

pd **PARKINSON'S DISEASE**
NEWS

a
helpful newsletter
for people
with **Parkinson's**
and their families



NEWS

**Associated
Neurologists, P.C.
69 SandPit Road
Danbury, CT 06810**

Sleep Disorder
Apomorphine
Memory loss
AND MORE...

pd PARKINSON'S DISEASE NEWS



A MESSAGE FROM DR. MURPHY:

In this edition of the newsletter, you will find information on the nighttime problems of Parkinson's patients, a particular set of maladies that patients often experience but don't usually discuss. Dr. Steve Peters, a neuropsychologist at Associated Neurologists, reviews the cognitive difficulties that PD patients may encounter. In addition, several of your questions are answered in the Q & A section. You will also read about the ongoing research protocols at Associated Neurologists.

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Nocturnal Problems in Parkinson's Diseases

A poor night's sleep almost invariably leads to diminished performance and decreased alertness the following day. This is especially true for patients with PD. In 1987, Drs. Lee, Blackburn and Campbell interviewed hundreds of patients with Parkinson's disease in the United Kingdom. They were specifically interested in the nighttime problems that these people encountered. The results were published nearly ten years ago and the article is one of the most comprehensive on the subject.

The average age of the patients surveyed was 68 and most had been diagnosed about seven years earlier. Nearly all patients were taking some form of medication to alleviate their symptoms.

The vast majority of patients reported some type of nocturnal disturbance. Inability to turn over in bed was the most troublesome symptom and affected 70 % of the patients. Approximately half the patients reported painful leg cramps. Nearly the same number of patients had vivid dreams or nightmares. Limb or facial dystonia (sustained involuntary and often painful muscle contractions), back pain, jerking of the legs, and the need for assistance in getting out of bed were also frequently reported complaints. Each of these was noted by about 30% of patients. Severe tremor upon awakening was also a problem for about one-fifth of the patients who were surveyed.

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The information and reference material contained herein are solely for the information of the reader. It should not be used for treatment purposes, but rather for discussion with the patient's own physician.



Support Groups in the Area

Caregivers:
Gladys Tiedemann
203 288-0546

Greenwich: Dee Coover
203 863-3881

Milford: Terry Swan
203 874-5070

New Canaan: Sally Driscoll
203 966-7125

New Haven: Donna Diaz
203 789-3936

Ridgefield: Irene Weck
203 431-0674

Shoreline: Jackie Dorwin
203 453-2655

Southbury: Margaret Clark
203 426-5534

Waterbury: Joan LaRose
860 439-2026

Young PD: Stan Wertheimer
860 439-2026

DAILY LIVING

Nocturnal Problems in Parkinson's Diseases

Continued from front

For some patients, particularly in the early years of the disease, morning is reported to be the best time of day. In this particular study, there was little difference in the number of patients claiming to be at their best (27%), worst (35%), or neither (39%) first thing in the morning.

The nature of these nighttime problems is complex and they are not exclusively due to PD. For instance, the commonest complaint reported by 80% of these patients was the need to get up from bed to use the bathroom. While Parkinson's disease contributes to this predicament, there are many older patients without PD who have the same need. Specific PD-related nighttime problems are related to the time of day that the last medication was taken, the duration of the disease, the number of concomitant medications as well as the disruption of normal sleep architecture caused by PD.

It is worthwhile discussing nocturnal symptoms such as these with your neurologist -only half the patients in this survey did- since many of them can be alleviated with medication. Using controlled release Sinemet (carbidopa/levodopa), adding or increasing a nighttime dose of a dopamine agonist, adding Comtan (entacapone) or even Eldepryl (selegiline) can all be helpful remedies. Difficulty turning in bed can also be improved by sleeping on silk sheets, sleeping without clothes, or in severe cases, installing a trapeze bar over the bed.

A good night's sleep is of vital importance!

RESEARCH UPDATE

We continue to conduct clinical research into more effective treatments of Parkinson's disease. Here is a brief update on what we are doing.

Imaging Study: Parkinson's can sometimes be a difficult diagnosis to make and there is no x-ray or blood test that can confirm that someone has PD. There is a new investigational imaging technique using a SPECT scan that has been evaluated on more than 1200 people with PD. A SPECT scan measures the amount of dopamine producing cells in the brain and it involves injection of a small amount of radioactive material, similar to a bone scan. I am collaborating with Drs. Ken Marek and Danna Jennings at the Institute for Neurodegenerative Diseases in New Haven, CT. In this study we are looking for patients with either early PD or atypical Parkinson's. If you are interested, please let Dr. Murphy or Joan Ellen Gereg know.

Dopamine agonist patch: This trial involves a transdermal patch that will deliver a dopamine agonist directly into the bloodstream. Presently available dopamine agonists include Mirapex, Parlodel, Permax, and Requip. These medications play an important role in treating patients with PD because of their long half-life in the body and their ability to stimulate the dopamine receptors in the brain more continuously than short-acting compounds like Sinemet. This

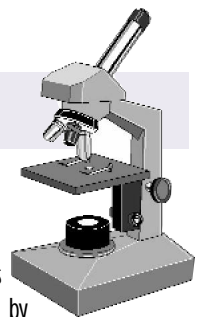
study takes the concept of continuous stimulation even further by applying the medication directly through the skin.

The patch will be tried on two separate groups of patients, those who have not yet started on Sinemet or an agonist and a second trial will look at those patients who are already taking Sinemet but for whom the medication has begun to wear off towards the end of the dose.

Apomorphine trial: We are running three separate trials of this medication. It is a drug that is injected, like insulin, under the skin as needed. It works quickly -within minutes- at alleviating the "off" periods that can unpredictably appear in Parkinson's patients. Patients who experience sudden episodes of stiffness, tremor, freezing or other Parkinsonian symptoms and are already taking Sinemet and one of the agonists are potential candidates for one of these trials.

It is certainly an exciting time for research in PD!

Please feel free to call about any of these trials.





IN OUR EXPERIENCE...

ANSWERING YOUR QUESTIONS



Cognitive Changes in PD *Stephen C. Peters, Psy.D.*

Although PD was once considered to be largely a disorder of motor functioning, clinical research using neuropsychological measures (specialized sensitive testing of brain functioning) and the longer life expectancy of the population in general, have revealed significant cognitive symptoms over the course of the disease.

The loss of dopamine's effect on certain frontal parts of the brain interferes with goal and strategy development and maintaining and shifting attention. The ability to handle more than one task at a time, sticking with the task at hand, and shifting back and forth between two different tasks can be affected. There can also be problems with getting started on a task, generating solutions to new or complicated problems without external guidance (hints or clues), and temporal organization/sequencing (planning things in a specific order). Although PD may influence these areas mentioned above (called "executive abilities"), PD patients usually continue to have insight and concern over their cognitive symptoms and can use behavioral strategies to compensate for this. This suggests that the loss of dopaminergic influence produces changes in some frontal areas and spares functioning in certain other frontal brain regions.

Changes in visual perceptions involving visual analysis ("seeing the big picture"), discriminating visual details and visuoconstructional abilities (i.e., putting things together, building things with many parts) are common.

In terms of memory, the recognition of information is better than the ability to recall information without a hint or clue. It is this ability to freely recall and bring up information stored in the brain that is the most evident memory problem in PD. The ability to register (perceive information), consolidate (put all the information together) and store it (put it away in the brain) appears to be generally unaffected. Therefore, once again, hints and clues such as Post-It notes, appointment books, calendars, spreadsheets, etc. can help compensate for this cognitive symptom.

The prevalence of depression in PD is relatively high. Depression alone can cause significant problems in memory and attention. Although depression is consistent with changes in neurotransmitter systems, to some degree this is also a psychological reaction to the changes brought on by having to adjust to the disease. Because motor slowing and decreased facial expressiveness are part of the disease it is important to discuss with those concerned whether or not one actually feels "down in the dumps" or discouraged.

Lastly, the frequency of dementia is somewhat higher in PD than the general population (approximately 15%). However, the development of the cognitive changes noted earlier in this article are those typically related to PD and have no bearing on the development of dementia. Dementia is not more common in those with earlier onsets of PD (before age 55) and the length of duration of the disease is also not a predictor of dementia.

If you have concerns about cognitive changes, please discuss these with your neurologist who may order a neuropsychological evaluation to measure these symptoms.

I hope this information proves helpful and informative. Please visit our website at www.associatedneurologists.com for more information.

Q Why can't I smell any more?

A Many patients with Parkinson's disease report that they have lost their sense of smell. Sometimes this may affect their taste as well. The loss of smell often occurs several years before the diagnosis of Parkinson's is made. Unfortunately, little can be done to restore the sense of smell.

Q Soon after I started taking Comtan my urine turned orange. Is this a problem?

A No. A sizable percentage of patients who take Comtan report a change in the color of their urine, most often to orange or brown. It is harmless and requires no treatment.

Q My wife sometimes has difficulty swallowing her Sinemet CR. Can I crush it?

A No. Sinemet CR is a controlled release formulation that contains a specially formulated matrix that allows for slow absorption. Crushing the CR destroys the matrix and defeats its purpose. If she has difficulty swallowing, you may want to discuss switching her to regular Sinemet tablets.

Q Can you recommend a book on Parkinson's?

A There are many good books on the subject. I particularly like Parkinson's Disease: A guide for Patient and Family by Roger Duvoisin, M.D. and Jacob Sage, M.D. by Lippincott-Raven. I am partial to this book because these are two of the physicians who trained me during my neurology residency. The book is quite comprehensive and well written. Another book on PD that should be available in October 2001 is Power Over Parkinson's, Fighting Like a Tiger, Thinking Like a Fox by Abraham Lieberman, M.D. It is available at Amazon.com or through the National Parkinson's Foundation.