER MEALS. The trend is to eat smaller meals more often during the day, consuming mainly carbohydrates, and having the majority of their daily protein [45-60 mg for adults] in the evening, when activity levels may be decreased. This kind of eating plan has been encouraged and endorsed for all of us for many years by nutrition experts. Changing the way we eat can be both easy and fun!

### **Movement Disorders...just what ARE they?**

Parkinson's Disease is only one of many diseases called "Movement Disorders". Movement disorders are chronic, often painful, and debilitating neurological conditions that affect the ability to control movement. Having a movement disorder can make it difficult – or even impossible – to do the routine things in life that most people take for granted.

Parkinson's affects nearly two million Americans and is the largest neurological disease in the world. Yet this number is small when compared to all of the American people who suffer from movement disorders...more than 40 million, nearly one in seven people! Following is a quote from a person with a movement disorder:

"Having a movement disorder can feel at times like being a prisoner in your own body, or as if your body has a mind of its own. I think the hardest part is

how misunderstood and isolated you can feel. It wasn't until I received an accurate diagnosis and treatment that I felt I had control over my life again"  
Quote from "Life in Motion"

Movement Disorders include the following:

Ataxia      Oromandibular Dystonia  
Blepharospasm      Parkinsons Disease/Parkinsonism  
Corticobasal degeneration      Progressive supranuclear palsy  
Dyskinesias [paroxysmal]      Psychogenic movement disorders  
Dystonia [all types]      Restless leg syndrome  
Essential tremor      Rett syndrome  
Generalized Dystonia      Segmental Dystonia  
Hereditary spastic paraplegia      Spasticity  
Huntingtons disease      Spasmodic Dystonia  
Limb Dystonia      Spastic Dystonia  
Meige syndrome      Stdenhams chorea  
Metabolic disorders      Tardive Dyskinesia/Dystonia  
Mitochondrial disorders      Tics/Tourettes syndrome  
Multiple system atrophy      Torticollis/cervical Dystonia  
Myoclonus      Wilsons disease  
Neuroacanthocytosis      Writers cramp

### **CAREGIVERS ~ how you can help**

The very best way a caregiver can help is to get e-d-u-c-a-t-e-d by utilizing local, regional and national resources!

In many cases, the caregiver is as shocked and upset as the newly diagnosed PD patient. After all, you didn't "sign on" for THIS! As the caregiver, everything will change for you too. As previously stated, the changes to come may surprise you with a better life. The quicker you can understand the "possibilities of PD", the quicker you can help provide a safe and loving environment in which everyone can flourish.

Read as much literature as you can digest, talk in depth with your Neurologist about what changes the future might bring. It may be helpful to speak to a counselor or your religious leader about your initial feelings to avoid making the PD patient the focus of your anger and frustration. With a little knowledge, you will realize that although Parkinsons Disease cannot be cured at this time, it certainly can be well managed for most people. Not all of the symptoms on the rather extensive list may or will come along in time. Not all of the "stages" you hear about will, for sure, affect each PD patient. This disease remains a "medical mystery" as research continues at fast-track rates to find ways to slow it down and maybe even cure it.

Focus and comment on how well the PD patient adapts to accomplish what once were easily-done tasks and chores. Study the effect of protein on the medication and adjust your meal times to maximize mobility and provide healthy, small meals more often. [This can be a lot easier and a lot more fun than the old "three squares a day!"] Parkinsons Disease foundations provide a wealth of excellent ideas on making your home more PD friendly, fun and safe physical exercises which will do both of you good, data which can help you prevent certain potential problems from happening.

Realize, at the start, that the caregiver also needs to be taken care of! Don't immediately drop out of your favorite clubs, stop your hair and nail appointments, cancel your membership or participation in your favorite hobby or pastime associations. PD is not the end of the world – for you or for the PD patient! Make time to nourish yourself. If you don't, who will? If you need assistance to arrange time for yourself, don't hesitate to explore the many possibilities in our local and regional areas. [Please see the listing of caregiver resources on the last page.] Remember, you are in a position to influence the events to come – are you going to focus on what is now lost OR are you going to focus on the good that is to come? The choice is up to you, and that choice will influence every member of your family as well as your future. While most people agree that Parkinsons Disease can be an uninvited irritation, many consider the lifestyle changes it encourages to be a true blessing!

Take some time to look at how you handle change. Do you try to avoid it and react with fear when something suddenly happens or do you try to be proACTIVE and take care of things before the need is intense? Here is an example to consider:

The PD patient you are caring for has poor balance and you are afraid they will fall and hurt themselves.

REACTIVE: Wait until they break a hip before you make your home safer and before you have even looked at a cane or walker, thinking you'll get them when they are needed.

proACTIVE: Observe carefully what simple changes to your home can prevent falls, such as bathroom grab bars, hand bars in long hallways, removing scatter rugs etc. If balance remains an issue, obtain prescriptions for any mobility aids – and purchase them – prior to needing them. A cane, rolling walker or battery-operated chair may not be a necessity at the time you consider them, but they will be life and health-savers to have when and if you need them. Pre-anticipate what will increase patient mobility and independence plus prevent injury. Don't just THINK about it – take steps n-o-w to get any and all equipment into your home which will enhance quality of life for all!

## Accessing SUPPORT Services

As a caregiver, you don't have to – and probably couldn't – handle everything all by yourself! Explore the local and regional resource agencies which can give you assistance in the following:

- \* Identifying Support Needs
- \* Finding Assistance in your community ~ Locating resources right in your own back yard!
- \* Providing Guidance in applying for Social Security Disability and/or Medicare benefits
- \* Preparing Advance Directives/Living Wills
- \* Estate Planning
- \* Exploring Transportation Resources
- \* Guidance on Respite Care and Home Care Health Providers
- \* Insight into Long-Term Health Care Facilities

Don't be discouraged and PLEASE, don't be afraid to ask for help! None of us expected this "PD Adventure" so, of course, we had no reason to know these things ahead of time. You don't need to have nerves of steel and be able to leap tall buildings...you just need to open yourself to the many caring people and programs who are waiting to make your journey into today and tomorrow more positive.

**Yesterday is history.  
Tomorrow is a mystery.  
Today is a gift.  
That's why it's called the PRESENT!**

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This document was created by Sarah Johnson for training In-Home Support Services, a Public Authority, Amador County, employees. It is not intended to replace medical supervision by your professional health care provider. proACTIVE Parkinsons Project, 209-296-2575.