



The American Parkinson Disease Association

WINTER 2008 NEWSLETTER

A Quarterly Newsletter by The American Parkinson Disease Association, Inc. ©2008

ATYPICAL PARKINSONISM

By Lawrence I. Golbe, MD, Professor of Neurology, UMDNJ-Robert Wood Johnson Medical School, New Brunswick, N.J.

You may have been told by your doctor that you have not Parkinson's disease but "atypical parkinsonism," "Parkinson's-plus" or "Parkinson's syndrome." Confused?

INDEX

- 1 Atypical Parkinsonism
- 2 President's Message
- 3 Support Groups-PD and APDA
- 4 Q&A
- 5 F.Y.I.
- 10 How To Choose a Physical Therapist
- 12 Information on Parkinson's Disease

Paul Maestroni, DVM,
Director of Scientific and Medical Affairs,
Editor

Vincent N. Gattullo
President

Joel Gerstel
Executive Director

National Headquarters
Parkinson Plaza
135 Parkinson Avenue
Staten Island, N.Y. 10305
1-800-223-2732
www.apdaparkinson.org
apda@apdaparkinson.org

National Young Onset Center
Glenbrook Hospital
2100 Pfingsten Rd.
Glenview, Ill. 60026
1-877-223-3801
www.youngparkinsons.org
apda@youngparkinsons.org

West Coast Office:
10850 Wilshire Blvd.
Los Angeles, California 90024
1-800-908-2732

What is "Parkinson's syndrome"?

A "syndrome" is a group of signs and symptoms that often occur together and may be caused by any of a variety of diseases. A "disease" is an abnormal process, usually with a specific cause. For example, the syndrome called the "flu," which includes fever, muscle aches, cough and headache, can be the result of any of several diseases, only one of which is an infection by the influenza virus.

Similarly a combination of slowness, muscle rigidity, tremor and impaired balance is a syndrome called "Parkinson's syndrome" or just "parkinsonism." The disease that most commonly causes it is "Parkinson's disease" (PD). PD is strictly defined as parkinsonism associated with gradual loss of certain groups of brain cells that, as they sicken, form within them microscopic balls called Lewy bodies.

Parkinsonism may also be caused by about a dozen diseases other than PD. Most of these cause other signs and symptoms in addition to the parkinsonism, which is why they are also called the "Parkinson-plus" disorders or the "atypical parkinsonisms."

Progressive Supranuclear Palsy

The most common atypical parkinsonism is "progressive supranuclear palsy" or PSP. There are only

about 20,000 people with PSP in the US, while there may be one million with PD. What's "atypical" about PSP is its failure to respond to levodopa/carbidopa or other PD medications, difficulties looking up and down, an erect or even backwardly arched neck posture, and the relatively early appearance of falls, slurred speech and swallowing difficulty. Most of these features can occur in PD, but not with the intensity or frequency with which they appear in PSP. Instead of Lewy bodies, the brain cells in PSP have "neurofibrillary tangles." While Lewy bodies are mostly made of a protein called alpha-synuclein, neurofibrillary tangles are made of a different protein called "tau."

Multiple System Atrophy

The next most common atypical parkinsonism is "multiple system atrophy" or MSA. In addition to parkinsonism, MSA usually features the type of poor coordination and balance that arises from disorders of the cerebellum, giving some sufferers a "drunken" appearance. Other "atypical" features in most people with MSA are low blood pressure, sensations of being too hot or cold, constipation, urinary difficulties and brief episodes of shortness of breath or sleep apnea. These arise from "dysautonomia" which is a loss of brain cells that control the autonomic

continued on page 9

Dear Reader:

"I didn't know that!"

How often have we heard this statement, and even more interesting, how often have we uttered it?

I am amazed what we take for granted that people know. As I am out speaking to groups both nationally and locally here on Staten Island, I am shocked by a surprised response to the information about APDA's contribution of more than \$30 million to research, or network of 62 Information & Referral Centers across the country, or response to more than 50,000 telephone requests for free educational literature annually.

We publicize these facts in national media, on our Web site and through articles in our newsletter that is mailed to more than 200,000 people. The Better Business Bureau and other not-for-profit monitors report our financial contributions assiduously. Our army of 56 chapters works continually to raise awareness. And yet, in the mass of information with which we are bombarded with every day - 3,000 advertising messages a day, according to the Newspaper Association of America - it is not surprising that much gets lost in the mix.

Several years ago, I read an article in a business publication about a young college student whose mother had been diagnosed with a degenerative neurological disease. She visited the association's Web site to donate the small amount she was able to. It was there that she discovered that she could create her own personal site to encourage friends to donate as well. Though she referred to herself as "technologically illiterate," she was able to complete the site and within a week more than \$2,000 was contributed. She was able to get out her message instantly, not have to ask her friends face-to-face for a donation, and generate a significant donation.

That is why it is so important for everyone who is committed to finding a cure for Parkinson's disease and supporting those who are already diagnosed and their

caregivers to get out the message of our work. Local media outlets are available, especially community TV stations, and can be contacted by anyone. Look for the public affairs or news features departments.

Recently I was asked to appear on the Joey Reynolds Show, a syndicated radio program broadcast from New

York City and aired in 200 U.S. cities. Again, after listing the accomplishments and objectives of APDA to the listening audience, I heard, "I didn't know that!"

None of us is an entertainment or sports celebrity, or likely has access to mass media attention, but our daily commitment to "Ease the Burden - Find

the Cure" for Parkinson's disease can be advanced by our individual message to support the battle.



APDA president with WOR Radio's Joey Reynolds
Photo by Mark Kasner

A handwritten signature in black ink, appearing to read 'Vincent N. Gattullo'.

Vincent N. Gattullo
President

Exelon® Patch Release

FDA approved the use of the Exelon® patch for the treatment of Parkinson's disease (PD) and Alzheimer's disease dementia.

Application of the once-daily skin patch offers a new approach in the treatment of mild to moderate PD dementia, providing a continuous delivery of drug over 24 hours.

The use of a skin patch rather than oral capsules reduces the gastrointestinal effects commonly seen with this type of drug. ■

SUPPORT GROUPS -

By Terri Hosto, MSW, LCSW

Department of Neurology
Washington University School of Medicine, St. Louis, Mo.

The main goal of Parkinson's disease (PD) support groups is to educate participants about the many aspects of this disease. Information about symptoms, treatments and medication side-effects, significance of nutrition and exercise and resources available for PD patients and care partners help participants gain useful knowledge about the disease and how to manage it.

Support groups enable participants to ask questions, discuss common concerns and offer emotional support to one another. They provide a place to share feelings in a caring atmosphere and exchange helpful coping strategies like completing everyday tasks in more efficient and less stressful ways. The give and take nature of support groups encourages participants not only to receive information and support from others, but to give care and support to others as well. Support groups serve as social outlets where people with PD meet other people living with PD. Participants tend to form bonds of friendship in light of their common situation. Groups also offer comfort and hope by meeting others who are coping well under similar circumstances.

Support groups come in many different forms and may vary in size from just a few participants to much larger groups with twenty or more participants. Membership typically consists of a combination of PD patients and family care partners.

Specialized groups may be available to address the needs of those who share a common interest, such as newly diagnosed patients, young-onset patients, deep brain stimulation patients or adult children caregivers. Each group will have its own character since its participants represent a range of symptoms as well as a mix of

personalities, age groups, religious backgrounds, and financial conditions. However, the situation that they all have in common easily outweighs their differences.

Support groups are facilitated by either a health care professional or an experienced family member and/or patient coping with the disease. Most meetings ordinarily last about one to two hours and are conducted in an informal, conversational style. Outside speakers sometimes are invited to address specific topics such as new medications, legal and financial planning and home safety.

A newcomer may be overwhelmed at first by the information discussed in a meeting. Knowing beforehand what to expect can help an individual prepare for the group experience. If possible, talk to the group facilitator in advance and explain your interests and concerns in joining the support group. Ask about the composition of the group, the structure and ground rules of the group meetings, and what is expected with regard to group participation. If you do not receive the help you need after a meeting or two, try another group, or try the same group later when their program seems to better fit your needs.

Although support groups alone cannot give you all the education and emotional support needed to deal with PD, they can be a valuable source of help. Joining a support group should be just as important as regular visits to the doctor. To find out more about your closest support groups, contact your nearest Information and Referral Center.

To obtain more information about support groups, how to start one and the APDA Support Group Program, request the new brochure "How to Start a Support Group" from the APDA national office. ■





BY ENRICO FAZZINI, DO, PhD
Associate Professor Neurology
New York University, New York
University of Nevada, Las Vegas
N.Y. Institute of Technology, Old Westbury



Q: I understand that a new dopamine patch is available. I am 43 years old and I have had PD for nine years. I have tried many medications but I am only able to tolerate Sinemet 25/100 and I take it every two hours while awake. I am not doing well. I am too jumpy or can't move at all. Is the patch for me?

A: You need to be on a medication which lasts longer than Sinemet and which will smoothen out your "on/off" fluctuations. Neupro (rotigotine) is a dopamine agonist and it is available as a 24 hour controlled release patch. Requip (ropinerole) is another dopamine agonist which will soon be available as a 24 hour time release tablet. Either of these medications should help, but you must remember that when you add the

dopamine agonist to the Sinemet you may increase dyskinesia and you must gradually lower your Sinemet at the same time that you gradually increase the dose of Neupro or Requip.

Q: My husband was told he has diffuse Lewy body disease. He has tried Sinemet but all it does it make him confused. He is forgetful and slow. What can I do? The other doctors have given up on him.

A: Diffuse Lewy body disease is a disorder in which patients have severe cognitive impairment in combination with signs of Parkinson's disease. These patients do best on a medication to improve memory and concentration (Aricept or Exelon), a mild sedative at bedtime (Seroquel) and a very small amount

of Sinemet (25/100 one-half tablet in the morning and afternoon).

Q: I was just diagnosed with Parkinson's disease. How long will I be able to walk?

A: Parkinson's disease gradually progresses over decades. Most patients do very well for many years. Eventually after 10-13 years, fluctuations in response to your medications will occur and then after 15-20 years, your balance and/or cognitive skills may worsen. Make sure that you see an experienced Parkinson's disease specialist every three months for continued adjustments of your medication schedules. Be assured that our progress in treating this disease will be much faster than the progression of your symptoms. ■



ER and TRAVELING SUPPORT AVAILABLE

The unfortunate experience of an Irish Parkinsonian, traveling overseas and unable to communicate with officials, mistaken for being intoxicated, forced to take a cold shower, and returned to his country, has resulted in a pocket-size guide with helpful advice for Parkinson's patients when traveling or requiring an emergency room visit (copy attached).

The bright orange tri-fold card authorized by Dr. Joseph Friedman, medical director of the Warwick, R.I. Information & Referral Center, also includes the phrase "I have Parkinson's disease. Please allow me time for communication." in English, German, French, Italian and Spanish, and patient identification space.

A copy of the card is available by calling **800-223-2732**

Award, Elections Highlight APDA Annual Meeting

Patrick McDermott was elected 4th vice president and Nicholas Corrado, treasurer, during APDA's annual meeting, Dec. 2 at the Hilton Garden Inn, Staten Island. Former New York State First Lady Matilda Cuomo was elected an honorary director, and Andrew Finn and Adam Hahn were elected to the board. Mrs. Cuomo is a former board director and was the featured speaker at APDA's national headquarters dedication in November 2005. David Richter, president of the Arizona Chapter, was elected the West Coast representative.



Dr. J. Eric Ahlskog, center, receives APDA's Fred Springer Award from president Vincent Gattullo and Jay Springer, right, during the 2007 annual meeting.

J. Eric Ahlskog, PhD, MD, chairman of the Mayo Clinic's Movement Disorders Center, received the 2007 Fred Springer Award. Dr. Ahlskog, author of "The Parkinson's Disease Treatment Book: Partnering with Your Doctor to Get the Most from Your Medication," was presented a \$10,000 check and plaque by APDA president Vincent N. Gattullo.

The meeting also included talks by James Bennett, PhD, MD, a member of the Scientific Advisory Board, and Joseph Conte, board member and senior vice president for quality management for North Shore-Long Island Jewish Health System. ■

The Challenge(s) of Change

A message from the National Young Onset Center

This is the first in a series of columns to be written by Julie Sacks, director of the APDA National Young Onset Center, addressing the particular concerns of younger PD patients and their families.

"People don't like change." It's an old adage that many of us tend to grab hold of when there's a significant change in life. It speaks to the resistance we feel when we must face something new or unexpected. Even when the changes are positive ones, they can leave us feeling a little off-kilter, as if we've lost our balance. And what about the unexpected changes – the not-so-positive ones that can make us feel a bit like the flattened cartoon characters we remember from childhood?

Certainly, we all know that despite our resistance, change is perpetual and inevitable. For most, however, change occurs very slowly – a new wrinkle here, a gray hair there – slowly enough that adapting to it doesn't create tremendous stress. How, though, are we to adapt, to recover our balance when we experience an unexpected and shocking change? How do you adapt when you're young and told you have Parkinson's disease?

First, keep in mind that adaptation is not a one-time occurrence; it's a process in which you continually adjust in order to accommodate whatever you are facing. One of the most difficult things about a chronic illness, particularly a progressive illness like PD, is that you and those who care about you are likely to experience a more pronounced awareness of the changes occurring in your body and the impact those changes have on your daily life.

While it is impossible to prevent change, it is known that understanding and support from others help us manage it. APDA National Young Onset Center was created to do just that – to help you contend with the continual process of adjustment and re-adjustment. Contact us at 877-223-3801 or visit us at www.youngparkinsons.org. Whether you are newly diagnosed or have been living with PD for many years, the National Young Onset Center is here to provide you with the information, support and resources you need to handle the changes, both big and small, that come your way. ■

F.Y.I. is a guide to the efforts and successes and recognition of the hundreds of volunteers and staff who work daily to help ease the burden and find a cure for millions of persons with Parkinson's and their caregivers across the United States.

STANLEY DASHAW

A Legacy of

In today's society living to age 91 is admirable. Continuing to write, entertain and sail at that age while battling Parkinson's disease is remarkable. But founding an international center to support world peace at a major academic institution and starting a manufacturing company based on your fifth major invention could only be accomplished by Stanley Dashaw.

Everyone who interacts with the indomitable nonagenarian professes admiration – from those who work closely with him daily to the doorman at

his Los Angeles condominium that is lined with photos taken during his many trips around the world.

A native New Yorker and Great Depression survivor with a love for writing and photography, in 1949 Stanley, then owner of a successful business machine sales agency in Michigan, attracted world attention when he outfitted his 76-foot schooner *Constellation*, and with his family – his wife, Martha, 7-year-old son, Stephen (Skip), and 3-month-old daughter, Leslie – began a 15-month nautical adventure. Local newspapers caught the excitement of a young family's odyssey pursuing its dream and headlined its progress as they crossed the Great Lakes and sailed

down the East Coast and through the West Indies and the Panama Canal. When the family docked in Los Angeles, it was arriving at the port that would be the Dashaw's home for more than half a century.

By the late '50s, Dashaw Business Machines – which “started out as a hole-in-the-wall operation in 1952,” according to *The San Francisco Examiner* – was one of three major companies producing credit cards with almost \$4.5 million in sales. The U.S. Patent Office copyright No.#192,306 was issued to Dashaw Business Machines, Inc. for a “Combined Printing and Punching Data Recording Machine” that would revolutionize the credit-card industry. Stanley



Stanley Dashaw greets Congresswoman Jane Harman at the 2007 Dashaw Center awards.

Survival and Service

had been developing addressograph machines since he was 20 years old, but being the lynchpin for the creation of the first bank credit-card system, BankAmericard, was the mother lode!

Stanley continued his quest for industrial innovation and is credited with the worldwide introduction of the single-point mooring system, Imodco, for offshore oil transportation (1964), inventing of the "Dashaveyor," a people and cargo carrying system (1965), and a wastewater treatment system, Biomixer, used around the world (1990).

Today, he is contagiously enthusiastic about his latest invention, the Dashaway, a system for making people more mobile, and the machine he credits with giving him back his life after his PD diagnosis, a fracture, and serious spinal deterioration.

Invented with exercise physiologist Charles Blunt, the Dashaway combines walking stabilization, exercise components, fall prevention, and back-pain relief by decompressing the spine, increasing endurance and flexibil-

ity. With the patent pending, Stanley and his crew are finalizing their manufacturing, distribution and marketing strategies.

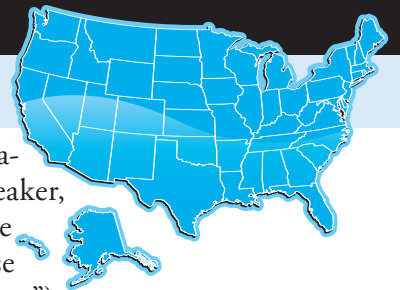
But Stanley's proudest accomplishment is the UCLA Dashew International Center for Students and Scholars, which he and his second wife, Rita, created more than 40 years ago based on their belief that strengthening international ties and promoting peace among nations begins with cross-cultural understanding among people.

Undaunted by his physical challenges, Stanley Dashew, a person with Parkinson's, today continues his exceptional life as father, inventor, entrepreneur,

industrialist, photographer, philanthropist, champion of world peace, and writer. His autobiography is aptly titled, "You Can Do It!" ■



Stanley Dashew Demonstrates His Latest Invention



**IN THE
MIDWEST**

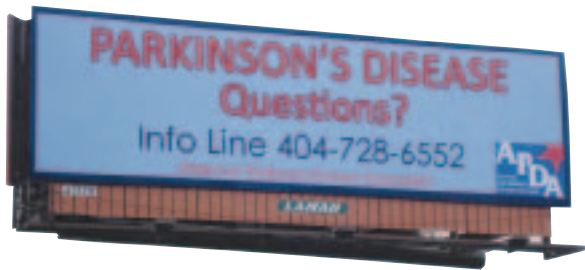
Mary Egger, APDA's Nebraska Chapter president, is still marveling at the Weitz Company's \$35,000 contribution via its Fifth Annual Volleyball Challenge. "These wonderful people have contributed more than \$100,000 to the chapter since the beginning of this event." The tournament began as a way to help a Weitz employee who was diagnosed with PD. "When it hits home like that, that's when it really drives you to participate," said a fellow employee. Forty nine teams competed this year with Jobsite Supply the winner. "This support has enabled our chapter to donate more to research and fund many of our local programs," Mary said.



Nebraska Chapter president Mary Egger, right, joins in proudly displaying the Weitz Company's proceeds from its 2007 volleyball tournament.

**IN THE
SOUTH**

Mary Louise Weeks may not have put APDA on the map, but she certainly has put it on the Atlanta, Ga. highways. Via an in-kind donation from William Wilkins, chairman of the Wilkins Media Company, \$70,000 worth of billboard design, production and space tells motorists how to get assistance in 15 different locations around the Atlanta area.



The "one for the road" in Atlanta is an APDA helpline.

The 250 people who attended the annual Parkinson's Disease Community Education Days in Virginia came away with lots of information. Sponsored by the Richmond Metro Chapter and the I&R Center of Charlottesville with the Southeast Parkinson's Disease Research Education and Clinical Center (PADRECC),

**IN THE
WEST**

the two-day event featured keynote speaker, author John Argue ("Parkinson's Disease & The Art of Moving"), who demonstrated movement and speech techniques for daily living activities. APDA Scientific Advisory Board chairman Dr. Frederick Wooten from the University of Virginia faculty and PADRECC's Dr. Abu Qutubuddin were also included in the program.

There was a very different menu for the Northeast Texas Chapter's "Lunch with the Pharmacist." Dr. Amie Blaszczyk, assistant professor of geriatrics at the Texas Tech School of Pharmacy, discussed Parkinson's medications during the event's dining portion followed by informal and unrushed one-on-one discussions with three senior attendees for the students and their guests.

David Richter's first function as APDA's newly elected West Coast representative to the board of directors was a pleasant one. He presented a check to executive director Joel Gerstel for \$18,500 representing the proceeds from the Arizona Chapter's El Tour de Tucson event



Newly-elected West Coast Representative David Richter, right, surprises Joel Gerstel, executive director, with an \$18,500 check during the annual meeting.

**IN THE
NORTHWEST**

APDA's Washington Chapter is one of several organizations funding a statewide database being created to identify persons with PD. The University of Washington and the VA Puget Sound Hospital in Seattle are jointly directing the ongoing grassroots project that actively involves voluntary patient participation and can be a valuable resource for both patients and researchers. ■

nervous system. The dysautonomia of MSA was called “Shy-Drager syndrome” before it was recognized in the early 1990's as part of a specific disease that can have several forms. Like PSP, MSA causes earlier balance problems than PD and medication for PD usually has little benefit. However, there is medication for most of the dysautonomic features. In MSA, the protein that aggregates is alpha-synuclein, as in PD, but it does so in a different set of brain cells and looks different from Lewy bodies. The protein aggregates in MSA are called “glial cytoplasmic inclusions.”

Corticobasal Degeneration

The third leading atypical parkinsonism is “corticobasal degeneration” (CBD).

CBD affects one side of the body first and worst. This is also true, but to a far lesser extent, for PD. For PSP and MSA, the problem is usually symmetric, with left and right sides affected nearly equally. CBD, in addition to parkinsonism, features abnormal posturing of limbs called dystonia, abnormally heightened reflexes as elicited by tapping with a hammer, and small, sudden, rapid involuntary movements called myoclonus. Its most distinctive feature is apraxia, which is a loss of the ability to perform complex movements with the hands or feet. There is also difficulty with the ability to perceive the spatial features of objects. At present, no medication is effective, unfortunately, and the disorder is treated with physical therapy. In CBD, the protein that aggregates is tau, as in PSP, but it does so mostly on one side of the brain, and disproportionately in the area of the brain responsible for planning complex movement tasks, the frontal lobes.

Dementia with Lewy Bodies

“Dementia with Lewy bodies” is a parkinsonian disorder that often starts with confusion, depression or psychosis (that is, hallucinations or delusions). However, the mental symptoms appear before or together with the movement symptoms and not afterwards, as in PD. The movement difficulty may even be very mild and, as for most of the atypical parkinsonisms, tremor at rest is far less common than in PD. In DLB, the behavioral symptoms can vary greatly over periods of minutes to days and can include periods of unresponsiveness, elaborate delusions and visual hallucinations in addition to the difficulty with memory and thinking. The hallucinations of DLB can occur without levodopa or other dopamine-

enhancing medications, while in PD, any hallucinations are a side effect of those medications. The parkinsonism of DLB responds to levodopa/carbidopa. The movement and behavioral symptoms can be severely and dangerously exacerbated by drugs that block dopamine such as Haldol (haloperidol), Compazine (prochlorperazine) and Reglan (metoclopramide).

Vascular Parkinsonism

Another common condition causing atypical parkinsonism is “vascular parkinsonism” or “arteriosclerotic parkinsonism.” This is the eventual result of many tiny strokes, no one of which may be large enough to cause symptoms at the time it occurs. The strokes can be seen on an MRI scan. Over the years, the cumulative effect causes movement difficulty, especially with walking and other movement of the legs. The condition does not respond to PD medication, but its progression can often be slowed or even stopped by controlling risk factors such as high blood pressure, smoking, or high lipids. Physical therapy is helpful in dealing with the gait problem.

How Do I Tell If I Have Atypical Parkinsonism?

Atypical parkinsonism rather than PD should be suspected when someone with the parkinsonian syndrome has little or no response to a moderate dosage of levodopa/carbidopa or when there is the early appearance of falls, behavioral changes, swallowing problems, abnormal eye movements, bladder problems or lightheadedness on standing. The physician should order an MRI scan, which can show the small strokes of vascular parkinsonism, the asymmetric shrinking of corticobasal degeneration, the unusual pattern of brain shrinkage of progressive supranuclear palsy, or the abnormal pattern of iron and scarring of PSP or multiple system atrophy. Some other radiologic tests such as PET and SPECT can also be helpful in special circumstances.

While the atypical parkinsonisms are more difficult to treat than PD, the good news is that they do not run in families nearly as often as PD does. While 20-25% of people with PD have some close relative with PD, fewer than 1% of those with PSP, MSA or CBD have a relative with atypical parkinsonism. For DLB and vascular parkinsonism, the fraction is slightly higher. The causes of the atypical parkinsonisms are starting to be worked out. As we learn more about the abnormal processes in the brain cells in these conditions, treatments that may slow, stop or even reverse their course will become possible. ■

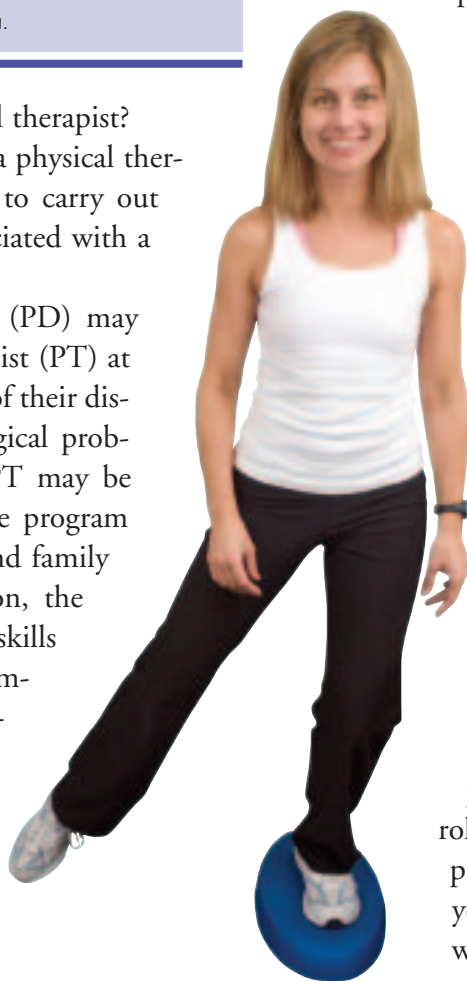
HOW TO CHOOSE a PHYSICAL THERAPIST

By Jeffrey Hoder, PT, DPT, NCS
Movement Disorders Clinic
Emory University, Atlanta, Ga.

When should one go to a physical therapist?

Individuals should be referred to a physical therapist when there is a loss of ability to carry out functional activities or life roles associated with a disease, injury or dysfunction.

Persons with Parkinson's disease (PD) may find the need to see a physical therapist (PT) at various stages throughout the course of their disease. With a new onset of neurological problems or when newly diagnosed, a PT may be helpful in establishing a safe exercise program and providing education to clients and family members. With changes in function, the therapist may assist with functional skills re-training, home modification recommendations, adaptive equipment, balance training, or just instructing caregivers. As the persons with Parkinson's disease require follow-up with their physicians, the physical therapist should be seen as a resource to improve the quality of life and ease stresses which may be related to physical limitation.



Problems associated with Parkinson's disease that may benefit from PT are:

- Getting in and out of bed
- Walking
- Going up and down stairs
- Carrying out life roles in a safe, independent and efficient manner.
- Inability to return to work or recreational activities
- Loss of flexibility and strength
- Dizziness
- Impaired coordination
- Decreased endurance
- Poor balance
- Falls
- Difficulty with mobility

Some states allow you to go directly to a physical therapist without a physician's referral first, however, your insurance policy may require a visit to the primary care physician first or may limit access to preferred providers.

Choosing a physical therapist

You can choose your own physical therapist. Your therapy should be provided by a licensed physical therapist with a graduate degree from an accredited physical therapy program and who has passed the national licensure examination. The minimum educational requirement is a master's degree, yet most educational programs now offer also the doctor of physical therapy (DPT) degree.

Is there a therapist right for me?

Physical therapists have wide ranges of experience and specializations. Many outpatient clinics will specialize in orthopedics, while many hospital based clinics will specialize in neurology. Just like a physician, which therapist you choose to go to may depend on your specific needs. There are many PTs who have specialized training and have gone on to receive advanced certification

in areas such as neurology, geriatrics and orthopedics.

The American Board of Physical Therapy Specialties offers board certification to therapists who provide a substantial amount of clinical proficiency and have passed an extensive examination.

A person with a history of Parkinson's disease may choose to go to a physical therapist who specializes in neurology.

What is a Neurologic Clinical Specialist (NCS)?

A NCS is a licensed physical therapist who has completed more than 4000 hours of neurologic clinical practice while working with individuals who have neurologic dysfunctions and has demonstrated competency in the following areas:

- Patient care (examination, evaluation, diagnosis, prognosis, intervention)
- Patient education
- Interpretation of research administration consultation
- Passing the neurologic clinical specialist examination and being certified in neurologic physical therapy by the American Board of Physical Therapy Specialties (ABPTS).

What can one expect from a therapist?

Neurologic physical therapists perform examination and evaluation to establish:

- A functional diagnosis
- A prognosis for functional recovery
- The need for physical therapy services
- A plan of care which may consist of direct intervention, coordination of services and discharge planning

Interventions may include:

- Therapeutic exercise
- Muscle strengthening
- Stretching
- Aerobic conditioning
- Sensory training
- Coordination of movement
- Balance training
- Functional skills training
- Instructing patients in directing their own care
- Instructing caregivers in assisting with mobility
- Environmental evaluation
- Discharge planning

- Case management
- Referring to other professionals
 - Aquatic exercises
- Documentation, communication with others,
- Patient - related instructions
- Striving to help their patients/clients to achieve goals.

If balance tends to be the main issue, there is a number of physical therapy clinics and physical therapists that specialize in balance retraining. "Vestibular rehabilitation" specializes in balance, dizziness and inner ear function. If orthopedic issues tend to be the major problem (joint replacement, fracture, back pain), many outpatient clinics specialize in orthopedics and sports medicine. It may be wise to inquire if the therapist has worked with clients who have Parkinson's disease.

Your first visit should include an evaluation by the physical therapist. Based upon the results of the examination, you and your therapist should work together to set specific goals to optimize function that you would like to achieve during your course of therapy.

Goals may include:

- Remediate impairments or learn compensatory movement strategies
- Reduce functional limitations (a restriction of the ability to perform an activity or task in an efficient, typically expected, or competent manner)
- Optimize health and well being
- Prevent injury, functional limitation and disability.

The therapist should design a plan of care and propose a timetable to achieve these goals. He/she will likely provide you with instructions to perform exercises at home to facilitate your recovery to meet your goals.

To locate a PT who specializes in neurological care in your area, you can go to www.neuropt.org and click on "locate a NCS therapist" towards the bottom of the page.

Much of this information has been taken directly from the APTA and Neurology Section of the APTA websites on finding a PT.

This article has been adapted from the one appearing in the Spring 2007 issue of the APDA Atlanta, Ga. Information and Referral Center newsletter.



Information on Parkinson's Disease

Single copies of the following publications may be obtained free of charge by writing to the national APDA office or by calling 1-800-223-2732, faxing to 1-718-981-4399, or contacting any of the 62 APDA Information and Referral Centers.

EDUCATIONAL BOOKLETS

1. **Basic Information about Parkinson's Disease**
Brochure (English)
2. **Parkinson's Disease Handbook** - Symptoms, causes, treatment - booklet (English, German, Italian)
3. **Be Active** - An exercise program for people with Parkinson's disease - booklet (English)
4. **Be Independent**- Equipment and suggestions for daily living activities - booklet (English)
5. **Speaking Effectively** - Speech and swallowing problems in Parkinson's disease - booklet (English)
6. **Good Nutrition** - booklet (English)
7. **Young Parkinson's Handbook** - booklet (English)
8. **Aquatic Exercise for Parkinson's Disease** - booklet (English)
9. **My Mommy Has PD... But It's Okay!** - booklet for young children.

The Next Step After Your Diagnosis: Finding Information and Support-Booklet can be obtained by calling 800-358-9295 and requesting booklet AHRQ Publication No. 05-0049

EDUCATIONAL SUPPLEMENTS

The Family Unit; The Fine Art of "Recreation & Socialization" with PD; Mirapex® in the Treatment of PD; Fatigue in PD; Healthy Aging; Keys for Caregiving; Medications to Be Avoided or Used with Caution in PD; Neuro-Ophthalmology and PD; Medical Management of PD and Medications Approved for Use in the USA

DVD

Managing Parkinson's - Straight Talk and Honest Hope. Created by the Washington State Chapter of APDA for newly diagnosed Parkinson's patients and their loved ones.

APDA WEB SITE

www.apdaparkinson.org for PD I&R Centers, Chapters, Support Groups, education and information material, meeting dates, publications, medical abstracts, clinical trials and research application guidelines.

WORLD PARKINSON DISEASE ASSOCIATION WEB SITE

www.wpda.org. A weekly updated source of world news.

Center For Complimentary and Alternative Medicine

The National Center for Complementary and Alternative Medicine (NCCAM) at the National Institute of Health is dedicated to exploring complimentary and alternative healing practices in the context of rigorous science, training complementary and alternative medicine (CAM) researchers, and disseminating authoritative information to the public and professionals.

Medline Plus: Drugs and Supplements www.nlm.nih.gov/medlineplus/druginfo/herb_all.html offers extensive information including background, uses, safety, evidence for, dosages, and potential interactions for more than 100 vitamins, herbs and supplements. ■

Age Does Have Its Rewards

A charitable gift annuity can mean guaranteed life income for you while assuring your legacy in helping APDA's mission to find a cure for PD and support those with the disease and their caregivers. Rates are calculated by age, so the older you are, the more you will receive. Your financial protection is also a Parkinson's patient's hope.

| Age | Rate of Return |
|-----|----------------|
| 60 | 6.4% |
| 65 | 6.7% |
| 70 | 7.2% |
| 75 | 7.9% |
| 80 | 8.9% |
| 85 | 10.4% |
| 90 | 12.0% |

Call Executive Director Joel Gerstel at 800-223-2732, ext.120, to discuss annuities and other planned-giving opportunities. ■

Materials concerning research in the field of Parkinson's disease, and answers to readers' questions are solely for the information of the reader and should not be used for treatment purposes, but rather as a source for discussion with the patient's health provider.