

PSGTC NEWSLETTER

September–October, 2010

Message from the President

Summer is over and now it's time to buckle down and get back to work and reconnect. Fall reminds us that our time is limited and we should savor every golden hour before the cold and dark days descend on us. Looking forward to seeing everyone at our kickoff luncheon in September.

Helen Robertson



Mid-Stage Parkinson's :

Like most aspects of Parkinson's disease, the mid-stage is very individualized. During this phase, symptoms become less easy to suppress using medications, and new problems, some related to PD and other provoked by the medications themselves, may develop. The term mid-stage has more to do with these changes than it does with the length of time since diagnosis. Some people experience mid-stage issues soon after diagnosis, while others may not encounter them for five or more years.

Movement Symptoms of Mid-Stage PD

In mid-stage Parkinson's, your medications may begin to "wear-off" substantially before it's time for the next dose, leading to "off periods, which occur when the beneficial medication effect quickly drops off.

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Splish ~ Splash

The Water Exercise group is really making waves. They are splashing up a good time as they work hard on their "BIG" curriculum and other muscle strengthening techniques. If you are not familiar with the "BIG" curriculum, it is specially designed for Parkinson Patients and helps with motor coordination. Cindy Nolan, PT at Baylor All Saints Movement Disorder Clinic has put together a really great program and is planning on extending it very soon. So, get your water wings ready and sign up when the time comes.

Exercise Class by Bob Belisle

Our Exercise group meets on the 2nd floor of Broadway Baptist Church on Monday, Wednesday and Friday from 10:30 to 11:30.

We were so pleased that Ryan Barfoot has been able to join us again this summer. He is a medical student who has helped with the exercise group in the past. He is so encouraging and uplifting. He adds that little extra "UMP" to our routines. We really enjoy having Ryan and are thrilled to hear that he plans on being with us through the entire coming school year on Fridays every week.

We will not meet on Monday, Sept. 6. Labor Day, but hope you will be joining us soon and often. We have a good time and work on our muscles at the same time. Caregivers are welcome to exercise with us.



**For Support Group information call our Help Line at (817) 275-1909
Visit our Website: www.psgtc.org**

Our meetings are held on the 3rd floor of :

**Broadway Baptist Church
305 W. Broadway, RM 302
Fort Worth, TX 76104**

September 27 meeting will be a luncheon held at 11:30 am with lunch provided by Professional Caretakers

Speaker: **Pam Brandon with Area Agency on Aging**



Our kick-off program for this year will be presented by Pam Brandon, who represents the Family Caregiver Education Program, a project of the Area Agency on Aging and Aging and Disability Resource Center of Tarrant County. Pam works with hundreds of families across North Central Texas by providing education, resource information and support to caregivers and their loved ones. She brings a special understanding to us, as she was a caregiver for her mother, who also had PD. You won't want to miss this dynamic and enlightening program that will be packed with valuable tips and ideas for caregivers and care receivers!

Let's face it – Parkinson's is a busy disease. It's also a family affair. Between doctor visits, managing medication, dealing with daily, if not hourly physical and emotional changes that take place, it's no wonder you get worn out! But like any chronic illness, there are things that you can get a handle on – like learning how to get organized, preparing for a doctor visit, taking care of legal and financial matters, and our favorite – medication management. When we take care of the things we CAN take care of, it allows us time to focus on the important things – our relationships, emotional well being and how to find joy in each day. Like Michael J. Fox, we can embrace the attitude of "Always Looking Up"!

BOD MEETING will be held after the meeting

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October 25th meeting will be at 1:30 pm. Our speaker will be **Carol Crosby with Medtronic**. Medtronic is the producer of many of the Deep Brain Stimulator equipment used by some Parkinson patients. I am sure she will be able to answer your questions on Deep Brain Stimulator surgery.

Refreshments will be provided by Ann Pace.

Our Web Site

www.psgtc.org

We continue to work on our Web Site and make updates as necessary. We have added a new page called "Latest News". This web page is intended to keep you abreast of happenings between Newsletters.



Caregivers Corner

Loretta Belisle

The caregivers meet on the 2nd and 4th Friday of each month. We meet at 10:30, the same time as the Parkinsonians are exercising in the adjoining room. It is an excellent time to gather with other caregivers and share experiences and helpful tips. We welcome all caregivers to join us, whether your patient is able to exercise with the group or not.

Advice from Other Caregivers

Written by Zanda Hilger, AAA

Following is a list of the top 20 ideas from family and professional caregivers, educators, and support group facilitators from their own experiences and that of others with whom they work.

- Involve the care receiver in decisions unless that person is incapable of doing so. No one likes to be told what to do even if your intentions are to be helpful.
- Recognize that their independence is probably being diminished and they are experiencing a sense of loss of independence and identity.
- Think of how you would feel if the roles were reversed.
- Patience, patience, patience...
- Be prepared. Keep documentation up to date: doctor's names and medications, medical/legal directives, lists of financial records/accounts.
- Communicate with friends, family and others and ask for help in meeting care receiver needs and what you need.
- Take care of yourself! It is difficult to help someone else if your health (mental and physical) is suffering.
- Take care of yourself ~ that means proper diet, exercise, rest and diversion.
- If you don't take care of yourself, you can't begin to take care of someone else.
- Educate yourself. Find your resources and use them: contact Area Agency on Aging or Meals on Wheels, go online to websites such as www.familycaregiversonline.net
- Don't try to do it all ~ enlist whatever help you can.
- Obtain help from someone: family, friend, church or synagogue, to give you relief for at least several hours during the week, OR if you can afford it, hire someone to come in. Ask about the Respite Program at the local Area Agency of Aging.
- Make some ME time.
- Make a life for yourself either continue working full or part time or have regular volunteer and community activities.
- Maintain or improve spiritual practices and physical health.
- Take time for fun, friendships and learning every day.
- Maintain a list of things for which you can be thankful.
- Build the relationships. Communicating openly between family members ~ caregivers, elders, siblings, as much and as well as possible, will make everything else easier.
- Share. Share your feelings, your experiences and ideas, resources you've discovered.
- Know that you are not along.

Mid-Stage Parkinson's : Managing the Movement Symptoms

(continued from page 1)

When this happens, movement symptoms that formerly remained hidden for hours, such as tremor or stiffness, may become more troublesome than they were in earlier years.

Mid-stage often includes the onset of dyskinesias. Dyskinesias are involuntary writhing movements that are caused by dopamine medications, and tend to occur at the peak of the medication effect and taper off when the medication effect wanes. Many people experience both "on-off" fluctuations and dyskinesias: when their medications are working, they are mobile but experience dyskinesias, and when their medications wear off, dyskinesias subside, but Parkinson's symptoms are more pronounced.

Dystonia--an often painful, sustained cramping and twisting motion -- can be provoked by medication, but more likely occurs in the "off" unmedicated state. A common form is toes that curl under or upwards, often first thing in the morning.

Two additional symptoms are important to address because they can increase the risk of falls. The first is postural instability, or impaired balance and coordination. The second, freezing, happens when a person feels stuck to the ground and finds it difficult to start walking. It often occurs when a person launches forward after rising from a chair, after he or she is standing still, or while walking, in which case the body continues its forward motion, but the feet stay planted.

Tips for Managing these Symptoms

Manage your Medications

The first step in addressing mid stage movement symptoms is to ensure that your medications are well managed so that they last longer, symptoms are better controlled and dyskinesias are minimized. Unfortunately, postural instability and freezing do not respond to most available medications, and supplementary strategies involving physical therapy and fall prevention are needed.

The timing of medications can impact how you feel, so a key part of good management is sticking to a schedule. It is also a good idea to go through a complete list of symptoms and problems with your doctor, and to be certain about the role, dosage and timing of medications.. If your symptoms fluctuate, it is helpful to keep a detailed record of your response to medications throughout the day, indicating meals, sleep and daily activities, for one week prior to your next appointment with your doctor. Some neurologists and support groups have pre-printed sheets for you to use. Doctors use these reports to make informed adjustments, e.g., adding a new class of medications or adjusting the dosages or timing of them.

Work with a Physical Therapist

For postural instability, it may be helpful to work with a physical therapist (PT). With a referral from your neurologist, a PT can perform an evaluation and develop a program that may include fall

prevention, balance training and the proper use of assistive devices such as canes or walkers.

Break Your "Freeze"

There are a few strategies that may help with freezing. Try marching in place until you feel the freeze break. Rocking side to side can also be effective. Another tip is to try singing out loud--preferably a song with a marching beat. Lastly, some people find that if they drop a string or piece of paper on the floor, and then step over it, this can break the freeze. Different tips may work at different times. So, if one doesn't work, try another.

Seek a Second Opinion

Don't be afraid to seek a second opinion from a movement disorder specialist (MDS), a doctor who specializes in Parkinson's. If you are already being treated by one, another may offer fresh insight.

Talk to Your Doctor about DBS.

When you or your loved one has tried these solutions and problems persist, it may be time to consider deep brain stimulation surgery (DBS) DBS is not for everyone, but recent research indicates that when it is done on appropriate candidates, it offers symptom control superior to that which is obtained with the best medication management.

By Parkinson Disease Foundation



SEPTEMBER—OCTOBER, 2010

SEPTEMBER 2010

Sun	Mon	Tue	Wed	Thu	Fri	Sat
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5	6	7	8	9	10	11
12	13	14	15	16	17	18
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26	27	28	29	30		

September
Schedule of Events

- Monday, Wednesday and Friday—Exercise at 10:30 Room 206 of Broadway Baptist Church

Sept. 6 Labor Day NO EXERCISE

- Second and Forth Friday—Caregivers Meeting at 10:30 in room adjoined by Room 206
- Sept 27, at 11:30—Fall Luncheon 3rd Floor Meeting Room

OCTOBER 2010

Sun	Mon	Tue	Wed	Thu	Fri	Sat
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3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30
31						

October
Schedule of Events

- Monday, Wednesday and Friday—Exercise at 10:30 Room 206 of Broadway Baptist Church
- Second and Forth Friday—Caregivers Meeting at 10:30 in room adjoined by Room 206
- Oct 25 , at 1:30—Membership meeting 3rd Floor Meeting Room

Meetings are held at:
Broadway Baptist Church
305 W. Broadway, Room 302
Fort. Worth, TX 76104
For info about our group call:
Help Line (817) 275-1909
Website: www.psgtc.org

PARKINSON'S SUPPORT GROUP
OF TARRANT COUNTY
P. O. Box 939
HURST, TX 76053

Web Address: www.psgtc.org

**PARKINSON'S SUPPORT GROUP OF TARRANT COUNTY
MEMBERSHIP APPLICATION AND RENEWAL FORM**

Date _____
Name of Parkinson Patient _____
Name of Spouse/Family Member/Other _____
Address _____
Home Phone _____ Cell Phone _____
e-mail _____
Preferred Type of Membership: _____ Family (patient and partner (\$20.00 per year)
_____ Professional (\$30.00 per year)
_____ Lifetime(\$200.00)

Make check payable to PARKINSON'S SUPPORT GROUP OF TARRANT COUNTY (or PSGTC)
Mail to: Merry Ann Bench, P. O. Box 939, Hurst, TX 76053

The contents or opinions expressed in this Newsletter are those of individual writers and do not constitute an endorsement or approval by Parkinson's Support Group of Tarrant County.