

The Parkinson Path

FALL 2016



*A quarterly journal
for people with
Parkinson's, their
families and
care partners.*

News from the PANC Board

WELCOME to TWO new Support Groups!

The **Parkinson Support Group of Lakeport** has joined the PANC network! Mr. Philip Meyers is a Parkinson Disease Advocate and facilitates the monthly group meetings.

The newest group – **The Parkinson Support Group of Elk Grove** is being held at the Senior Center of Elk Grove. PANC board member, Mr. Myron Jantzen will serve as the interim facilitator until the group establishes its own leadership.

Davis Phinney Foundation's VICTORY SUMMIT

Thanks to the Davis Phinney Foundation for bringing its VICTORY SUMMIT to Sacramento October 8, 2016! The event drew together over 800 folks who enjoyed the extraordinary, all-day conference on PD.

New Board Member

Ms. Christine Grmolyes has recently joined the PANC Board of Directors. Ms. Grmolyes is a family consultant with Senior Care Solutions and has tremendous experience in serving on the boards of the Alzheimer's Association and the Del Oro Caregiver Resource Center. We are so fortunate to have her on our team!

If you are interested in working with us, please contact us! panc@parkinsonsacramento.org or call 916-357-6641

Respite Subsidy Programs

As of mid-September, 53 Respite Subsidies have been awarded to folks across Northern California. PANC provides up to \$450 of care services to relieve someone caring for a person with PD and who needs a bit of a break. The actual care relief is assessed and arranged by one of three Caregiver Resource Centers – Del Oro, Redwoods and Passages – that collectively serve approximately 30 of California's counties. Of note, the National Parkinson Foundation granted \$10,000 to PANC this year (from the 2015 Moving Day San Francisco / Silicon Valley event) that is supplementing PANC's ongoing Respite Program. More info is available online.

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Mike's New Diagnosis of Parkinson's Disease: A Clinician's Perspective

Suketu M. Khandhar, M.D.

Medical Director, Movement Disorders Program, Kaiser Permanente



For the past two years, "Mike", a construction foreman, had noted occasional difficulty using his right hand. He reluctantly saw his primary care physician who ordered x-rays and routine blood work. Weeks passed until he learned that his tests were normal. He sought another opinion, this time by an orthopedic surgeon, who reassured him that the arm and hand were not fractured. He was referred to a neurologist who tested his strength and ordered an MRI of the brain. The imaging was normal and Mike was told that he hadn't had a stroke. Months went by, and now it was noticeable that he did not swing his right arm and he began to develop a little tremor. Co-workers noticed. Mike began to feel anxious and worried whether his job was at risk. He saw another neurologist who, within ten minutes, gave Mike a diagnosis of Parkinson's disease (PD), a prescription and told him to return in six months for a follow up. As you can imagine, Mike left the neurologist's office in a daze and feeling vulnerable.

This scenario is certainly not the one I feel is optimal for patient care but is one that is all too common. Ideally, the following considerations should immediately come into play at the first diagnosis of PD. Mike needs to be empowered so that he, his family and his medical team can best manage his disease.

Information.

At the time of diagnosis, Mike's neurologist should explain the underlying pathology of PD and give Mike a clear understanding of how this relates to his PD symptoms. This may include what the expected course / trajectory of the disease is as it pertains to his particular situation. Mike –and his family - may need time to develop their own questions for the doctor. The neurologist and the care team should be available to answer those questions (either by office visit, telephone, e-mail or other form of telemedicine).

Plan of Care.

The Plan of Care is a dynamic guide for the patient and the care team. Mike's medical care team should include his primary care physician, neurologist, physical therapist and pharmacist. To make the most of his medical treatment plan, Mike needs to understand all of his medications and how they affect him as well as how to report side effects that may occur, or if his condition changes. Conversations with members of his care team are essential in this phase of the process. There are many therapies and specialty care treatments that may be appropriate for Mike over time.

Commitment.

Mike must take ownership of his diagnosis and well-being to achieve the quality of life he desires. Personally, I strongly encourage patients to lead an active life style (to include exercise and social activities). I would introduce Mike to PD advocacy groups, like the Parkinson Association of Northern California, in an effort to lead him to a supportive "community", but Mike must be the one to take the initiative to engage in those resources. Further, I expect my patients to be knowledgeable and active participants in maintaining their overall health.

These are the things Mike, or anyone with a new diagnosis of PD, will need to be successful during their journey with Parkinson's disease.

Think JOY

By: Dorothy Ross

When I was diagnosed with Parkinson's,

my doctor stressed the importance of exercise for people with PD. She said it didn't matter what I did, as long as I moved for at least a half hour most days.

So, for several years, I kept up the same kinds of exercises I had been doing all along. I assumed yoga poses until I could no longer maintain my balance in those pretzel postures. I took the dog for shorter and slower walks. Instead of getting more exercise, I was gradually settling for less.

Frustrated by my slump into inertia, I sought the advice of a physical therapist. "What's the best exercise program for people with PD?" I asked him.

"Think JOY," he said. "If you enjoy it, you'll keep it up. I could prescribe a workout routine for you, but if you didn't have fun with it, you'd stop doing it. Try some new activities until you hit on something that you would be joyful doing, even if it wasn't good for you."

So I experimented with Tai Chi, Nordic pole-walking, stationary bicycling, and even horseback riding. I liked some of these activities better than



others, but *joy* eluded me until the Dance for Parkinson's program came to town. I had never in my life taken a dance class and I did not have high expectations for this latest offering that sounded like an oxymoron. Parkinson's and Dance just didn't seem to go together

To my surprise, moving to music made me feel-joyful!!

My first dance class was more than five years ago and I've seldom missed a session in all that time. But it might not be dancing that brings you *joy*. Perhaps swimming or snowshoeing or tandem bicycling would be more appealing. Make the effort to try a variety of activities, and the whisper of *joy* just might surprise you.

Like love, *joy* can be hard to define, but also like love, you'll recognize *joy* when you find it.

RESEARCH

In 2015, PANC donated \$10,000 to UC Davis for the specific use for research to learn more about Parkinson's disease. Dr. Norika Malhado-Chang, a movement disorder specialist is leading the 2016 work on this grant. The project entails looking for bio-markers that foretell the possible development of PD. Work on this project is underway. Findings will be reported when they become available. Stay tuned!



Getting The Most From Your Caregiver

By Craig Falk

I recommend you begin the employment relationship with your caregiver by providing clear written expectations.

Include a care plan that details which tasks are to be completed by the caregiver. For example, cooking, personal care (bathing and toileting), medication reminders, transportation, assistance with mobility, and housekeeping.

Another important expectation is that the caregiver must document their activities each day.

Typically this would include a check list of the required tasks. It is also helpful for the caregiver to summarize in narrative form the day's activities along with any changes in the client's condition, mood, and conversion. This form gives you and the caregiver an opportunity to track the client-caregiver relationship, providing a written history of events.

Create a Care Log Book that contains all pertinent documents: The Care Plan, the task check list, narrative notes, contact information and rules of the house. Consistent monitoring and evaluation of the Care Log Book will provide a communication tool among all parties and will keep the caregiver motivated to do his/her best.



If you want something done in a particular way, make that clear to the caregiver. For example, even though it might seem obvious to you that two tablespoons of coffee grounds is just right to make five cups of coffee, some people prefer three. If your caregiver talks too much or is doing something else that annoys you, politely ask them to stop. This feedback will give them the opportunity to change. Avoid the "I have

a guest in my home" syndrome when dealing with a caregiver. They are employed to provide service as a caregiver.

As much as possible, provide the caregiver with a consistent schedule. When you cancel days, they usually go without work. This is fine on an occasional basis, but not routinely. Drop in unexpectedly to see how your

loved one and caregiver are doing. Observe how he responds to the caregiver. Does he appear afraid? Does it appear that the meals are appropriate, varied, and balanced?

Finally, treat your caregiver with respect and appreciation. Saying please and thank you will do wonders. Almost all

caregivers are working for more than a paycheck - they truly enjoy helping others. If you treat them with respect and appreciation they will do almost anything to accommodate your needs.

Craig Falk is the founder of Craig Cares, a Sacramento area in-home care agency. His booklet, *Safe and Sound at Home – A Guide to Finding the Best Caregiver*, is available for free at www.craigcares.com

WORDSMITH



Directions - Create as many four (or more) letter words as you can using the letters in the Key Word.

Letters for each new word may only be used as many times as they appear in the Key Word.

How many words can you build within 10 minutes?

Key Word: DOPAMINE

KEEP IT MOVING!

Do you find yourself struggling to get out of a chair or a car? Is it tough to get off the couch or the toilet? Many people with Parkinson's disease have a difficult time standing up.

Sit-to-stands maneuvers are a "great bang for your buck" exercise to help you continue to stand with strength and ease. Simply use a kitchen chair (WITHOUT WHEELS) and set it close to the table. Position yourself on the chair. Then, stand up from the chair with or without hands, whichever is safest for you. Make sure when you lean forward to stand up, you keep your nose over your toes to make it easier and safer to stand up. Upon standing, make sure your chest is out and shoulders are back. If you need to hold on to the table or a walker, do so. Sit down nice and slow and controlled.

Practice this move 10 times in the morning and 10 times in the afternoon.

Research shows this exercise can be helpful with balance, strength and stamina.

Christine Shade, PT, DPT, NCS
Neurological Clinical Specialist





Regional Support Groups

Support Group Contact: Caroline Cormier,
panc@parkinsonsacramento.org; 916-357-6641.

*For details and contact information see full list at
www.parkinsonsacramento.org/support.*

Sacramento

Arden/Arcade

3rd Thursday, 10 a.m.
 Arden Christian Church
 4300 Las Cruces Way
 Keith Tronson
 916-395-2771
keithtronson@sbcglobal.net
 Jim Morris 916-359-4859
jgmo@winfirst.com

Northeast Sacramento Area

4th Thursday, 1 p.m.
 St. Marks Unified Methodist Church,
 Room E-24
 2391 St. Marks Way
 Sean Tracy 916-482-7014
sstfam@winfirst.com

Caregivers Lunch Bunch

3rd Tuesday, 11 a.m.
 Ettore's, 2376 Fair Oaks Blvd.
 Anne Spaller 916-728-9333
aspaller@deloro.org

Gold River Lewy Body Dementia (Collaboration Group)

2nd Thursday, 10 a.m.
 Eskaton Lodge Gold River
 11390 Coloma Road
 Denise Davis 916-930-9080
Denise.Davis@alz.org

Men's Group

1st Thursday, 10a.m.
 Crown Plaza, Theater Room
 1071 Fulton Avenue
 Arnold Loveridge 916-485-0150
arnoldvl@surewest.net
 Jim Morris 916-359-4859
jgmo@winfirst.com

Post DBS Patients

See class schedule, location and
 contact information at
[www.parkinsonsacramento.org/
 db-class-support](http://www.parkinsonsacramento.org/db-class-support)

South Area

2nd Thursday, 1 p.m.
 Asian Community Center
 7375 Park City Drive
 Casey Jones 916-422-7407
francesellen310@comcast.net

Auburn

3rd Tuesday, 1:30 p.m.
 Pioneer United Methodist Church
 1338 Lincoln Way, Auburn
 Cindy Christensen 530-355-0742
cindypoe2000@yahoo.com

Caregivers Luncheon

2nd Tuesday, 12 p.m.
 (No meeting June/Dec)
 Awful Annie's Cafe
 13460 Lincoln Way, Auburn
 Sally Horst 530-878-2226
kandshorst@suddenlink.net

Chico

1st Wednesday, 1:30 p.m.
 Sycamore Glen Ret. Community
 1199 Diablo Ave.
 Della Nicola 530-624-6442
MrsNicola4@gmail.com

Davis

3rd Thursday, 1:30 p.m.
 Davis Senior Center
 646 A Street
 Dorothy Ross 530-756-6024
parkofdavis@gmail.com

El Dorado Hills

2nd Tuesday, 12 p.m.
 Four Seasons Community Building
 Media Room
 3186 Four Seasons Dr.
 Betsy Alver
 916-933-2465
ldalver@sbcglobal.net
 Donna Rixmann 916-0712-9642
donna@yogapeace.net

Elk Grove

3rd Wednesday, 10 a.m.
 Senior Center of Elk Grove
 8830 Sharkey Ave.
 Myron Jantzen 916-686-4555
mpjantzen@aol.com

Folsom

4th Monday, 10 a.m.
 Folsom Senior & Arts Center
 48 Natoma Street
 Yvonne Haskell 916-353-1301
yhaskell@juno.com
 Mary Cabaluna 916-987-1684
cabalunaem@comcast.net

Fort Bragg

1st Friday, 2 p.m.
 Mendocino Coast District Hospital,
 Redwood Room
 700 River Drive
 Joseph Mayfield 707-937-2707
Mayfield@mcn.org

Grass Valley

2nd Friday, 1:30 p.m.
 Atria Grass Valley
 150 Sutton Way, Grass Valley
 Nancy Lockwood 530-272-7950
nmlockwood@aol.com

Lakeport

2nd Monday 2-3:30 p.m.
 United Christian Parish
 745 N. Brush St. (Free Parking)
 Phil Myers 707-263-4624
 Lin Pifer 707-263-5728
 Phillip.e.myers@att.net

Lincoln

3rd Tuesday, 10 a.m.
 Granite Springs Church
 1170 E. Joiner Parkway
 Brenda Cathey 916-253-7537
 bjcathey@gmail.com
 Marsha Mobley Kilian 916-295-4047
 marshakilian@me.com

Lodi

3rd Tuesday, 10 a.m.
 Temple Baptist Church
 801 S. Lower Sacramento Rd.
 Ron & Maureen Olsen 209-745-1011
 molsen@softcom.net
 John & Jean Whitted 209-368-2809
 jtwitted@hotmail.com

Caregivers Group

3rd Tuesday, every other month,
 from 10 a.m. to noon.
 Call for location & directions.
 Jean Whitted 209-368-2809
 bjwhitted@hotmail.com

Loyalton

1st Friday, 1:30 p.m.
 Golden West Restaurant
 Main Street, Hwy 49, Loyalton
 Betty Ferguson 530-993-4002
 fergi45@gmail.com

Modesto

3rd Wed., 1:30-3:30 p.m. Jan.-Nov.
 Trinity United Presbyterian
 Church
 1600 Carver Rd.
 Convenient free parking.
 Debra Watson 209-552-9043
 modestoparkinson@outlook.com

Napa-Young Onset

4th Sunday, 3 p.m.
 Covenant Presbyterian Church
 1226 Salvador Ave.
 Joe Burger 707-266-6156
 jeburger99@gmail.com

Orangevale

1st Thursday, 10 a.m.
 Eskaton Fountain Wood Lodge
 8773 Oak Avenue
 Deborah Johnson 916-987-0668
 debzdots@gmail.com

Oroville

1st Thursday, 1:30-3 p.m.
 Feather River Senior Center
 1335 Myers Street
 Carol Rawlins 530-282-8769

Placerville

1st Tuesday, 1:30-3 p.m.
 Senior Center Dining Room
 937 Spring Street
 Larry Morgan 530-622-8941
 larry.morgan5541@sbcglobal.net
 Tom Schulz 530-644-3473
 macschulz@aol.com

Redding

2nd Friday, 12:30 p.m., Social Time;
 1-3 p.m., meeting. Speakers start at
 1:30 p.m.; 3-3:30 p.m., Loud Crowd,
 speech therapy
 First United Methodist Church
 1825 East St, Redding
 Kim Hawkins 530-945-7628
 rickiel2010@gmail.com

Roseville

1st Tuesday, 1:30-3 p.m.
 Maidu Community Center
 1550 Maidu Drive
 Harry Butler 916-837-3366
 hapbutler@comcast.net

Sonoma County

1st Saturday, 1 p.m., Feb/Mar/
 Apr/May/June/Oct/Nov
 2nd Saturday, 1pm Aug/Dec
 NO meeting in Jan/Jul/Sept.
 Christ Church United Methodist
 1717 Yulupa Ave., Santa Rosa
 Kathy Osbun 707-538-5178
 osbun@aol.com
 Marc Alexander 707-431-8767
 malexander109@comcast.net

Stockton

2nd Thursday, 1:30 p.m.
 O'Connor Woods, West Hall
 3400 Wagner Heights Rd
 Mary Ann Behrens 209-477-6496
 mbehrens64@gmail.com

Vacaville

1st Sat., 1:30 p.m.
 Community Presbyterian Church,
 Rm 2
 425 Hemlock Street
 Theresa Pate 707-642-2173
 theresa3842@sbcglobal.net
 Marlene Roberts 707-446-3862
 rrx@comcast.net

Vallejo

1st Saturday, 10:00 a.m.
 Comm. Presbyterian Church, Rm 2
 2800 Georgia St.
 Theresa Pate 707-642-2173
 theresa3842@sbcglobal.com

Woodland

4th Tuesday, 1 p.m.
 No meeting Jul/Aug
 Woodland Senior Center
 2001 East Street
 Bernadette Murray
 530-661-1950
 bemurray2008@gmail.com

Yountville

Every Thursday, 9-10 a.m.
 Veteran's Home
 Eisenhower Annex 2, TV Room
 200 California Drive
 Richard Lindsey 707-944-4591
 richardlindsey@cdva.ca.gov

Yuba City

2nd Monday, 1 p.m.
 Sutter Medical Foundation
 969 Plumas St., Suite 208
 Janice Herbert 530-673-3064
 Joe Carmona 530-751-2509
 celina-carmona@sbcglobal.net
 George Chumbley 530-671-0767
 gchum@syix.com
 Mary Lou Chumbley 530-671-0767
 lchum@syix.com



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