

Connecticut Parkinson's Working Group Newsletter

April 2002

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WORKSHOPS – 10->NOON BEFORE MEETING

CONNECTICUT PARKINSON WORKING GROUP MEETING 20 April 2002

at the Connecticut Valley Hospital, Middletown from 1 PM onward

Saturday

Refreshments (drinks & snacks) provided by Brian C.'s employer Crystal Rock.

Directions to Connecticut Valley Hospital, Haviland Hall, Middletown, CT

From Route 9 Southbound:

Exit 12 - Silver Street exit, then left onto Silver Street. Take first right onto Eastern Drive. Go left at main entrance onto Flood Dr. (greenhouse on right hand side). Follow Flood Dr. to first stop sign; at stop sign (in front of daycare center); take a right onto Harvey Drive. Entrance to parking area is right after daycare center on left. Haviland Hall is directly across from parking area and just before the A frame chapel.

From Route 9 Northbound:

Exit 12 - Bow Lane. Right at the exit onto Bow Lane, an immediate left onto Harvey Drive. Parking area is on your right in front of A frame chapel. Haviland Hall is directly across from parking area.

Car Pooling: If you need or can supply a ride PLEASE contact Jackie Dorwin.

If there are any questions you may email Jackie Dorwin at jdorwinataol.com, telephone **203.453.2655**, or Stan Wertheimer at stan.wertheimeratgmail.com, telephone **860.572.9965**.

This is an absolutely crucial meeting; if you attend one meeting this year, make it this one. We will discuss a constitution for the CPWG and our application for tax-exempt status. We need these classifications to accept grants such as Pfizer's gift of \$5000 that we recently received. We will nominate people who will be responsible for running the CPWG in the future. We will also discuss the statewide information initiative that is an expansion of the successful one done in Guilford in February. In a way this meeting is the one at which the CPWG is formally born.

When Automatic Body Functions Go Awry **Toni de Marcaida, M.D.**

There are many issues in Parkinson's disease (PD) that does not always attract as much attention from physicians and caregivers as mobility. Yet, these other complaints may be every bit as disturbing as motor symptoms. There are automatic functions of the body, governed by the autonomic nervous system that are also frequently affected in PD. Automatic body functions include the control of blood pressure, swallowing and digestion, urination and bowel movement, sweating, sexual activity, and salivation. At this early point in this article, I am sure that there are already more than a few heads nodding in agreement. Indeed, problems with automatic body functions are very common in PD.

What is the point of this discussion? I think primarily it is for people with PD (PWP) to recognize which of their symptoms can be "blamed" on PD, and which ones may be heralds of other unrelated conditions, because certainly, PWP can get sick with other things too. Secondly, I would like to run through a few remedies and treatments, which can be considered if the symptoms get too disturbing or disabling.

Let us start with blood pressure issues, a potentially serious problem for PWP. The control of blood pressure may be compromised in PD for a couple of reasons. First because of intrinsic impairment of blood vessel control by PD and PD plus syndromes, and second because PD medications can produce hypotension (low blood pressure) as a side effect. Symptoms of orthostatic hypotension include dizziness or lightheadedness when getting up from a chair, fainting after standing up, postural-induced fatigue or weakness, neck and shoulder achiness (coat-hanger achiness) when standing. Lightheadedness after a heavy meal can also be a symptom of hypotension resulting from post-meal shunting of blood away from the brain and toward the stomach where a lot of post-meal activity is going on.

What to do about it? First, get up slowly from the chair at all times. Never jump up to answer the phone or get the door. Next, drink more water and add salt to the diet. Also keep legs elevated whenever sitting for prolonged periods of time. This avoids pooling of blood in the legs while they are dangling down from the seat. Wear elastic stockings that keep the circulation going in the legs even when they remain dependent and immobile. Last, review your list of meds; if there are antihypertensives (high blood pressure meds) contact the doctor who prescribed them to ask if your blood pressure is still high, or has been very low lately. If the blood pressure has become low because of PD or the PD medications, then perhaps some of the antihypertensives should be stopped. This should only be done upon the doctor's orders. NEVER stop your blood pressure medications on your own. If all else fails, there are medications for orthostatic hypotension that can be started by the physician. Blood pressure should be measured while a person is lying down, then a few minutes after sitting up, then a few minutes after standing up, in that order.

Constipation is another common problem in PD. The remedies are to increase fluids, increase fiber in the diet, and increase physical exercise. Vegetables, fruit, and whole grain are good sources of fiber. Lactulose, milk of magnesia, senokot, metamucil, and similar products are stool softeners that can be used safely daily. If possible, use these products before going for chemical laxatives.

Urinary frequency, urgency and nocturia are also common complaints. It should be taken into account however, that in older people, problems with prostate enlargement in men and stress incontinence in women are also common. As such, before saying that problems with urination are due to PD, a urologic evaluation should be performed. If the troubles are due to PD, then there are medications such as oxybutinin, intranasal desmopressin and other anticholinergic medications, which may help. Some people observe that urinary frequency and an urgency to void are experienced most when they are in the "off" state. It is also most common at night. Fluid intake should be limited later on in the night to try to reduce this problem.

Sexual impotence can also be distressing, and one should not hesitate to discuss this with the doctor. There are many causes of this problem, and other medical conditions such as diabetes, depression, and hormonal problems, as well as medication side effects from antihypertensives, antidepressants, and MAO inhibitors can be implicated. Eligibility for oral medications to help with impotence should be discussed with the physician. There are strong contraindications for using such medications, including cardiac problems, which need to be discussed before considering taking medications.

Swallowing problems should also be recognized early to avoid complications such as developing pneumonia because food or water "went down the wrong tube". Gastrointestinal dysfunction in PD also includes indigestion, bloating, and gastric reflux from impaired esophageal and gastric motility and emptying. These problems potentially impair the absorption of levodopa (sinemet) in the gastrointestinal system. They can also occur as a manifestation of the "off" state in PD. Medications such as cisapride or domperidone can help. Treating constipation is also helpful to decrease bloating and delayed gastric emptying. Some of these symptoms however, are also worsened by PD medications like dopamine agonists and anticholinergics.

Excessive sweating and drenching sweats in the "off" state has also been reported. Dopamine agonists and treating the "off" state help. Excessive sebum production (dandruff, seborrheic dermatitis) is also common, because of impaired control of sebaceous glands as well as immobility of facial muscles. Medicated soaps and shampoos are helpful. Blepharitis from decreased eye blinking should also be treated with artificial tears.

Excessive salivation or drooling is also a result of decreased swallowing reflexes from PD more than to impaired function of the salivary glands. Chewing gum, anticholinergic medications, or botulinum toxin injections can help drooling.

Now, if you have come to the last paragraph of this article and have NOT yet fallen asleep, then perhaps you have another problem that is common in PD – a sleep disorder (insomnia perhaps?). But then, that is the subject for yet another article at another time.

It is always a pleasure and a privilege to participate in the activities of this community. Please give me a call if I can be of any further assistance. And remember, if you are able to, do participate in Parkinson's disease research. It is the only way we can continue to move forward in our efforts to either coexist peacefully or "beat" this disease.

[Ed. The following is part one of a two-part article. Here we find out a little about Kevin Flynn who has been diagnosed with PD for many years. In the second part Brian gets down to the nitty-gritty of how PD has affected Kevin's life.

An Introduction to Kevin F.

Brian C.

Having Parkinson's disease can really get you down. Well, not me, not yet. I've only experienced it for a few years and my symptoms are mild to say the least. But I've met someone through sharing rides to quarterly meetings whose Parkinson's symptoms are quite debilitating and I would think he'd be quite "down". But Kevin Flynn just seems to see it as one more challenge that won't get in the way of his life.

It's my nature to be immediately comfortable with someone who readily shares life experiences. I think Kevin is probably that way also. His condition has pretty much robbed him of the pleasure of conversation. We've chatted on our Middletown trips about common interests, and I intended to share some of Kevin's experiences with you.

I've spent some time day sailing along the shores of Long Island Sound and I consider myself a novice. Get me out of sight of land and I'd be dead in the water. Literally. But I someday want to sail offshore. Kevin has been there and done that. Over lunch one Saturday we began by talking about Kevin's career so I could gain some perspective, and I think what Kevin has done is interesting.

Kevin was...a nerd and a geek...in the time before the masses discovered computers. His was the age of plastics. Graduating in the second class to receive a BS degree in Plastics Engineering from Lowell University, Kevin was at the forefront of a technological wave. It was 1959, long before electronic calculators. Engineering student to used slide rules. I think of that classic line in "The Graduate" when a guest at Dustin Hoffman's college graduation party has "just one word to say", *Plastics*. That movie was made almost ten years after Kevin graduated.

Kevin's first job was as a research and development engineer. Several career enhancing moves gave Kevin the confidence and experience to make another job change to a position overseeing product development of a material known as high density polyethylene (HDPE), that translucent resin used in milk bottles. It was 1966 and the company was Allied Chemical Corporation. Kevin's responsibilities included serving as liaison in its involvement with development of packaging products for its major customers.

Kevin worked closely with General Foods as Allied developed the first plastic containers for food products. Cool Whip started a new era in food packaging when it appeared in its plastic tub during the Sixties. Kevin tells me that Allied enjoyed immediate success because consumers readily accepted the new treat in its throw away, plastic container. Initially packaged at plants in the East, Cool Whip, which is essentially an edible foam material, stored well in its tightly sealed tub. But General Foods rushed to build a plant on the West Coast because its delicious new product couldn't be trucked over the Rockies. The drop in atmospheric pressure as the trucks climbed higher into the mountains caused the product to swell until the lids popped off and what was left was a trailer load of sticky goo.

n 1973, Kevin went to work for Bio-Medical Sciences as the Supervising Engineer for development of their sole product, a single use oral thermometer. Funded by pharmaceutical giants Johnson and Johnson, and Baxter Labs, as well as 3M Corporation, the introduction of this unique temperature strip was expected to be met with limitless demand where there was a need for sterility. Kevin explained that the product had 50 tiny dots attached to a plastic strip. Each dot was composed of a resin whose formula was changed just slightly to offer varying melting points from every other dot on the strip. The dots were graded and the ones that melted indicated the body's temperature. Kevin was responsible for the production of these temperature sensitive resins.

While at Bio-Medical Sciences, Kevin returned to school to earn a Masters in Business Policy from Columbia. Unfortunately for Bio-Medical, it was a time when people were less aware about the spread of infectious diseases and the company ceased operations in 1978. But its product is everywhere today.

While Kevin was Technical Director at Hubbell, Inc he was diagnosed with PD. He remained at Hubbell until 1984, then went to work as a Supervising Engineer at TIE Communications in Seymour. TIE was *the* telephone systems manufacturer superstar during the Eighties. Kevin ran the technological side of the import-export division.

Kevin said there was a VP at TIE who recognized his symptoms because he had a family member experiencing PD. It did not have a negative impact on his career. TIE saw beyond the symptoms and recognized the experience and knowledge that Kevin displayed.

Kevin traveled extensively while at TIE spending periods in Japan and Korea developing their markets. In 1989 TIE was forced to close its doors.

Kevin published his own trade industry specific magazine for a couple of years. In 1991 he went to work for the State of Connecticut where he finished his work life as a career counselor with the Department of Labor in 2001. Today, he spends one day a week working with learning disabled children helping them to keep pace with their classmates.

What's remarkable to me is that I've met a man who was involved at the development stages of products that I take for granted. The work done by Kevin and his peers has truly improved my daily life. I'm glad to have made his acquaintance and I thank our group for giving me the opportunity to get to know him.

Epiphany

Stan Wertheimer

A few months ago I was asked if I was interested in a project initiated by a respected reflexologist in Mystic, call her R. She had been intrigued by work being done in California by a woman, call her CW, who claims to have developed a protocol that results in "recovery from Parkinson's" which she calls the Parkinson's Recovery Project (PRP). It is based on a Chinese healing method called Yin Twina that deals with the meridians of the body and the pressure points in your feet that access all meridians. CW's claims that PD is the result of an insult to one of the feet at some past time which can be reversed by the application of "forceless spontaneous release" (FSR), which is holding the feet in certain ways. R wanted four participants for a two-year commitment once a week for training after she attended a workshop run by CW. She would accept no payment.

As you might expect, I was skeptical, which I told R, but willing to consider it. I called my neurologist and explained the situation; he said he saw no reason for me not to participate. An integral part of the PRP is the gradual reduction of medication, if the PWP is on medication, under the supervision of an MD. In the Patient's Handbook published by CW she points out possible trauma one might experience over the two years of treatment as well as a belief that as many problems a PWP has are due to the medication as to the PD, perhaps more. In particular, she states that many PWP mistake dyskinesias for tremor.

I agreed to join R's group. I figured that the least that would happen is that my feet would get a good working over by R. We started individual work with R around November 2001. The sessions were enjoyable

so I had no regrets about joining. One of the participants, A, had been seeing an accupuncturist for two years and had gone from being largely incapacitated and in a wheelchair to being fully mobile while cutting medication in half. The accupuncturist performed FSR on A, who continued to see him.

At the beginning of March 2002 R sent us all an email from CW; she warned that unsupervised reduction in medication had resulted in several deaths. She also said that not reducing medication in people benefiting from her methods had resulted in fatalities. And the clincher was that she had not seen one case where the supervising MD had done medication reduction correctly.

I met with R the next day and we talked for an hour. After reading CW's email there was no choice: treatment must stop. In the course of our discussion, however, some things became clearer than they had ever been in the past. Most had to do with the relationship between PD and medication. First, it reinforced my realization that I am a drug addict. I must have my meds regularly – if I don't my body lets me know in no uncertain terms. I look forward to the results of the meds and would forgo many of life's pleasures to have the meds work properly, such as giving up eating certain foods and doing enjoyable activities that would interfere with my schedule. If I stop the meds I would have "withdrawal symptoms" and might even die. In a financial pinch I would choose meds over food, social contact, and most of what makes life worthwhile. There is no doubt that I am an addict.

Secondly, although I am taking meds to alleviate symptoms of PD I am no longer sure which symptoms are due to PD and which are side effects of the meds. For example, constipation is a symptom of PD, but it is also a side effect of several of my meds. Similarly for depression, difficulty sleeping, increased sweating, fatigue and unusual movements (!!). About the only one of the PD symptoms I can't find listed is rigidity. Thirdly, I have no idea where I am in the progression of PD and there is no good way to find out. I might be at the same place I was when I was diagnosed in 1989 and experiencing symptoms due to the meds, or I might be producing no dopamine and am being saved by the meds. People used to go on a drug "holiday" where all meds would be stopped for as long as a week to see where they were; this is no longer done, as far as I know. The reasons are clear; going off meds "cold turkey" can be dangerous, and, as I once experienced, going back on after the holiday does not get you back to where you started for a long time – perhaps never. There are ways of determining probable progression (in particular brain imaging) but they are not widely available. I have been imaged since about 1993 on almost a yearly basis.

Finally, I don't know how meds have affected the progression of PD. There is a widely held belief that Sinemet causes increased neuron death (my neurologist convinced me that there is no good evidence to support this) and selegiline is supposed to slow the death of neurons in the substantia nigra, which many now dispute. How about Comtan, Tasmart, Amantadine, Requip, Mirapex? Do they affect the life of dopamine producing neurons? And what about dosing: Does a large bolus do more damage than delivering medication uniformly over time? I wish we knew.

The ramifications of the above discussion are many: One is the importance of knowing whom I can trust and of regular in-depth dialogs with my neurologist. I don't expect my MD to have all of the answers but together we can do much better than either one alone. Another is that I cannot rule out alternative therapies. Just because no one funds a clinical trial to evaluate CoQ10 doesn't mean that it may not be as beneficial as some high priced prescription drug, and accupuncture might alleviate symptoms as well as drug X. The importance of being able to tell where I am in the progression of PD looms larger in light of the factors above. It would be great to have a simple reliable test. I have been participating in an imaging study since the early nineties, which is one way of possibly telling where I am.

My epiphany was understanding the connection between PD and the medications one uses, confounded by the lack of knowledge about what causes PD and how all the meds work. I had thought about all of the points mentioned above at one time or another, but never had the issues been so clear as when I had that discussion with R.

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**DISCLAIMER: Articles in this newsletter are for information only.
Any questions of treatment should be discussed with your physician.**

WRITE! your representatives in congress.

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