

Parkinson's Patients Support Groups, Inc.

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Don't Forget Yourself!

Home Instead Senior Care

Excerpted from "Stages of Senior Care: Your Step-by-Step Guide to Making the Best Decisions" 2009

Being a caregiver is a tremendous responsibility. Not only should you consider the health and well-being of your loved one, but also of yourself.

Take some time to consider these points:

How Stressed Are You?

As stresses build one upon another, you may also lose your ability to help your loved one. Ask yourself what you can do to reduce the stress on yourself.

Get Others to Help

If you are the primary caregiver, make it clear to others that if you have to do the job all alone, over time you may break down (and possibly drop responsibility for Mom or Dad altogether). It's not easy but try to develop a procedure, a couple of key phrases, perhaps, that you are comfortable with that enable you to ask for help.

Protect Your Body and Mind

Surveys indicate that caregivers are less likely than noncaregivers to practice preventive self-care, including health care.

Confront Your Emotions

Research indicates that people who take an active role in dealing with caregiving issues (and solving related problems) are less likely to feel stressed than those who simply worry or feel helpless.

8 Ways to Help Yourself

Here are some tips for avoiding and managing caregiver stress...

1. Workout -- Exercise and enjoy something you like to do (walking, dancing, biking, running, swimming, etc.) for a minimum of 20 minutes at least three times

per week.

2. Meditate -- Sit still and breathe deeply with your mind as quiet as possible whenever things feel as if they are moving too quickly or you are feeling overwhelmed.

3. Ask for help -- According to a national survey by Home Instead Senior Care of adults who are currently providing care for a loved one, 72 percent do so without any outside help. Reach out to others for aid.

4. Take a break -- Make arrangements for reliable fill-in help (family, friends, volunteers, or professional caregivers) and take single days or even a week's vacation. When you're away, stay away. Talk about everything but caregiving; read that book you haven't been able to get to.

5. Eat well -- Eat plenty of fresh fruits, vegetables, proteins, including nuts, beans and whole grains.

6. Take care of yourself -- Just as you make sure your loved one gets to the doctor, make sure you get your annual checkup. Being a caregiver provides many excuses for skipping many chores. Don't skip your checkups.

7. Indulge -- Treat yourself to a foot massage or manicure; talk a walk, rent a movie, have a nice dinner out, or take in a concert to get away from the situation and to reward yourself for the wonderful care you are providing to your relative.

8. Support -- Find a local caregivers support group that will help you understand that what you are feeling is normal for someone in your position

This article was forwarded by Robin Riddle.

This newsletter was assembled by the Morgan Center in Santa Clara. Thank you!!!

Just Can't Stop: Compulsivity in Parkinson's

By Jacob Bentley, M.A. and Jeffrey Shaw, Psy.D.

In addition to the physical and motor problems in Parkinson's disease, some individuals also experience behavioral and psychological symptoms.

Some have difficulty controlling impulses and struggle with problematic behaviors such as excessive gambling, hypersexuality and **punding**.

There can also be problems associated with obsessive thoughts or compulsive behavior related to eating, shopping or internet use.

Often the diagnosis of **obsessive compulsive disorder** – or **OCD** – applies. Obsessive thinking is characterized by interfering recurrent or persistent thoughts. These thoughts serve as a source of anxiety for people and prevent normal functioning. **Punding** is a unique class of behaviors with obsessive-compulsive qualities. The term punding refers to repetitive, aimless actions.

Individuals prone to punding may neglect their personal hygiene, medication regimen and normal sleep patterns in favor of performing relatively unimportant tasks.

Others' attempts to intervene with these behaviors may be met with opposition and irritability even though the punding individuals may readily admit that the activity brings them no sense of fulfillment.

However, those struggling with punding may not recognize the disruptive nature of the activity.

Pathological gambling is defined by an inability to abstain from gambling despite severe personal or familial loss.

The prevalence of **excessive gambling** among individuals with Parkinson's is relatively low, but many people with no history of problematic gambling develop problems when taking certain Parkinson's medications.

Hypersexuality refers to enhanced interest in sexual activity and may also be increased by medications that manipulate dopamine.

Enhanced sex drive may cause interpersonal tension between partners, **increased use of pornography**, or **non-characteristic sexual behavior**.

This type of compulsive behavior may be related to a lack of impulsive control or an increased drive for sex, as both of these processes are related to the activity of dopamine in the brain.

A confounding factor is the often implied "don't ask, don't tell" policy concerning issues of sexuality.

Sometimes the physician is the last to know about the problem.

A number of factors can contribute to the emergence of such difficulties for Parkinson's patients. An association between dopamine-active medications, physiological brain changes and impulsive behavior has been highlighted in the existing research.

However, the development of obsessive thoughts, compulsive behaviors and reduced impulse control is likely related to the convergence of a number of factors, including the stress of coping with a chronic health issue and social isolation.

Management of impulse control and compulsivity in Parkinson's can be assisted through several means.

Many of these issues are highly personal for patients, which may keep the problem more secretive.

However, early intervention is crucial because these behaviors can have a compounding effect on individuals and families already coping with Parkinson's.

Under the guidance of the neurologist, dopamine-influencing medications may need to be reviewed.

Often behavioral experts such as psychologists, psychiatrists and other mental health specialists are necessary to change patterns of behavior and rebuild damaged relationships.

Relationship counseling is often necessary to help families deal with separating the behavior from the person they love.

Sometimes legal and financial experts are needed to help protect families and individuals from the actions that developed from the compulsive behaviors.

Edited from March/April 2008 issue of Parkinson's Post.

This article was forwarded by Charmaine Eng.

A Brief Chat Can Boost Your Brainpower!

Chatting with another person can boost your brain's performance, according to a study published in the January 2011 issue of *Social Psychological and Personality Science*.

Researchers measured the cognitive performance of 192 university students before and after they engaged in a variety of social interactions. The scientists found that engaging in a brief, friendly conversation of about 10 minutes' duration boosted participants' executive function, a type of cognition that includes short-term memory, ability to ignore distractions, and self-awareness.

What Do We Say When Someone Asks, “How Are You?”

By Rev. Larry LaPierre

Just because someone asks, “How are you doing?” doesn’t mean that they really want to know. I’ve known that for a long time. So, why is it important now? Well, now I have Parkinson’s Disease (PD). To those of you who have Parkinson’s Disease or are a care-giver for someone with PD you know what it means. About a year ago I made a list of PD symptoms that I had or could remember having. At the time I was living with twelve symptoms (before the most recent adjustments in medication), and I could remember eight symptoms that had disappeared after earlier increases in medication.

I find that there are four groups of people who will listen if I start telling them how I really am. My neurologist, geriatrician and a friend who is a physician listen as professionals. My wife listens as the one who loves me and knows me the best and is also a nurse with experience in neurology. People who have PD are the third group. The fourth group is the people who have or have had someone with PD in their families. These are the groups of people to whom I can respond in some depth when they ask, “How are you?”

Other people may not want to know. Some are curious but lose interest when I begin to spell out what living with PD is like. The ones I really have difficulty with are the ones who rush in to assure me that “You won’t die from PD.” My psychiatrist, who was also board certified in neurology, put that observation into perspective. She said, “MOST people won’t die from Parkinson’s Disease.” It was a helpful bit of reality testing. The other bit of reality testing that I appreciated was from the person who recently said to me, “You won’t die from Parkinson’s Disease, but it will certainly make you miserable.” So, how much reality testing do we do with people who ask, “How are you doing?” I never got to that stage with my brother. The words were hardly out of my mouth about my diagnosis a few years ago when he asked, “Will I get it?” Then there was the person at church who, when I explained why the PD limited my ability to drive, asked, “Oh, is that (the PD) that ‘trembly’ thing?”

At the first church men’s group that I went to when we moved out here my tremors were not under

control. I felt like I needed to explain the tremors, but I did it clumsily. I said, “The tremors aren’t because I’m afraid. They’re because I have Parkinson’s disease.”

I still say too much. Someone heard me explain that I couldn’t eat the dessert that was being offered to me because I had just taken my medication. Another lady in the group wanted to know what it was for and what the drug was. About the time I was explaining L-dopa, dopamine and neurotransmitters (I was a chemist years ago), her eyes glazed over, and I stopped my garrulous commentary.

What can we say when someone asks “How are you doing?” I am trying to remember to say as little as possible unless it’s someone who understands PD. Why? Most simply don’t have the time for a short course on PD symptoms. They just want to be assured that I’m OK. Instead, I need to talk to people in the four groups so that I can be heard for what I am—a person living with Parkinson’s disease.

About Larry LaPierre:

Larry is a retired United Methodist minister, and he is also a retired VA chaplain (Vermont). He has a Doctor of Ministry degree, and he is a Board Certified Chaplain in the Association for Professional Chaplains. He was on the faculty of Dartmouth Medical School for several years. He is on the planning committee of the support group in Willow Glen, and three times a year he leads a discussion group for the people with Parkinson's. He has been attending for three years--ever since he and his family moved to California.

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Does Music Have Charms to Soothe Parkinson's?

Man's observation that his tremors stopped leads to pilot study. By Cindy Larson of *The News-Sentinel*
<http://www.news-sentinel.com>

An amazing thing happens to Russ Eplett when he attends Fort Wayne Philharmonic concerts. The music appears to quell the symptoms of his Parkinson's disease.

“When I sit down in the Embassy and my hand is shaking, as soon as the music starts, it stops,” he said.

Eplett shared his observation with Philharmonic President and CEO J.L. Nave III. That led to interest by the Philharmonic's Innovation Task Force. The end result is a pilot study the task force will conduct in collaboration with IPFW's music therapy department and the Fort Wayne Parkinson's Support Group.

The study will look at the impact of music on Parkinson's, a neurological disease.

To test the impact of its music, the Fort Wayne Philharmonic will perform three concerts at IPFW's Rhinehart Recital Hall featuring string, woodwind and brass instruments.

About 35 people with Parkinson's will attend the concerts and fill out a simple one-page survey using a Likert scale to assess their symptoms before, during and after the performances. A typical Likert scale asks respondents to rate a statement selecting one of five choices that range from strongly agree to strongly disagree.

The public is invited to these free concerts as well.

“We wanted to make it open to the public and free so the Parkinson's patients wouldn't just feel like guinea pigs,” said Pamela Kelly, a physician and chairwoman of the Philharmonic Innovation Task Force.

Participants will rate typical symptoms of Parkinson's including tremors, stiffness, difficulty with handwriting, swallowing, energy level and dyskinesia, or involuntary movements.

“We wanted to keep it very simple,” Kelly said. “We

had a list of probably 50 different symptoms.” According to Nancy Jackson, director of IPFW's music therapy program, the effect of music on Parkinson's disease hasn't been studied before. This pilot study could be a launching point for further investigation. It will answer the initial question, “Is there reason we should look more closely?” Jackson said.

Kelly believes this study is just a starting point. “I think it's going to generate more questions than answers,” she said.

If the pilot study gives a reason for researchers to look into this issue further, “we're very easily set up to take the next step,” Jackson said. They plan to record the live performances and play them for the people with Parkinson's to see whether listening to the same music, but recorded rather than live, has the same effect.

As for Eplett, he already knows the answer to that. “If I take the same piece recorded and play it, it doesn't have the same effect,” he said.

Eplett, who sings in the Philharmonic Chorus, loves watching and listening to the philharmonic musicians play music, and pays particular attention to the complexity of it — the rhythms and harmonies. He believes the intensity with which he listens to the music is what abates his symptoms.

“I strongly suspect it's a matter of how much interest you have in the music,” he said.

For Eplett, who was diagnosed six years ago, the effects of live music are so profound the tremors quit during the live performance, resume during intermission and go away again when the second half of the performance begins.

When he sings in the chorus, however, his symptoms sometimes worsen.

“It's because I'm tense,” he said. He worries the tremors will get so bad he'll drop his sheets of music.

Medications for Parkinson's can ease symptoms. However, Eplett said the medicine he takes works inconsistently on his symptoms. He said having

Parkinson's "really is annoying." His Parkinson's began with a tremor in his finger that progressed to his right hand; now he also has a tremor in his right foot. Parkinson's gets progressively worse. Celebrities with the disease include Michael J. Fox and Muhammad Ali.

Because no studies have been done on the effect of music on Parkinson's, it's possible Eplett's reaction is simply an anomaly. If that's the case, the study would end.

Another possibility could be the power of suggestion creating a placebo effect. Others with Parkinson's might think their symptoms get better when listening to music, when in fact they actually don't. Subsequent studies eventually would weed out any placebo effect, Jackson said.

Eplett realizes he can't go around all the time with a symphonic orchestra in tow to abate his symptoms. But he does hope the study will help researchers to "understand better why this effect happens and come up with something that can be used."

Jackson's hopes are similar. Ultimately, she'd like to see the research result in new techniques that could help those with Parkinson's improve the quality of their lives.

This article was forwarded by Steven Russell.



For current lists on exercise classes, and support group information/activity calendars, please log on to www.ppsg.org. These lists are maintained by **Steven Russell**.



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In Caring for My Husband, I Learned to...

By Flora; forwarded by Robin Riddle

Adapted from Fall 2006 Mind Matters, a publication of UCSF's Memory & Aging Center

Plan ahead for the future. With the doctor's advice, the environment can be set up so that when it is needed you are prepared. The needs can change dramatically overnight.

Accept help. Gus was at great risk for falls and there have been many *angels* who rushed to assistance when he fell. Never turn down help even if you would rather do it yourself. **It is much easier to accept help when it is offered than to find it when you need it.** Shop around and follow through on references for health care providers.

Seek advice on how to maximize your finances. Use resources to become informed about financial help: library, internet, social security, Medicare, medical insurance, county social services, senior services and support groups.

Be patient. Arguing or rationalizing with a dementia patient is futile. Try waiting a while or approaching the subject differently. Ask direct questions requiring simple answers. Sometimes arguing about a hallucination or delusion is not as helpful as having a cheerful conversation about the imaginary.

Get out of the house each day. Change of scenery is helpful for all. Having neighbors or friends come over to read or visit can provide brief respites.

Get organized. Keep a journal, logging in important changes, events such as falls, reactions to drugs, etc.



A Note to Our Readers

This newsletter is for informational purposes only. Readers are advised to consult a trained medical professional before acting on any of the information in this newsletter. The fact that a particular treatment, nutrient, herb, or supplement is discussed in this newsletter in connection with any illness or condition does not necessarily mean that it is safe and appropriate for everyone or that the editor or PPSG recommends its use for that illness or any condition.



Get Some Sleep: When People Act Out Their Dreams

By Lisa Shives, M.D.

CNN Health - The second time Charlie was awakened by his wife's screams because he was slapping her in his sleep, he decided to move into the guest bedroom. The third time he hurled himself from his bed and put a big gash in his forehead, he decided to come to the sleep center.

Charlie has REM behavior disorder, or RBD. For each violent episode, he could recall the dream that he was having that prompted him to action. It is very common, and was true in this case, that when the person with RBD attacks his bed partner, usually he is dreaming that he is saving his spouse. In the dream, it is the bad guy he is hitting.

RBD occurs when people are able to act out their dreams or usually their nightmares. Most of us are not able to do this because in REM sleep, which is where we have our vivid dreams, our muscles are very relaxed, almost paralyzed. If we reason backwards from what happens in RBD, we see that this is a self-protection mechanism so that we don't throw ourselves off a cliff fighting the saber tooth tiger.

We do not know what causes this disorder, but there is a strong association with Parkinson's disease and similar neurodegenerative diseases. The RBD can precede the development of the neurological disorder by as many as 10 years. It is important that a physician treating the patient with RBD follow him closely for early signs of neurologic disease.

I keep speaking of the patient as "him" as if it is always men who are affected. Indeed, this disease is extremely male-dominant for unknown reasons. Nine out of 10 cases of RBD occur in men over the age of 50.

Although, I usually have a high suspicion for RBD just from the clinical history, most sleep specialists recommend an overnight sleep study because other disorders can masquerade as RBD. There is a phenomenon called pseudo-RBD which is caused by obstructive sleep apnea .

OSA tends to be worse in REM and when the patient has an awakening out of REM due to apnea, he can act out his dreams, and the story can be very similar to RBD. This pseudo-RBD is eliminated when we treat the sleep apnea. Also, there is a small chance that the person is having nocturnal seizures so the sleep study is important to rule that out.

Although it is sobering to get this diagnosis because of the connection to neurodegenerative disease, the good news is: 1. Not everyone gets Parkinson's disease; 2. RBD is usually very well treated with low dose clonazepam. Clonazepam is a benzodiazepine which acts as a muscle relaxant as well as a sedative and anti-anxiety agent.

Charlie is now on low dose clonazepam with no further symptoms, and he is very happy to be back in bed with his wife of 50+ years.

This article was forwarded by Steven Russell.

In Honor

Donations were recently received in honor of the following individuals:

Nancy Bennett, Pierina Fanucchi, Nasrollah Ghavami, John F Klein, Jr. , Ed Lagrutta, Benjamin Nelson, and Robin Riddle.

In Memory

Donations were recently received in memory of the following individuals:

Gladys Allegro, Karl Barrell, Betty Bogart, Rea Caldiera, Jim Cawthra, Fletcher Chan, William F. Chin, Herbert S. Chu, Ernst Epstein, Donald Gardner, Lillian E. Harris, Larry Hepner, Susan Hobbs, Kay Iwasaki, Arthur Richard Kamrath, Art Kezer, Leon Lauris, William J. Malone, Albert A. Maurer, Jim Neal Murphy, John Neenan, Donald Nelson, Stephen Ngin, Gary Randall, Harley Roth, Belle Rudoff, K. William Sasagawa, Ted Sieverson, John G. Strong, Hens R. Ude, Donna Vadnais, and Howard Wan.

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, education and community awareness of Parkinson's disease. Please mail your donations to: **PPSG, P O Box 60188, Sunnyvale, CA 94088**

Cognition and Memory Improve Dramatically In Mice When Brain Compound Levels Were Decreased

ScienceDaily (July 6, 2010) — For the first time, scientists have linked a brain compound called kynurenic acid to cognition, possibly opening doors for new ways to enhance memory function and treat catastrophic brain diseases, according to a new study from the University of Maryland School of Medicine. When researchers **decreased** the levels of **kynurenic acid** in the brains of mice, their cognition was shown to improve markedly, according to the study, which was published in the July issue of the journal *Neuropsychopharmacology*. The study is the result of decades of pioneering research in the lab of Robert Schwarcz, Ph.D., a professor of psychiatry, pediatrics and pharmacology and experimental therapeutics at the University of Maryland School of Medicine.

"We believe that interventions aimed specifically at **reducing** the level of kynurenic acid in the brain are a promising strategy for cognitive improvement in both healthy patients and in those suffering from a variety of brain diseases ranging from schizophrenia to Alzheimer's disease," says Dr. Schwarcz.

Kynurenic acid is a substance with unique biological properties and is produced when the brain metabolizes the amino acid **L-tryptophan**. The compound is related to another breakdown product of tryptophan known as quinolinic acid. In 1983, Dr. Schwarcz published a paper in the journal *Science* identifying the critical role excessive **quinolinic acid** plays in the neurodegenerative disorder Huntington's disease. He has since designed a therapeutic strategy targeting quinolinic acid for the treatment of Huntington's disease. Dr. Schwarcz also is involved in a company called VistaGen, which pursues the development of neuroprotective drugs based on this concept.

In the study published this month, Dr. Schwarcz and his colleagues at the Maryland Psychiatric Research Center -- a clinical and basic science research center at the University of Maryland School of Medicine -- examined mice that had been genetically engineered to have more than 70 percent lower kynurenic acid levels than ordinary mice. These mice were found to perform significantly better than their normal peers on several widely used tests that specifically measure function in the hippocampus. The hippocampus is a critical area of the brain for memory and spatial

navigation. The mice were clearly superior in their ability to explore and recognize objects, to remember unpleasant experiences and to navigate a maze. The engineered animals also showed **increased hippocampal plasticity**, meaning they had a greatly improved ability to convert electrical stimuli into long-lasting memories.

"These results are very exciting, because they open up an entirely new way of thinking about the formation and retrieval of memories," says Dr. Schwarcz.

"Kynurenic acid has been known for more than 150 years, but only now do we recognize it as a major player in one of the fundamental functions of the brain. Our most recent work, still unpublished, shows that new chemicals that specifically influence the production of kynurenic acid in the brain predictably affect cognition. We are now in the process of developing such compounds for cognitive enhancement in humans."

"I feel confident Dr. Schwarcz's determined pursuit of answers for the desperate patients suffering from devastating neurodegenerative disorders such as Alzheimer's disease and Huntington's disease, and psychotic disorders such as schizophrenia, will pay off," says E. Albert Reece, M.D., Ph.D., M.B.A., vice president for medical affairs, University of Maryland, and John Z. and Akiko K. Bowers Distinguished Professor and dean, University of Maryland School of Medicine. "His work creates hope for these patients and their families, and his findings are making a significant impact on the field of neuroscience and psychiatric medicine."

Kynurenic Acid

From Wikipedia, the free encyclopedia

Kynurenic acid (KYNA) is a product of the normal metabolism of amino acid L-tryptophan. It has been shown that kynurenic acid possesses neuroactive activity. It acts as an antiexcitotoxic and anticonvulsant, most likely through acting as an antagonist at excitatory amino acid receptors. Because of this activity, it may influence important neurophysiologic and neuropathologic processes. As a result, kynurenic acid has been considered for use in therapy in certain neurobiological disorders.

Volunteers, the Heart of the Community!!!

A special thank-you goes to **Pete von Scheven** who is assisting the PPSG Board in moving our operational data into **Salesforce.com** and will assist us with projects related to our community outreach including the webpage, email communications and more. The following tells us a little bit about him.

Pete von Scheven was born in San Francisco and at a young age moved to the Peninsula where he still resides. After graduating from UC Santa Barbara, Pete moved to Seattle, Washington, where he lived and worked for Microsoft for nearly 4 years. Pete returned to the Bay Area, in part to help care for his father who was diagnosed with PSP (Progressive Supranuclear Palsy, a form of Atypical Parkinson's) in 1997. Today, Pete resides in San Carlos with his wife of 7 years and their two girls, aged 5 and 2. Currently working with the Salesforce.com Foundation, Pete's professional career allows him to work closely with non-profit organizations as they utilize Salesforce.com's software to help those who are doing good work, do better.

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Use caution if you talk while walking, said Leonard LaPointe, PhD. **New Study:** Twenty-five adults (average age 64) with Parkinson's disease and 13 without the disease walked on sensor-embedded mats or carpeting while performing talking tasks such as counting. **Results:** The risk of falling increased in both groups as they shortened and slowed their strides and awkwardly varied their stances in order to walk and talk simultaneously. Those with Parkinson's were at highest risk of falling.

Leonard LaPointe, PhD, professor of Communication Science and Disorders, Florida State University, Tallahassee.



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