

Parkinson's Patients Support Groups, Inc.

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Sleep and Parkinson's Disease

By Melanie M. Brandabur, MD

Clinic Director, The Parkinson's Institute

Most patients with Parkinson's disease will have problems with sleep at some point in their illness. The causes of sleep disturbances in PD are many and varied, and often overlap. It is important to diagnose and treat these issues, because poor sleep at night is a common contributor to poor motor function during the day, as well as other problems such as excessive daytime sleepiness.

Unfortunately, it is often the case that a nonspecific complaint of difficulty sleeping results in a prescription for a sleeping pill, instead of an examination of what the specific sleep difficulties are. The patient and family members can help by making careful observations about issues pertaining to sleep, thus assisting the doctor in making more specific and useful suggestions.

There are some interventions that may be helpful with most sleep issues in PD. This includes eliminating caffeine in the afternoon and evening, having set hours for waking and sleeping, limiting naps to no more than 20-30 minutes, and spending some time outdoors in natural sunlight every day. These principles are called "good sleep hygiene."

In some cases, your primary care doctor or neurologist may recommend consultation with a doctor specializing in sleep medicine for more specific diagnosis and treatment of sleep difficulties. This may involve a polysomnogram, or sleep study which involves patient sleeping while being monitored so that changes in heart rate, movements and oxygen saturation can be measured.

Following is a brief discussion of some common sleep problems encountered in PD:

Wearing-off of medications:

One of the most common problems with PD is the wearing-off of anti-Parkinsonian medications. In early PD, most patients still have a fairly good supply of dopaminergic

neurons within the brain and medication is typically geared towards the daytime hours when they need additional dopaminergic medications to improve function. Since PD is progressive, the number of dopamine neurons continues to diminish over time and the patient often notices a return of symptoms, often in the evening and nighttime. This may result in difficulty getting ready for bed or getting comfortable for sleep. If the medication effects wear off during the night, the patient may be unable to turn over in bed or get up safely to use the bathroom. Profuse sweating is another symptom that can occur when the medication wears off during the night.

Most of these symptoms are treated fairly easily by medication adjustments such as additional levodopa or dopamine agonist during the evening hours and/or at bedtime. Some non-medication adaptations that may help include installing a bedrail or floor-to-ceiling pole to aid mobility while turning over or getting in and out of bed. Using satin sheets or nightwear to make movement easier once in bed may also be helpful.

REM Sleep Behavior Disorder (RSBD)

Rapid Eye Movement, or REM sleep is the phase of sleep during which dreams occur. Normally, people are paralyzed during this phase, but in RSBD people appear to act out their dreams; sometimes just talking, but often thrashing around, yelling out or even attacking whoever is nearby. This can result in bruises or even serious injury to the patient or sleeping partner. RSBD is quite common in PD and may precede motor symptoms by years or even decades. Symptoms may respond to small doses of clonazepam. However, like any sedating medication, this must be used cautiously to avoid falls or confusion during the night. In addition, patients with Obstructive Sleep Apnea should generally have this condition treated before sedation is used to avoid worsening the sleep apnea.

Obstructive Sleep Apnea (OSA):

OSA is a fairly common occurrence in people with PD. In this condition, airflow ceases periodically, often in association with snoring. The episodes of apnea are often accompanied by decreased levels of oxygen in the blood

and other changes in metabolism. This can result in high blood pressure and increased risk of stroke and heart disease. Sometimes, the treatment is as simple as adjusting sleeping position. Often, however, the treatment consists of wearing a facemask or nasal device connected to a small machine that applies positive pressure to keep the airways open and facilitate airflow. This is called a CPAP machine. It may take some adjustments to get used to wearing the device during sleep, but the decreased risk factors and improved restful sleep is worth the effort and discomfort.

Early AM waking

Many patients are able to fall asleep without difficulty but awaken frequently during the night or wake up early in the morning and are unable to go back to sleep. The patient may describe worrying or ruminating over concerns in his or her life. This often results from anxiety or even depression, perhaps due to changes in serotonin and norepinephrine levels in the brain in PD. For this reason, treatment of mood with a selective serotonin reuptake inhibitor (SSRI) may be useful.

There are other sleep difficulties that occur in PD as well. Careful observation of the circumstances surrounding sleep difficulty will enable your physician to diagnose and treat the problem, often in a more effective manner than by simply prescribing a sleeping pill.

Walking in My Daughter's Wedding

By Dean Prescott, Vice-Chair, PPSG

It was a short walk, as walks go. It had seemed so far away when they first made the announcement. It was hard to understand how this moment was already here. At this point I just wanted to be sure I was putting one foot in front of the other without tripping on Sarah's dress. The bridesmaids were all in the room, waiting for their moment, while the groomsmen seated the guests. I peeked into the room to see my daughter in her dress and was stunned by the way she looked. "What do you think, grandpa?" I was asked by one of the bridesmaids. "Beautiful," was all I could say.

A light breeze chilled the guests as they waited patiently after being seated. They were treated to a view of evergreen trees made greener by the deep blue sky above and Lake Tahoe in the background below.

Suddenly it was time, wedding music began to play. The bridesmaids lined up with their partners and began the procession down the aisle until there was only the flower girl (Natalie, my granddaughter), the

ring bearer and me and Sarah. A handsome young man, the ring bearer was having a hard time holding the pillow that held the ring. It would not stay balanced on the one hand while the other hand was holding on to the flower girl. I showed him how to bunch up the bottom of the pillow in his hand and he was ready to go. Down the aisle they went and then it was only me and Sarah.

It didn't seem possible that so much time had passed to bring us to this moment. Wasn't it just the other night that I was reading her a bedtime story and she was asking me to read it again and again?

We waited for the music to change. Then one step at a time we proceeded as the faces in the audience began to appear. The seats were fuller now than when I had peeked out earlier. I kept my concentration on my gait as we walked slowly down the aisle to where the groom was standing, alongside the minister and the bridesmaids and the groomsmen. I shook his hand and kissed my daughter, just like the rehearsal. I found my seat, next to my wife and watched the rest of the ceremony.

It wouldn't seem like such a short walk would be such a big deal and thankfully it wasn't, but as little as a month earlier it might have been much different. The effects of Parkinson's disease and the medications used to treat it had reached a point where without medication, I could barely take a step; and with medication I could walk, but my right arm and leg would gyrate out of control for hours at a time.

The Deep Brain Stimulation Surgery that began six weeks earlier with two probes being implanted into my brain would reduce my dependence on medication, improve my basic level of ability, and reduce the side effects of the medications. How the procedure accomplishes even one of these functions, I don't understand.

Two weeks after the initial surgery doctors implanted the stimulator into my chest and connected it to the probes with wires just below the skin. They would not activate the stimulator until two weeks later, just two weeks before my daughter's wedding.

The initial adjustments with the stimulator are done with the patient off medication. That meant another night of trying to sleep while my legs twitched. This time it wasn't quite as bad. In fact I was able sleep

some that night and I was able to walk slowly to where I was being tested the next day. I had expected to need a wheelchair.

They ran me through the usual tests before turning on the stimulator. First the box where they have the patient stand up straight, then lean in various directions, then the walls move in various directions, then floor moves in various directions, all with the goal of seeing where you lose your balance. Then there are more tests that are repeats of previous tests such as finger tapping, leg tapping, hand twisting and, of course, walking.

Now it was time to turn the stimulator on and when they did I didn't feel any different. When they ran through the tests again, however, I immediately noticed a dramatic difference in my ability to perform them. They used the results to determine how to adjust the initial settings on the stimulator. In adjusting the stimulator, they have to allow for the effect of the medication. If they adjust the settings too high some of the old side effects may return.

The stimulator comes with a controller. When put up next to the implanted stimulator, the controller can turn the stimulator on and off and even up and down to a limited extent, but the major adjustments are done by the nurse who is trained to make adjustments using a separate controller that adjusts the strength and frequency of the signals being sent from the stimulator to the probes. The nurse showed us how to turn the stimulator on and off while we waited for the medication to take effect. There are certain circumstances where the stimulator needs to be turned off and other circumstances where the stimulator can be accidentally turned off and may need to be reactivated, so we both needed to know how to use it.

It has been eight weeks since the initial adjustment of the stimulator and four weeks since I went in for a second adjustment. My next appointment is in two more months. I have been told that it can take up to six months before they get the ideal adjustment. Overall I have experienced considerable improvement in some areas and have been frustrated with the lack of improvement in others. The biggest difference has been a reduction in the dyskinesia that had become very difficult to deal with. I have had good deal of improvement in getting in and out of chairs. My voice is stronger for the most part.

Getting a consistent stream of medication is still a problem. Carbidopa/levodopa is the most effective drug used for Parkinson's, but it has limitations. One is that there is no even delivery system. You take a pill and it slowly breaks down in the stomach (depending on what else is in there), gradually getting stronger until it reaches maximum effectiveness, then gradually slows down until you are due for your next dose in about four hours.

To improve the effectiveness of carbidopa/levodopa it comes in a "long acting" or "controlled release" formula that generally has the same effect but is spread over a longer period of time (4-6 hours).

To further complement the carbidopa/levodopa therapy there is a group of drugs called "agonists" that mimic the effect of carbidopa/levodopa. These drugs include Mirapex® and Requip®. These drugs help extend the effectiveness of carbidopa/levodopa. They have been helpful in allowing me to sleep through the night. However they have been linked to compulsive behavior in some cases. They generally are not strong enough to be used alone in advanced cases. The uptake on these drugs is also different from carbidopa/levodopa, further complicating the dosage formula.

This may be an oversimplification of the situation, but I think it gives you a general idea of some of the problems in taking Parkinson's medications. The trick is to take enough to help get the patients moving, but not so much that they become dyskinetic and to make that situation (we'll call "normal") last as long as possible.

The DBS has helped in finding that spot, but there is still a way to go.

Disclaimer

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**This newsletter is assembled by The Morgan Center.
Thank you!**

A Summary for the PPSG Luncheon

By Charmaine Eng, Chair, PPSG

This year, PPSG held a combined Volunteer-Caregiver Appreciation Luncheon, September 15, at the Golden Peacock Restaurant in Fremont. Attendees came from all over the Bay Area to participate in the event. Three outstanding speakers were invited to speak on the program. Julie Groves, OTRL, of Therapy in Your Home, gave an excellent presentation full of hints, titled, "What You Do Is Important; Research Proves It; Practical Tips How To Do It." Dr. Grace Liang, a neurologist from the Parkinson's Institute, specializing in Movement Disorder, spoke on the latest updates and current information in Parkinson's disease. Vivian Silva, MSW, Geriatric Care Manager was unable to attend at the last moment, but kindly offered the content of her talk, "Taking Care of Business" to be printed. (See article.) The luncheon menu was abundant and tasted well. Door prizes were given out. Rose Saxton displayed her beautiful artwork. Charles, son of PPSG Board Member Curt Chadwick, video-taped the speakers, and the tape will be available to support groups for viewing. PPSG would like to extend their thanks to all the volunteers who helped out to make the luncheon a success, particularly to the co-chairmen, Carla Gwosden, and Viola Mays.

Due to unfortunate circumstances, the keynote speaker for a recent luncheon was unable to attend, so has made her speech available for this newsletter. With sincere regrets, Vivian I. Silva, MSW wrote:

Taking Care of Business....

Years of experience working with elders and their caregivers has brought to the forefront many valuable tips I'd like to share. When focusing on taking care of a loved one, we often forget that 'taking care of business' needs to be a top priority to avoid complications in the future. From assessing our support circles to legal documentation, an array of tasks await our attention.

First question to consider is who's on the list to call if you become ill?

Begin by assessing your support circle. Divide the list in three sections—names of family or friends you KNOW would help you if you asked (a good reminder); names of people you've never asked but think they might help (give them a try!); and, names of those in your circle but never thought of as possibilities (take a risk and ask anyway)...in other words, know your options and begin to widen your circle of support.

Support systems can include a church group of volunteers such as Love, Inc. or Heart of the Valley, joining a support group and exchanging help for one another, and getting to know a Geriatric Care Manager (check with your local

senior center) can be a tremendous support with knowledge of community resources.

Give yourself permission to ask for help. We can't do life alone...we need others to give us meaning and our circle of friendships provide health benefits. Researchers are beginning to note that not having a support system can be even more detrimental to our health than smoking! Allow yourself time for a fun event. Taking time to rest allows our mind, body and spirit to recover from daily stressors.

The second question refers to what kind of formal support is available.

Local assisted living facilities or retirement communities allow a weekend stay or even longer for your loved one and gives you time for a vacation to freshen your mind and body as well as investing in your health so that you can continue to be the devoted, loving caregiver that you are. If you prefer care in the home, many agencies in the community provide live-in caregivers while you take a break.

The following summary will give you an idea of the types of long term care options.

Assisted Living (can range from 6 to 100+ rooms):

These residential care facilities need a license so are under the auspice of Dept of Social Services and subject to annual survey process. Care services may be billed separately to include medication management, assistance with bathing, dressing and grooming, incontinence care and escorting to doctor appointments.

The rooms may have a microwave and a small refrigerator. Access to care attendants may include nursing assistants, certified nursing assistants, licensed vocational nurse or a registered nurse. Typically three meals a day are prepared as well as personal laundry service.

Board and Care home are private homes that operate as an assisted living program under RCFE license but usually house 5-6 residents only. Rates can be found from \$1,200.00 to \$4,000 approx. per month.

Skilled Nursing Facility (nursing home) involves the highest level of care as medical care is necessary and 24/7. Can be subsidized by Medicaid (known as MediCal in California) but often beds are not available. Some skilled nursing facilities are specific to Alzheimer's patients as they needed be locked up to prevent wandering out of the building. Private pay can run \$6,000 and up per month. People are often mistaken that Medicare will indefinitely cover expenses for a nursing home. Medicare (Part A) covers a short-term stay for rehabilitation services (check guidelines). After first 21 days, a co-payment is typically required (Part B) will pick up some cost of additional rehab services if certain criteria are met. If you have a long term care insurance policy, it's absolutely necessary to read the fine print and understand what is covered and what is not,

whether in the home or out of the home. Every policy is different.

A variety of reasons prompt a caregiver to find a facility for their loved one. The care receiver requires medical needs not able to be provided in the home, a caregiver is exhausted due to sleep deprivation or disruptive behavior, incontinence is another reason or safety issues for the care receiver.

Many caregivers continue to care for their loved ones at home. For safety reasons, modifications such as wheel chair ramps; grab bars for shower, bath, toilet area; raised toilet seat; shower chair, handrails; extra lighting in the hallways, and at least one entry without steps are some of the possible additions.

The third question involves legal issues. Are your papers in order? Do you have all the important papers in one place? Do you and your loved ones have an Advance Directive for Health Care? What about a Durable Power of Attorney for finances? A client came to me upset because her husband had a stroke, was in a nursing home at the cost of \$7,000 per month and she was not on his checking account. Because he couldn't speak or write and didn't designate her officially to take over the finances in case he could no longer (which is what happened), she could not access his bank account. I sent her to an elder law attorney but she incurred unnecessary stress trying to solve the problem which could have been taken care of sooner thus avoiding the crisis. (Advance Directive resources: Senior Adult Legal Assistance (SALA) 408-295-5991 (some senior centers take appointments); Family Caregiver Alliance @ 1-800-445-8106; El Camino Hospital has volunteer to help fill out forms for Advance Health Care Directive)

Patients are protected as far as right to privacy. A physician may not even talk to the spouse about a health condition without a HIPAA form on file. A HIPAA form gives permission for those of your choice to get information regarding your health status (when in hospital for example).

The last question refers to a Plan B. The reality is caregivers may not outlive the care receiver. This happens to about 25% of caregivers. I learned this the hard way because I worked with a client with Parkinson's disease and her friend was her caregiver and died before my client did. We were not prepared, having assumed she would always be her caregiver. Please consider a Plan B...in case something happens to you such as a long-term illness or death, that you have a plan of care for your loved one. This may be as simple as asking your family members if they'd be willing to manage the care if needed.

Vivian I. Silva, MSW/Geriatric Care Manager
consultvsilva@yahoo.com / 408-209-1247

Getting Help with Prescription Drugs

Getting and Navigating patient-assistance programs:

- www.NeedyMeds.org lets patients search for applicable programs, download application, search for local help with paperwork and find assistance based on location or disease.
- **Partnership for Prescription Assistance** (www.pparx.org, or 888.477.2669) helps match patients to more than 475 private and public programs with aid of an online tool. Has information on other types of assistance, such as help with co-payment and premiums.
- www.RxAssist.org allows patients to search a database of patient-assistance programs by medication. It provides tip sheets on getting free or low-cost medications, information on co-pay, generic drug and other types of assistance programs.

Discount drug cards:

- **Together Rx Access** Sponsored by nine major companies, this free card offers 20% to 40% discounts on retail prices for more than 300 drugs. www.togetherrxaccess.com or 800.444.4106.
- **Merck** and **Pfizer** offer separate discount cards for many of their medications. Discounts range from 13% to 50%. www.merckhelps.com/uninsured or www.pfizerhelpfulanswers.com.

Obtaining low-cost generic drugs:

- **Rx Outreach** offers more than 350 generic medications at a cost of \$20 to \$95 for 180-day supplies. www.rxoutreach.com or 800.769.3880.
- **Xubex Pharmaceutical Services** offers more than 250 generic medications at a cost of \$20 to \$30 for most 90-day supplies. www.rubex.com or 866.699.8239.
- **Wal-Mart, Target, Safeway** and other retail chains offer many generic drugs at \$4 for a 30-day supply with no eligibility restrictions. Several chains have recently lowered prices on 90-day supplies to \$10 and to \$15.

The above information was adapted from The Wall Street Journal, Tuesday, October 21, 2008 issue.

PPSG SUPPORT GROUPS

---NORTHERN REGION---

Berkeley 510.231.1998 roddy@raikow.com 510.524.4847
Eureka 707.442.5245 **Fremont** 510.656.6393
Fremont/Caregivers 510.574.2035 **Mill Valley/Marin County** 415.383.5145 **Oakland** 510.763.4492 **Petaluma** 707.795.4858 ;707.766.8521 **Pleasanton Tri-Valley** 925.831.9940 jnbard@pacbell.net **San Leandro** 510.663.6435; 510.351.3224 **Santa Rosa/ New Caregivers** 707.539.2646 **Santa Rosa/Sonoma County Support Group** 707.526.4373 irizary@juno.com **Walnut Creek/Mt. Diablo Parkinson's Network** 510.236.7065 ; 925.284.2189 **Walnut Creek/Mt. Diablo Young Onset Supp Grp** 925.284.2189

---PENINSULA REGION---

Daly City 415.587.1285 **Los Altos/Young Parkinson's Supp Grp** 408.738.2505 deanp53@yahoo.com **Millbrae/Magnolia-Peninsula** 415.678.8455 millbraesupportgroup@gmail.com **Palo Alto** 650.529.2394 **Palo Alto/PD Under 50 Group** 866.250.2414 **San Francisco Support Group** 203 4150 **Clement St Susan Heath, RN MS** 415.379.5530 susan.heath@va.gov **San Mateo/Atypical Parkinsonism** 650.233.9277 riddle@stanford.edu **Sunnyvale** 408.733.5648

---SOUTHERN REGION---

Hollister 831.637.3839 ; 831.637.3839 **Monterey** 831.657.4241; 831.372.7510 **Salinas** 831.663.5926 **San Jose/Berryessa** 408.263.8485 **San Jose/Caregivers** 408.723.8116 **San Jose/The Villages** 408.223.8033 Access Pass Required **San Jose/Willow Glen** 408.265.3991; 831.427.0966 **Santa Cruz** 831.479.4485; 831.479.4485 **Saratoga** 408.867.1807

---CENTRAL VALLEY REGION---

Fresno (greater) 559.226.2673; 559.298.4080 **Merced** 209.384.3300 **Modesto** 209.529.5643 davejoann@sbcglobal.net **Pine Grove/Amador County** 209.296.2575 **Roseville** 916.489.0226 **San Andreas/Calaveras County** 209.296.2575 **Stockton** 209.465.9761 **Stockton/Young Onset** 209.406.9317 **Turlock/Forming** TBA TBA **Covenant Village** 2125 N. Olive Ave **Marianne Johnson** 209.634.3157 **Visalia/Central Valley Parkinson's Supp Grp** 559.622.9044 marydickerson99@comcast.net www.cvspsg.org

EXERCISE CLASSES

Berkeley: North Berkeley Senior Center, Thursday, 10-11:30 Kay Ellyard 510.848.5143 **Berkeley:** Mon. 1030-1200 & Tues 1-230, John Argue 510.985.2645 JCC East Bay www.parkinsonsexercise.com **Daly City:** Tue./Wed/Thu 930-1130, Doelger Sr. Ctr. Gym John Pantazy 650.991.8012 **Gilroy:** Gavilan College, Dave Ellis, 408.848.4878 **Hayward:** Kaiser Permanente, Wed. 10-11:30, John Argue 510.985.2645 **Kensington:** Tue. 1:30-3:00, John Argue 510.985.2645 **Los Gatos:** Thu 2-3P Balance Class Community Hosp. of Los Gatos Rehabilitation Ctr. 355 Dardanelli Lane \$10/session Samantha

408.866.4022 **Los Gatos:** Mon 2PM/Thu 1PM Parkinson's Lifelong Useful Skills (PLLU) balance, gait, posture and Tai Chi/Qi Gong The Terraces 8010 Blossom Hill Rd. Kujiweza Healing Arts Jane 408.315.1179 Parkinsons@sjogataichi.org **Monterey:** Monterey Peninsula College, Mark Clements, 831.646.4231 **Palo Alto:** CAR, Aquatic Therapy, 650.494.1480 **Palo Alto:** Avenidas Sr. Ctr. 450 Bryant St. 650.289.5400 **Palo Alto:** Sat 10-1130 Tai Chi/Qi Gong for Parkinson's Atrium Stanford Hospital Kujiweza Healing Arts Jane 408.315.1179 Parkinsons@sjogataichi.org **Redwood City:** Canada College, 4200 Farm Hill Blvd. Barbara McCarthy 650.306.3473 **Salinas:** Hartnell College, Melissa Stave, 831.755.6876 **Saratoga:** Mon. - Fri. 9-12; 1:30-3, West Valley Comm. Coll. Joan 408.741.2420 **San Bruno:** Mon/Wed 1:10-2:30, Tue/Thur. 12:35-1:50, Skyline College Bess 650.738.4286 **San Jose: Camden Community Ctr.** M/W 10:30-11:45 T/TH 10:00-11:15 Adapted Exercise M/W/F 1:00-3:30 Adapted Fitness 408.369.6438, **Houge Ctr.** Tue/Thur 10-11:45, **Easter Seals Comm Ctr.** Aquatic Exercise programs, 408.295.0228, **Evergreen Ctr.** Deanna, 408.369.6435, **Evergreen Valley College,** Rich Wagner, 408.274.7900 x 6447 **Southside Community Ctr.** M/W/F 1:00-1:45 Chair Exercises F 9:00-11:30 2:00-3:30 Tai Chi 408.629.3336 **The Villages:** Mon 11:30-12:30 Wed 11:15-12:15 Thu 11:30-12:30 Parkinson's Exercise Program(PEP) Kujiweza Healing Arts Jane 408.315.1179 Parkinsons@sjogataichi.org **San Mateo:** College of San Mateo, 1700 W. Hillsdale Blvd., John Hogan, 650.574.6469 **San Rafael:** Osher Marin JCC, San Rafael. 415.444.8000 **Santa Rosa:** 151 Sotoyome Street Rehab. Gym Tue 12:30-1:20 Balance Class Linda 707.543.2570 **Santa Rosa:** 151 Sotoyome Street Rehab. Gym Mon/Thu 12:30-1:20 Parkinson's Exercise Class Linda 707.543.2570 **Sunnyvale:** Tue/Thu 9-10, Sr. Ctr. 550 Remington Dr., Ruth Hanes 408.864.8873 **Sunnyvale:** Wed. 10-12 Beginning and Intermediate Wed 12-2 Intensive The Parkinson's Institute, 675 Almanor Ave., Marilyn Basham 408.542.5685 **Sunnyvale:** 1st and 3rd Thu 12-1 Shakin not Stirred vocal exercise group, the Parkinson's Institute, 675 Almanor Ave., Randy Hoffman 408.542.5658 **Walnut Creek/Mt Diablo:** Thu 1-3 Tremble Clefs vocal exercise group, United Methodist Church, 1543 Sunnyvale Ave., Elsie Chapman 925.682.0809 Joan Hodgkin 925.943.7393.

Thank you so much for your donations! Please use return address labels, to help us acknowledge your donation properly. Your generous contributions go to support newsletters, educations and community awareness of Parkinson's disease. **Please mail your donations to: P.O. Box 60188, Sunnyvale, CA 94088. Thank you!**

PPSG Board Meetings

You are welcome to drop by our board meetings and share ideas with us! We meet on the **3rd Monday** of the month between **1:30 and 3:30 PM** at the Parkinson's Institute, at 675 Almanor Avenue, Sunnyvale, CA 94085. To confirm meeting dates and time, please call us at **408.542.5610**. If you are planning to attend, please call Charmaine Eng at 408.723.8116 (dial *82 before the number).

Drawing on Social Support: Friends Can Be Good Medicine

We can't thrive and may not even be able to survive without a sense of connection to and support from others. In difficult situations such as widowhood, job loss, unemployment, complicated pregnancy, heart attack, and family care-giving, people who have a support network fare significantly better than those who don't. People need people who care, especially during life's difficult times. Supportive relationships are one of the most important resources you can have to help you sustain and manage difficult demands.

Because of the pressing demands on them, many caregivers find it difficult to sustain long-standing relationships. Over time, their support relationships become fewer and weaker. As a result, their coping resources become more fragile and they feel more vulnerable and alone. If your support network is becoming weak, strengthen it. Don't take it for granted. Take steps to include the people you most want to be a part of your life.

Know Your Support Needs

The type of support you need will vary. To determine what type you need, use these five categories:

Emotional support: Someone who recognizes, understands, and conveys appreciation for what you are experiencing; a confidant who is willing to listen to you and help you with acceptance and understanding.

Esteem support: someone who helps you to know and remember your strength and capabilities and how likable you are; a member of your fan club who believes in you and helps you believe in yourself.

Informational support: Someone who helps you to get the accurate and timely information you need to cope with your care-giving needs—insurance, medical systems, needed available services.

Tangible support: Someone who helps you to get tasks done. For example, home maintenance, food preparation, shopping, transportation, respite care, etc.

Companionship: Someone who shares your leisure time and activities, conversations and meals.

Identify Your Support Resources

Who are the people you can count on for support? What type of support do they each provide? Is it emotional, esteem, information, tangible, or companionship? Who adequate is your information system?

If your resources are low for any type of support, consider building people into your life who can be helpful in those areas. They may be family, friends, and spiritual advisors; or they may be a counselor or members of a support group. One-to-one counseling: Your situation and problems can seem overwhelming and unsolvable when you look at them from the inside out. A counselor can help you break down your problems into small, manageable parts that can be addressed one at a time. A counselor provides an objective, understanding ear that helps you cope and solve problems, thus improving your emotional well-being. Family and friends can lend additional support, but they too can be affected by their emotional involvement and might not be as objective as an outside person trained in this area.

Support groups: A support group is a safe, non-threatening environment where everyone has experienced similar feelings and situations. At support group meetings you can meet with other caregivers to share your feelings and exchange coping strategies. Now is the time to seek the support a group can give. You deserve it.

The following information is adapted from "TAKE CARE! A Guide For Caregivers On How To Improve Their Self-Care" booklet, published in 1989 by Amherst H. Wilder Foundation and a grant from the Medtronic Foundation. Printed copies of the 1989 publication TAKE CARE! are no longer available. The publication's text is provided free of charge at www.fieldstonealliance.org/client/client_images/pdfs/takecare.pdf The authors of this booklet are Jane Royse, M.S., and Sheryl Niebuhr, Ph.D.

Do You Need A Handyman/Job? Call the Proven People Senior Employment for Help

The Proven People is a No-fee job referral service agency. The agency matches workers (50+) with temporary, permanent, full or part-time jobs. Orders for jobs are taken from residents as well as for businesses. Their office is Located at the Sunnyvale Senior Center, 9:30am-3:00pm Monday - Thursday. Call (408) 730-7367/8 to make an appointment. You do not need to be a resident of Sunnyvale or a member of the senior center to qualify.

Gait and Balance Classes at the PI

The Gait and Balance Classes at the Parkinson's Institute are great and fun. Come check them out!

The Classes are held on **Wednesdays**. The **beginning classes** run from **10:30 -12 noon** and the **intermediate classes** run from **12:30 -2:30 pm**. A donation of **\$10.00 per session** is suggested. The classes are held at The Parkinson's Institute, at 675 Almanor Avenue, Sunnyvale, CA 94085. Please call **408.734.2800** if you have any questions.

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If you would like to receive a copy of our newly-assembled Caregiver's Packet, please call us at 408. 542.5610, or write to: PPSG, P.O. Box 60188, Sunnyvale, CA 94088.

If you would like to be removed from our mailing list or know someone who would like to be included, please take a minute, call us at **our NEW NUMBER 408.542-5610**, or e-mail ppsginfo@yahoo.com, and let us know. Thank you



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