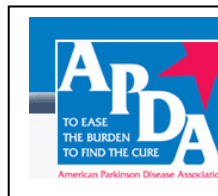


American Parkinson Disease Association, Inc
2929 Mossrock, Suite 200
San Antonio, TX 78230-5137



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NOTE

NOTE

Our Web Site is located at www.aapsg.org
Hosted by PCA Web Design & Hosting in Plano, Texas, Toll Free: 888-229-4747,
E-mail: info@pcawebdesign.com.

PLEASE NOTIFY US OF ADDRESS/E-MAIL CHANGES.

POC: Kim Johnson Vineyard kjv624@yahoo.com 1028 PR 1712, Mico, TX 78056.
We can't get information to you if we don't know where you are living.

See last page for support group information



American Parkinson's Disease Association, Inc
Alamo Area Parkinson Support Groups
2929 Mossrock, Suite 200, San Antonio, Texas 78230-5137
Phone 210-349-0096, www.aapsg.org
APDA I & R Center Phone 210-567-6688

Quarterly Newsletter, April 2009

Editor: Dianne Johnson, R.N.

Local News

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You may leave a message for any AAPSG Officer or Board Member at 210-567-6688.

Young onset Parkinson's disease: Treat or not treat?

Vikki Alvarez, MD

Parkinson's disease (PD) affects as many as one million Americans. It is in fact the most common disease of motor system degeneration and is after Alzheimer Disease, as the second most common neurodegenerative disorder. PD often first presents as a noticeable tremor in a limb while at rest. As the disease progresses three other very distinct problems arise: slowness of movement (bradykinesia), stiffness of limb (cogwheel rigidity), and gait instability/falls (postural instability). It is important to know that in some patients, resting tremor in a limb may not always be the initial presentation. Additional problems arise later on, and they can be combination of (but not limited to) sensory complaint like pain, memory loss, mood changes, anxiety, depression, sensitivity to temperature, constipation, etcetera.

The average presentation or onset of PD is generally around 60's. Unfortunately, around 5-10% of people diagnosed with PD are under the age of 45. Most doctors call this "PD in the

young or young onset PD (YOPD)". Medications available for treatment of symptoms of YOPD are the same as PD. These medications available are levodopa/carbidopa, pramipexole and ropinirole (dopamine agonists), entacapone and tolcapone (COMT inhibitor), rasagiline and selegiline (MAO-B inhibitor), trihexyphenidyl (anticholinergic), and amantadine. To date, there is no cure for PD or medication to slow or reverse the progression of disease. Although there are raw or preliminary data suggesting that some of the current medications available may potentially slow down the progression of disease (neuroprotection), the final words on their widely adaptation are still in the pipeline. As a result, the question of "when" and "how" to start treatment in PD patient, remain extremely challenging. While the treatment decision-making ultimately depends upon the treating physician and the patient, the goal is always to improve or "mask" the symptoms and to improve the quality of life. My usual approach after taking history and performing an examination is to ask my patient this question: "is/are your symptom/s bothersome or disabling?" Either bothersome or disabling, both of these symptoms will eventually affect the quality of life in patients with YOPD. If the symptom/s are mild and not bothersome, I usually

tell them that there is no right or wrong decision. That is, they can either take an anti-parkinsonian medication or not. However, if the symptoms are both bothersome and disabling, I encourage my patients to start on treatment. The decision as to what drug to use is highly based on the severity of their symptoms and tolerability to medications. To date, the most effective treatment to mask the symptoms of PD is carbidopa/levodopa or sinemet. Although sinemet is not for everyone with PD or YOPD, in some patients this is the drug of choice. For many years, however, there was great concern against sinemet and that the thought was this drug is toxic after long term use such that it causes disabling side effects after long term use (for example: involuntary dancing-like movement or dyskinesia). The old fashion approach was to delay sinemet for as long as possible. Until recently, it has been concluded that there is a lack of strong evidence for long term advantage of this approach. Therefore, the "levodopa phobia" should be discouraged. Rather, the goal should be to optimize the treatment of symptoms in YOPD patients and improve their quality of life. YOPD patient should discuss their medication options with their neurologist to determine the best medication to fit their needs.

Finally, regardless if the patient is 45 or 65, I can never say this enough: exercise, exercise, and exercise. Exercise can not only relieve some of the motor symptoms of PD and YOPD, but also aid in the improvement of muscle strength, coordination, balance and walking. Moreover, studies have shown that with regular exercise, PD patients are likely to require less dose of medication as compared to PD patients who don't exercise. Additional strategy has also shown to be effective including physical, occupational, speech, swallowing, and psychological therapy. YOPD patients should discuss this with their neurologist, who is familiar with their condition and knows the best and most ideal therapeutic strategy to fit their needs.

Suggested readings:

1. www.mdvu.org
2. Lang, Anthony. When and how should treatment be started in Parkinson disease? *Neurol* 2009; 72(suppl 2): S39-S43.



Ask your neurologist corner

Q

Doctor, why is my husband drooling? Is Parkinson's causing it? Is there medication for it?

A

A significant number of patients with Parkinson's Disease (PD) experience drooling or sialorrhea. Not only socially embarrassing, pooling of saliva in the mouth can also lead to more serious problem such as aspiration pneumonia. PD does not cause the salivary gland to produce more saliva, rather PD patient already have impaired or problematic swallowing, thus causing saliva to pool in the mouth. In some cases, drooling is a sign that the Parkinson medication is wearing "off". There are oral medications available to treat this problem but their usage is limited due to their unpleasant and unbearable adverse effects such as dry eyes, blurred vision, drowsiness, confusion, memory loss, and decreased urination. If pooling of saliva is moderate to severe, treatment with botulinum toxin injection maybe the best choice to avoid the adverse effects mentioned above. Other approaches, though not routinely done, are surgical interventions and radiotherapy. Speech therapy may help improve excessive salivation or drooling. Finally, a small hard candy may also help as it can stimulate swallowing muscles to contract thereby preventing pooling of saliva in the mouth.



Exercises for the Parkinson Patient:

Just as running water does not freeze, so moving muscles do not freeze

CNS Online - Know the facts. The maintenance of normal muscle tone and function is an important aspect of the treatment of parkinsonism. In part, medication administered for your illness achieves this goal. However, to realize the full benefit of the medication daily exercise and activity are essential.

TEN BASIC EXERCISES FOR THE PARKINSON PATIENT

1. Bring the toes up with every step you take. In Parkinson's disease, "you never make a move", without lifting the toes.
2. Spread the legs (10 inches) when walking or turning, to provide a wide base, a better stance, and to prevent falling. It may not look "beautiful," but neither does falling.
3. For greater safety in turning, use small steps, with feet widely separated. Never cross one leg over the other when turning. Practice walking a few yards and turn. Walk in the opposite direction and turn. Do so fifteen minutes a day.
4. Practice walking into tight corners of a room, to overcome fear of close places.
5. To insure good body balance, practice rapid excursions of the body. Backward, forward and to the right and left, five minutes, several times a day. Don't look for a wall when you think you are falling. It may not be there. Your body will always be there to protect you, if you will practice balance daily.
6. When the legs feel frozen or "glued" to the floor, a lift of the toes eliminates muscle spasm and the fear of falling. You are free to walk again.
7. Swing the arms freely when walking. It helps to take

body weight off the legs, lessens fatigue, and loosens the arms and shoulders.

8. If getting out of a chair is difficult, rise with "lightning speed," to overcome the "pull of gravity." Sitting down should be done slow, with body bent sharply forward, until one touches the seat. Practice this at least a dozen times a day.
9. If the body lists to one side, carry a shopping bag loaded with books or other weights in the opposite hand to decrease the bend.
10. Any task that is difficult, such as buttoning a shirt, or getting out of bed, if practiced 20 times it day, becomes easier the 21st time.

FOR TIGHT MUSCLES AND POOR POSTURE

STANDING

1. Stand in front of a wall, facing it about 8" away. Raise arms and reach as high as possible toward the top of the wall. Lean toward the wall and stretch.
2. With your back to the wall, alternate raising legs as high as possible by bending the knee as if marching in place.
3. Holding on to something secure, squat down as far as possible, bending knees; then come up.

SITTING

1. Sitting in straight-back chair, place your arms behind the chair and bring your shoulders back as far as possible; raise your head up and look at the ceiling.
2. Sitting In the same chair, grip the ends of a broom or mop stick with both hands, try to raise it over your head until you get it behind your head. Keep head and shoulders as erect as possible.
3. Sitting in same chair, place one leg at a time on another chair and press the knee straight. Keep it there 15 minutes. Try both legs together.
4. Sitting in a chair, raise legs up from the knee alternately, as if stamping your feet.

LYING ON A FIRM BED OR FLOOR

1. Lie on the floor or bed, flat on your back; try to press your body to the floor as flat as possible. Move your head from right to left as far as possible. Make sure your head, shoulders, back, and knees touch the surface.
2. Lie on the floor or bed on your abdomen. Do the following one by one:
Put your hands behind back and look up to ceiling, trying to raise your chest off the floor.
Kick your legs alternately, as if swimming.
Turn your head from right to left.

FOR BETTER BALANCE

1. Stand with hands on hips, feet spread apart:
Practice marching in place
Practice raising leg straight out to the rear.
Practice raising leg out to the side.
Practice drawing a circle with the leg.
2. Standing with hands at side, feet spread apart:
Lean forward and back
Lean to both sides
Lean in a circular motion and reverse the motion

FOR WALKING

1. When walking, REMEMBER:
Take as large a step as possible
Raise your toes as you step forward, hitting ground with your heels
Keep legs apart and posture straight
Swing arms and look straight ahead - your feet know where the floor is located.
2. Collect a dozen magazines; lay them out in a straight line. Space them so that you can take as long a step as possible. Practice walking over these magazines without stepping on them.
3. For a better swing to arms, walk holding a rolled magazine in each hand; keep elbows straight.
4. Practice walking sideways, backwards, and take big steps.

FOR TURNING

1. When practicing turning:
Keep feet spread-apart and head high
Use small steps; rock front side to side
Raise legs from the knees
2. If you feel glued to the floor:
Raise your head, relax back on your heels and raise your toes
Rock from side to side, bend knees slightly and straighten up and lift your toes
It sometimes helps if the arms are raised in a sudden short motion

FOR GETTING IN AND OUT OF A CHAIR

1. If you become glued a few steps before you reach the chair, try this: Don't aim for the chair but some object past it. Pass the chair as closely as possible and as you go by it sit down.
2. To sit down, bend forward as far as possible and sit down slowly. Get close to the chair. Do not fall into the chair.
3. To get up, move to the edge of the chair, bend forward and push up vigorously using your arms; try to count 1 2 3 GO! If you have a favorite armchair, raise

the back legs with 4" blocks. This will help you to get up easily. Don't let people drag you up by your arms, but help you by pulling you under your arms, or with a slight push on your back.

FOR GETTING OUT OF BED

1. Place blocks under the legs of the head of the bed. This will elevate the head of the bed, & make it easier for you to sit up and swing the legs off the bed.
2. A knotted rope tied to the foot of the bed can help you to pull yourself up.
3. To get to a sitting position, shift the body down and rock yourself by vigorously, throwing your arms and legs toward the side of the bed.

FOR USING YOUR ARMS AND HANDS

1. Practice buttoning and unbuttoning your clothes; practice cutting food and writing. Squeeze a ball or work with "Silly Putty." Keep your fingers busy many times a day. Tear paper; take coins out of the pocket; play the piano.
2. Always try to dress yourself completely. Use shoehorns, elastic laces, or extra-long shoelaces to get a better grip. Dress in the most relaxed and comfortable position, sitting or standing, but make sure you are in a safe position.
3. To keep elbows straight and shoulders loose, install a pulley in doorway; place a chair under it or slightly in front. Stretch your arms and shoulders in all directions. By working the pulley when seated, you can get a more vigorous pull.

FOR GREATER SAFETY IN BATHTUB AND TOILET

If it is difficult to sit down in a bathtub, try the following:

1. Place a bench, stool or chair inside the tub; have the legs sawed off to tub height. Sit on the chair and soap yourself. Use shower to rinse, or rubber shower extension.
2. Bathtub grab bars are available. Purchase only those that attach securely.
3. Raised toilet seats are commercially available.
4. Toilet armrest for getting on and off the toilet are available.

FOR SPEECH, FACE AND CHEWING DIFFICULTIES

1. Practice singing and reading aloud with forceful lip movements. Talk into a tape recorder, if one is available.
2. Practice making faces in front of a mirror. Recite the alphabet and count numbers with exaggerated facial motions. Massage your face with vigor when

washing and bathing.

3. When chewing food, chew hard and move the food around; avoid swallowing large lumps.

The previously outlined general exercises and suggestions are designed to help you. They are ancillary to medical treatment which should be carried out in consultation with your physician. In special instances where other diseases are associated with Parkinsonism, your physician may wish to limit the intensity of your physical activity. Conversely, more intensive physical therapy may be indicated and in some instances should be done under the direction of a physical therapist.

All activities possible should be engaged in: work, walking, shopping, house chores, gardening, visiting, senior clubs, church organizations, travel, theater, swimming, sports, gymnasium, health clubs, "Y" activities, etc.

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Attempting to zap Parkinson's through spinal cord

By LAURAN NEERGAARD, AP

WASHINGTON -Implanting a pacemaker-like device deep in the brain helps some Parkinson's disease patients move better, but could less risky zapping of the spinal cord work instead? It did in mice and rats nearly immobilized with Parkinson's-like symptoms: Scientists at Duke University Medical Center turned on the electricity and videotaped the rodents immediately scurrying around almost like normal.

The research, reported in Friday's edition of the journal Science, is just a first step. More animal testing is needed to tell if the approach could be tried in people. Implants in marmosets, a type of primate, are to begin soon.

But sufferers of chronic pain already can have spinal cord stimulators implanted that send electrical currents to block the "I'm hurting" messages sent to and from the brain. For Parkinson's, the idea is similar.

The 1.5 million Americans with Parkinson's gradually lose brain cells that produce dopamine, a chemical key to the circuitry that controls muscle movement. The result:

Haywire

brain signaling that leads to increasingly severe tremors and periodically stiff or frozen limbs. Medication helps early in the disease. More severely affected patients may try "deep brain stimulation," where wires are implanted inside the brain to deliver tiny electrical zaps that disable overactive nerve cells and improve motor control.

Exploring a less invasive approach, the Duke team attached tiny wires to the spinal cords of mice and rats whose brains produced so little dopamine that they had the slow, stiff motions of advanced Parkinson's disease.

When the electricity was turned on, the animals became 26 times more active and movement visibly improved in seconds, Duke Neuroscientist Dr. Miguel Nicolelis and colleagues wrote.

Why would it work?

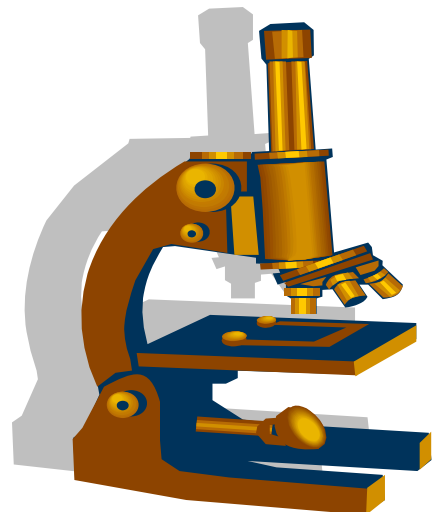
Proper movement requires orderly nerve cell firing to different muscles at different moments in time, like members of an orchestra must play in proper sequence for a symphony.

There's increasing if circumstantial evidence that rhythmic waves of brain activity, called oscillations, play a role in Parkinson's movement problems — and that interrupting those abnormal waves allows the more normal, symphony-like brain cell firing to resume, said Dr. Walter Koroshetz, deputy director of the National Institute of Neurological Disorders and Stroke, which helped fund the work.

The spinal cord stimulation appears to have sent a signal up to the brain that interrupted those oscillations.

Koroshetz cautioned that much work remains, including testing whether the stimulator's effect might last long enough to be useful.

But, "it's something that has definitely got some scientific traction to it," he said. "It's a really good idea."



Create this cute bunny vase for your Easter table from a pint jar, felt, and few other supplies.

Approximate Time: About 30 minutes.

Supplies:

- pint jar
- white felt
- pink felt
- wiggly eyes
- black marker
- 3 chenille stems
- pink pom pom or pink cotton ball
- white cotton ball
- scrap piece of cardboard or poster board
- pencil
- scissors
- hot glue gun and glue sticks

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Daily SuDoku: Sat 7-Mar-2009

easy

Craft Project: Bunny Jar Vase



Instructions:

Draw a bunny head, including the neck onto a piece of thin cardboard or poster board; cut out the design. Using this as a template, trace around the head onto a piece of white felt; cut out. Glue felt head to cardboard template and set aside.

For arms, draw a football shape onto cardboard that measures approximately 4 1/2 inches wide by 11 inches long; cut out. Using this as a template, trace around arms onto a piece of white felt; cut out. Glue felt arms around jar; they will overlap slightly in front.

Draw an inner ear onto piece of cardboard; cut out. Using this as a template, trace around inner ear onto pink felt twice; cut out both pieces and glue to inside of bunny's ears.

Glue on wiggly eyes, chenille stem whiskers, and pom pom nose. Use black marker to draw on the paws and to draw on a mouth. Glue the neck of the bunny inside the jar to hold in place. Glue white cotton ball at the bottom center on back of the jar for the tail. Fill the jar with fresh or artificial flowers.



CHEF'S CORNER

A recipe that has phytochemicals, antioxidants, a whole day's worth of vitamin K and folate, and is rich in magnesium, potassium, and vitamins A and C – just right for people with Parkinson's.

Oriental Spinach Salad

- 1 TB sesame seeds
- 3 TB vinegar
- 1 TB olive oil
- 2 tsp low-sodium soy sauce



TIP OF THE QUARTER

Don't hold the mayo!

If you've been buying low-fat or fat-free mayonnaise, you might want to think again. Regular mayonnaise is a good source of vitamin E, an important antioxidant, especially for people with Parkinson's disease. One tablespoon of Kraft Real Mayonnaise contains 1.7 mg of vitamin E – 17% of the recommended daily amount. Although it's not a good idea to overindulge in fatty foods, a tablespoon of mayonnaise a day is fine for most people. So if you prefer "real mayo" you now have a good reason to eat it!

Kathrynne Holden, MS, RD
<http://www.nutritionucanlivewith.com>



MEMORIALS

In Memory of Maurine Hausser
In Memory of Dr. John Huff
In Memory of Mr. Jesse Erben
In Memory of Deborah Lyn Raider
All by Barbara & Ricks Wilson

UPCOMING EVENTS:

CCPSG SPONSORS MEET THE PWP's BBQ PICNIC

The Neurology Clinic of Central Texas treats 433 people for Parkinson's Disease. Over 225 of these PWP's live in Comal County. The Comal County Parkinson's Support Group touches the lives of about 6 percent of these patients.

CCPSG has mailed personal invitations to more than 450 PWP's inviting them to a BBQ with all of the trimmings. The Comal County Parkinson's Support Group, along with AAPSG, is sponsoring a "Meet the CCPSG PWP's Picnic" on April 25th from 10:00am to 2:00pm, at Landa Park in New Braunfels, Texas. We want all of the PWP's in the Tri-county area to know that we are here to help them, their families and their caregivers, through education and discussion. We know that sometimes a friendly ear is all it takes to make life a little more bearable.

Please come join us for food and a good time. Leave with the knowledge that there are people in Comal County who understand, care and want to "Help Ease the Burden" of Parkinson's Disease.

If you would like to join us, please RSVP by April 11, 2009 to:

Tommy Dubuque 830-227-5303 tommydubuque@yahoo.com

Connie Srote 830-629-2497 csrote@satx.rr.com

Sally Webb 830-935-2529 sbwebb@gvtc.com

Parkinson's 5K Walk/Run Saturday, May 30, 2009

"To Ease the Burden Find a Cure"

DATE: Saturday, May 30, 2009

TIME: 8:00 AM-12:00 PM Walk
8:30 AM 5K Run

PLACE: McAllister Park
13102 Jones Maltsberger
San Antonio, TX

COST: Early registration / walkers: \$20.00
Morning of event: \$25.00

For more info: 210-567-6039 Dianne Johnson, R.N.

Annual Parkinson's Symposium Saturday, June 6, 2009

OMNI SAN ANTONIO HOTEL
9821 Colonnade Blvd.
San Antonio, TX
(210) 699-5831

\$129+tax Preferred Guest Room Rate

Cost: \$20.00 per person or
\$35.00 per couple

Time: 8:30 a.m. registration;

Program 9:00 a.m.-2:00 p.m.
Lunch Will Be Provided



AAPSG SUPPORT GROUPS

All Support Group Meetings are for PD Patients, their Caregivers, Family and Supportive Friends.

Alamo Area PD Support Group San Antonio

Second Monday every month except Oct, 1 PM. Sunset Ridge Church of Christ, 95 Brees Blvd.

Young-Onset PD Support Group San Antonio

Second Saturday every month, 10 AM. Newforest Estates, a Senior Lifestyle Community, Auditorium, 5034 New Forest Dr.

DBS Support Group “Live Wires”

Fourth Saturday every month, 10 AM. Location varies; call Sandra Farris, 830-257-3811 sandraf@windstream.net or Judy Hoopman 830-997-7705 ralanh@beecreek.net for current location

Caregivers Only Support Group, San Antonio

Second Tuesday every month, 10 AM. Bob Ross Senior Ctr, 2219 Babcock Rd. POC: Dianne Johnson, 210-567-6688, 651-9835, diannejohnsonrn@aol.com .

Austin Young Onset Parkinson’s Support Group

AJ Hernandez/ Facilitator 512-671-0605, ajhernandez@alumni.utexas.net

Austin (Parsons House) PD Support Group

Third Friday every month, 10 AM. 1130 Camino La Costa, Austin, POC: Deborah Bryson or Jaime Eyer 512-454-0524/ 512-238-6000. Accolade Home Care

Bastrop Argent Court Assisted Living Support Group

Fourth Thursday every month, 2 PM. 508 Old Austin Hwy, Bastrop. POC: Shasta Martini 512-321-9500 #252, Jenny Bankston 512-252-1512

Burnet PD Support Group

Second Wednesday every month, 2 PM. 309 Industrial Blvd = St/ Bldg Behind Hospital Business Offices/Rehab = Enter: Patient /Finance. POC: Lynn Wisdom 512-715-3363 or Susie 512-345-1380

Cedar Park (Ranch Retirement Living) PD Educational Support

First Friday every month, 1 PM. 1301 Whitestone Blvd, Call 996-0700 for info, POC: Ms Deborah Bryson, 864-4075

Comal County Support Group

Fourth Saturday every month, 10 AM. 801 W San Antonio St, New Braunfels (McKenna Event Ctr Children’s Museum). POC: Tommy Dubuque tommydubuque@yahoo.com or call 830-227-5303

Fredericksburg PD Support Group

First Monday every month, 10 AM. Fredericksburg United Methodist Church in a room off the Fellowship Hall, 1800 North Llano Hwy. Coffee, juice and snacks are served. POC Judy Hoopman 830-997-7705 or ralanh@beecreek.net

Georgetown PD Support Group

Last Thursday every month, 2PM. Scott & White Meeting Rm, 4945 Williams Dr, Georgetown,
POC: Beverly Edwards 512-863-8443 edwards107@verizon.net

Lower Rio Grande Valley PD Support Group

Call for information on meetings. POC: Cheri Horkmann, phone 956-554-6028

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