



BIG EASY FLEUR DE LIS PARKINSON'S SUPPORT GROUP



Minutes – Support Group Meeting 3-26-18

Leading our meeting was our friend, Sandra Andrieu, PhD, LSU School of Dentistry!

*Before the meeting opened, Millett White & Kelly Haber got the members involved in some fun! The **NOBA “Dance for PD”** free classes are held at the uptown JCC (5342 St. Charles Ave, N.O.) 11am – 12:15pm*

- * **Big Easy PD** incorporation is still in progress
 - * Dr.'s Office Rack Cards – Need Volunteers to replace - New cards available
 - * **MARIE & JIM McClelland**– Paula Shaffer coordinating food. To volunteer, send email to ArtGlass268@gmail.com **Driver needed to pick up food on Wednesday and deliver to them. Marie's Surgery is May 7th - please keep her in your prayers.**
 - * **FAMILY CAREGIVER SUPPORT GROUP** – Meetings are 10-11 am, first Wednesday of each month at the Home Care Solutions office at 3421 Causeway Blvd, Ste. 502 in Metairie. 504-828-0900, www.HomeCareNewOrleans
- DON'T FORGET ! This Is an annual event and very informative!**
- * **OCHSNER SYMPOSIUM 2018 April 28th Register now !! [504-842-8768](tel:504-842-8768)**
 - * Susan Falgout is creating a Lending Library of PD publications for the group that can be checked out. Since the national Parkinson's groups merged, they are not sending out free materials like they used to, but an individual can call or go online 800- 473-4636 , www.Parkinson.org. Information on pamphlet on back table
1) APDA- Emily Ciorciari ([718-981-8083](tel:718-981-8083)) 2) Parkinson's Foundation 800-473-4636

Our Presenters were from **Home Care Solutions** --Cathy Pruett. Georgiana Leavesley, Analiza Schneider

“Care Partners” is a preferred term to caregivers.

Their talk focused on dealing with the stresses of PD and dealing with the changes that come about in activities, work and lifestyle. It can be difficult for PD patients to accept help. There can be changes in roles within the relationship as to who does the finances, shopping, cooking, etc. The Care Partner often becomes a medical coordinator and medical advocate and also a student, learning about the disease.

Ways to Cope with Stress:

- Exercise for PD patient: Rock Steady Boxing, Ballet, Big and Loud therapy, and Dance therapy.
- Exercise for Care Partner: Walking, Dance, Yoga, Massage
- Set Limits on what you can do: Saying No can be hard. If others are asking too much of you, learn to say no.
 - **Tip: Ask for help from others. There are four sites which you can put on your computer which are calendars, where you can reach out and ask for help. Some also have phone apps. CaringBridge.org, lottahelpinghands.com, caringvillage.com, and caringzone.com.**
- Organize your environment.
- Accept what you cannot control. There's a lot we worry about, which we cannot do anything about. We cannot change the diagnosis, but we can change how we deal with it.
- Ask for help /accept offers from others.
- Engage in favorite activities. Card games and board games, reading, and mind puzzles help take your mind off worrying, getting together with family and friends. Cooking, collections, crafts.
- Count your blessings / list your assets.
- Focus on what you have today.
- Conduct problem solving.
- Use humor.

Ways to relax

- Listen to or play music
- Walk the dog, garden, and enjoy the outdoors.
- Activities which are productive are more beneficial. It is important to try new activities, even if you have doubts.
- Saying no. Sometimes you have to set new standards – like not leaving dirty dishes in the sink. You have to do what you can and accept it.
- Look at what is good in your life.
- Conduct Problem-solving. Figure out what you can do within your limits.
- Journaling helps to manage and track the progress of the disease and to put down your feelings.
- Reading

- Mindfulness – being in the moment, not worrying about what is ahead or past, just enjoy what you are doing at that time.
- Call a friend or family. Many falsely take the attitude that they “don’t want to bother others.” Call and reach out.
- Meditation – even 60 seconds of meditation can make a difference. You don’t have to have a still mind to do this. Close your eyes and focus on a single point – word, object, etc. Let your tension go.
- Refreshing or soothing drink
- Aromatherapy
- Hot bath or shower
- Deep breathing
- Release emotions, cry or fume
- Spiritual focus
- Decrease worry with distractions
- Respectful communications – respect your needs, but also respect the other person’s needs. Use ‘I’ statements.

There are obvious “losses” (radical changes) in the lives of both the Parkinson’s patient and the Care Partner. The best thing you can do is communicate, speak about your frustrations and how you can manage better. Express your feelings in a kind and positive way. Occasionally, the stress and frustrations on both partners is best addressed with a Social Worker or Counselor.

There can also be opportunities for growth and building strength.

Martha Good, Recording Secretary

Meeting dates for 2018:

- *April 30th Dr. Sarah Perez / Jan Grimes “Life Hacks “ & music lunch by **Impax Labs** / Judy Pontin
- *May 21st Mary Brocato - ACADIA-Pharm. Dr. Calegan PD Diet
- *June 25th Lori Bardet - Adamas Pharm. 985-373-8065 - (Gocovri) Dyskinesia
- *July 30th Baudry Therapy - Big & Loud
- *Aug. 27th Jill Siemssen – US WorldMeds (Apokyn / Xadago)
- *Sept.27th Jerry White - Medtronic (DBS)
- *Oct. 29th Roberta Powers - Lundbeck Pharm. - (Nothera) Orthostatic Hypotension

Visit our web site: BigEasyFleurDeLis.org

Join us on Face Book: *Parkinson’s Support Group in the “Big Easy”*