



FOR INDIVIDUALS IMPACTED BY PARKINSON'S DISEASE

THE INFORMANT

FALL 2008

I & R Center

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All material related to Parkinson's disease contained in this newsletter is solely for the information of the reader. It should not be used for treatment purposes, but rather for discussion with the patient's physician. Specific articles reflect the opinion of the writer and are not necessarily the opinion of the editor, the Information and Referral Center, the medical director of the Center or the APDA.

LIFE AS A PARKINSON'S CARE-PARTNER: HOW CAN I STILL BE ME? - CAROLYN ALLEN ZEIGER, PH.D.

After a loved one's diagnosis with Parkinson's how do we go on with life as care-partners? Reeling in shock, suddenly we are faced with a different life than we had imagined for ourselves. How can we still be "ourselves" in a "new" life?

Parkinson's brings about changes for *all* of us who live with it--changes in every aspect of our lives. In response, we can go on as if nothing has changed, until a crisis forces us in new directions, or we can take on the task of re-examining ourselves and our lives, and make some adjustments for both the short and long run.


Both as a person and a professional, I have found that a progressive, degenerative disease challenges us to reconsider the fundamentals of life: Who am I? What am I *able* to do vs. what I *want* to do--or *used* to do? What is my place in work/family? What is my life all about now? How do I give my life meaning and significance? Again, It's not just the patient whose life has changed. The Parkinson's Partner's life has been dis-ordered also.

Okay, so not everyone wants to

live "the examined life," let alone "the re-examined life," and questions like "Who am I?" seem so weighty and large. Nonetheless, I recommend taking a stab at it.

Initially, I couldn't do this myself. I was so devastated after my husband's diagnosis that I really couldn't look at the bigger picture. I was just trying to take in the very fact of my beloved husband going from exceptional health to declining into a debilitating, no-cure-in-sight life. My program was more like: Breathe. Stop crying. Eat. Try to sleep. Then, having had my feet knocked out from under me by PD once, I opted for re-thinking and re-gaining charge of my life as much as possible.

For my husband and myself,

taking on the challenge of the re-examined life has enabled us to work out new directions, individually and together, that have brought us fulfillment, even joy and fun. That is not to say that the losses are not there, that we never rage and grieve, but that has become the smaller aspect of our lives. I definitely like it better this way. Wallowing in misery only means rolling around in the mud until you are smothered... yuck! 

In the October 15 Caregivers' Brunch, we will explore ways to still be ourselves, while rising to the challenges of life with Parkinson's. For additional information on the caregivers' Brunch contact the I&R Center 877.872.6386.



Carolyn Allen Zeiger, Ph.D. has over 40 years experience in the fields of clinical, organizational and health psychology, including Vice President of The Athena Group, a consulting and training firm in Denver, CO, and Clinical Director of Comprehensive Psychological Services Group, a private multi-disciplinary mental health clinic that she founded in Boulder, CO. Carolyn's husband Paul has Parkinson's disease, as does her brother. She facilitates a Parkinson's caregivers' support group in Denver, and assists her husband Paul in teaching yoga to Parkinson's disease patients. She is a licensed psychologist in the state of Colorado, and a certified practitioner of Jin Shin Jyutsu®.

RISK OF FALLING



Lynn K. Struck, MD
Medical Director

Recently the Academy of Neurology developed parameters for screening and assessment of risks for falling for patients.

Parkinson's patients often have balance impairment and are at increased risk of falling. I am going to present some data that came from their report. Each year, there are more than 16,000 deaths from unintentional falls. Three-quarters of these occur in individuals over 64 years of age. There are nearly 500,000 hospitalizations and 1.8 million emergency department visits annually for falls.

There are several specific risk factors for falling. These included advanced age, muscle weakness, gait and balance difficulties, visual deficits, arthritis, depression, cognitive impairment, and impairment of activities of daily living. Also, there are several medications that pose an increased risk of falling.

There are several guidelines to help prevent falling. One thing is to be educated in the proper use of assistive devices. Secondly is to reduce medications as much as possible. There are also

several things that can be done in individuals' living situations to decrease the risk of falling.

I recommend each individual discuss their concerns of balance difficulties with their physician so appropriate recommendations can be given to minimize this risk.

REFERENCES

Practice Parameter: Assessing Patient's in Neurological Practice for Risk of Falls (An Evidence Based Review). Report of the quality standard subcommittee of the American Academy of Neurology Volume 70, February 5, 2008; page 473-479.



VOLUNTEERS

I struggle to think of another way of saying thank you to the many people who stepped forward this year to sit on committees, hand out food, setup and cleanup for an event, and the sponsors for our events who are listed in this newsletter.

As of August we are statewide, with over 30 support groups, three regional seminars and the annual statewide conference with an average attendance of over 400 people.

The support groups facilitators are fabulous in the manner of sharing information needed to

understand the diagnosis of Parkinson's disease. For many they have bravely moved the group into new territories, involving themselves into new events such as the Art @ the Capitol, Inspire me (a retreat-like event), and golf tournaments. Others stepped out into the county and state fair to distribute information on Parkinson's disease.

As the season begins to move to cooler weather, I invite you to volunteer to pick up a friend and go for a stroll. Call your friends for a card party or for a simple meal. Volunteering can be small or large.

Many of you had an opportunity to meet Heidi Sisler, one of our interns this summer. She displayed volunteering in a different light for the many who attended the June conference. When it was decided to offer lunch the day of the conference there was many discussions on how to do it efficiently. Well Heidi picked up the phone and called her friends. If her friends could not be there they volunteered their siblings. So maybe we can all learn from that...volunteer and bring your friends and/or family.

Thank you!



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Matching Gifts

Many companies and corporations will match your tax-deductible gift and double or triple the amount contributed to continue the APDA mission "To ease the burden and find the cure". Gifts can be in memory of a loved one or friend or to celebrate a special occasion. A card is sent to the designated person telling them of your generosity and thoughtfulness.

GOLF TOURNAMENT SUCCESSFUL IN RAISING \$22,220

A big thank you to Amy Harper for leading this June event to success. The day started with rain but at the end sun came out to give all the golfers a pleasant day to golf.

Thanks to the sponsors and volunteers the final amount given to the Iowa Chapter of the American Parkinson Disease Association was \$22,220 to support state events for people living with Parkinson's disease, their families and Parkinson's education.

For additional information on sponsorship or volunteering for this event contact Joel Jacobsen, 515.225.5556 or Amy Harper 515.225.5684.



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CARE PARTNER'S CORNER-HALLUCINATIONS

It is estimated that 25% of all Parkinson's disease (PD) patients eventually will suffer from hallucinations and/or delusions. Understanding the difference between hallucinations and delusions is important. A **hallucination** is a false perception about an object or an event, and it is usually sensory in nature. In other words, a person who has a hallucination may see, hear, smell or even taste something that does not really exist. Parkinson's patients sometimes see small animals or even people in the room with them, when in reality nothing is there. Occasionally, the PD patient may hear a voice or a noise without seeing anything, or they may actually feel something touch their skin, or have the feeling that something is next to them, when nothing is there.

A **delusion** is a false idea or belief. For instance, a patient may believe that a spouse is having an affair, or a child is stealing from them, or someone is spying on them, when there are no facts to substantiate this belief.

For many years scientist believed this was due primarily to long term use of Parkinson's medications especially levodopa and the agonist Mirapex™ and Requip™, however, two recent studies suggest that it may be much more

complicated than just medications alone.

One study conducted at the University of Virginia Health Sciences Center in Charlottesville, Virginia (Prospective Study of Hallucinations and Delusions in Parkinson's Disease, Holroyd, Currie Wooten), suggest that hallucinations while very common in Parkinson's disease are most likely of "multifactorial origin." The study suggests that there is a correlation between higher doses of levodopa and clinical hallucinations in PD patients, but that many factors, including the severity of the Parkinson's disease dementia, depression and visual acuity may all be important considerations in determining which patients will develop hallucinations and delusions.

One possible culprit may be imbalances in the chemicals of the blood that control water levels in the body and help with transmitting nerve impulses. Thus, dehydration alone may cause hallucinations and delusions in some patients under certain circumstances.

Kidney infections, respiratory infections or other infections in the body are also common culprits that cause mental disturbance. If hallucinations or delusions came on quickly an infection is a very likely

suspect.

Visual problems commonly associated with Parkinson's disease may be the cause of hallucinations as well, Parkinson's patients often suffer from dry eyes, blurred vision and other visual perception problems due to their Parkinson's. Complicate these factors with the normal aging process and visual acuity can dramatically be affected. An eye specialist can determine if a change in lighting or a change in prescriptions might help the problem.

In the study [Hallucinations, REM Sleep and Parkinson's Disease](#), published in *Neurology*, the author suggests that disturbances in REM sleep may also contribute to hallucinations and delusions in PD patients. "The visual hallucinations that coincide with daytime episodes of REM sleep in patients who also experience post-REM delusions at night may be dream imagery. Psychosis in patients with Pd may thereto reflect a narcolepsy-like REM sleep disorder."

Bad nutrition may even be the cause of mental disorders. The lack of certain vitamins and minerals has been linked to the

development of hallucinations and delusions in some patients. The link between poor nutrition and mental disturbances is well documented.

The first step in dealing with a patient, who is suffering from hallucinations and delusions, then, is to seek professional medical advise to determine the cause of the problem. A complete physical exam may be needed to determine if a person is suffering from an infection, poor nutrition or dehydration.

Having the the person's eyesight and hearing checked is also a must. Eyesight and hearing change with normal aging and may be worsened with Parkinson's disease. Making sure that the patient wears the hearing aid and/or glasses once they are prescribed is a must as well.

Changing the amount or the dosing time of some Parkinson's medications may be necessary. If so, your movement disorder specialist can make these changes as needed.

In some cases, it will be necessary for medications to be prescribed that can lessen the severity of the hallucinations and delusions.

DEALING WITH HALLUCINATIONS (CONT.)

Older traditional neuroleptics such as thiothixene and haloperidol should not be used because they may worsen motor symptoms in the PD patient.

(continued on page 5)

(continued from page 4)

Newer drugs such as quetiapine (Seroquel™), olanzapine (Zyprexa™) and clozapine (Clozaril™) can be prescribed without worsening PD symptoms. It should be noted that while clozapine is least likely to worsen PD symptoms, it may cause a drop in white blood cell count in some patients (about 2% of the population).

Once the causes of the mental disturbances have been determined, and proper steps have been taken to lessen the problem you may find the following helpful in dealing with the hallucinations and delusions on a daily basis.

First proceed with caution. Don't argue with the person about what he or she may hear or see. Unless the situation is dangerous, you may want to ignore the problems when possible.

Reassure the patient with kind words and gentle touches that you are there to help and protect. Gentle patting and soft spoken words may turn their attention away from the

hallucination and toward you.

Look for objects or situation that may be contributing to the hallucination. One patient thought he saw someone standing in his living room every afternoon. When the wife moved a floor lamp, the mysterious visitor disappeared. Another patient had a room filled with plants; late in the evening when the sun set the plants all seemed to come to life. Simply changing the lighting in the room and moving a few plants eliminated the


According to the aunt, "they were a constant source of companionship" and she "knew they were not real all along."

hallucination. Glares, reflections, lighting may all cause distortions that may contribute to the problem.

Distractions and diversions may also be helpful. Turning a person's attention away from an object or area that seems troubling and focusing on something else may provide temporary relief. Listening to music, looking at photos, taking a short walk, or some similar activity may provide the necessary distraction.

Occasionally, a person may ask you about the hallucination. For instance, they may ask if you see the

person standing in the room. BE honest, but supportive in your answer. You may want to respond that you know they see something, but that you do not see it. In this way, you validate their belief, without being critical or causing further arguments.

Lastly, determine whether the hallucinations is a problem for you or for the patient. Is it upsetting to the person? Is it causing them to act in a dangerous manner? If so, then actions must be taken to lessen the hallucinations. However, often patients find the hallucinations less bothersome than the caregiver sometimes patients find their hallucinations as a source of comfort. One example was a lady who had her aunt's medications changed because the aunt was constantly talking to small children and angels. When the hallucinations were no longer around the aunt because very angry and depressed. According to the aunt "they were a constant source of companionship" and she "knew they were not real all along." Ultimately, the aunt was put back on her old medication regiment. 

(Reprinted with permission from The Tulip Messenger, March/April 2008. Jo Bidwell)

Parkinson's Disease Quick Facts—Bookmarker

Many of you have asked for it and now it is available. A simple bookmarker listing some quick facts on Parkinson's disease. It is bookmarker with information on both sides including the contact information of the Information and Referral Center located in Des Moines. Contact your local support group or our office for the free bookmarker.



Parkinson's Disease Quick Facts

Over 1.5 million individuals are diagnosed with Parkinson's disease in this country.

Estimated over 40,000 additional individuals will be diagnosed this year.

Motor Symptoms

(Not all people with PD develop all these symptoms.)

- Tremor
- Bradykinesia
- Rigidity and freezing in place
- Stooped, shuffling gait
- Decreased arm swing when walking
- Difficulty arising from a chair
- Micrographia (small handwriting)
- Lack of facial expression
- Slowed activities of daily living
- Postural instability
- Difficulty turning in bed

Nonmotor Symptoms

- Diminished sense of smell
- Low voice volume
- Painful foot cramps
- Sleep disturbance
- Depression
- Constipation
- Drooling
- Increased sweating
- Urinary frequency/urgency

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SUPPORT GROUP- MARSHALLTOWN



The group meets in the YMCA in Marshalltown on the 2nd Wednesday of the month, for additional information on this support group contact Joyce Hughes 641.52.0349

RAGBRAI BY WILLIAM HINKLE

I rode in RAGBRAI many times in the pre-Parkinson's years – flying with the fastest, easily riding 100 miles a day, complaining only about the three H's – heat, humidity, and hills, sampling the best church meals in the state, devouring pie in most every town, greeting friends along the way...

Now, 2007 and 2008 have again been RAGBRAI years, but these have been since my Parkinson's diagnosis. So this year was different, it was hard! I no longer fly, and I no longer ride my bike 100 a day, rather around 30 miles is a major accomplishment. I ride many miles with the support drivers. I still enjoy the church meals and the pies and especially the friends old and new.

It was hard to answer the bell each morning at 5:00 a.m. when my body was stiff and unresponsive and medication were yet to be taken at 6:00 a.m. I struggled to get up, stretch, dress, line up for bathroom. Load bags, and then pedal. And breakfast needs were yet to be considered. It was difficult!

More than once I wondered: Why am I doing this? Where will this lead? What is my reason for being with this team?

Reflecting now I have some answers for my questions, some reasons why I was there. I believe that coincidence is God's way of staying anonymous, and I'd like to share examples to prove God's hand was guiding my way.

I was there to help distribute informational materials to many people along the way who saw our Pedaling for Parkinson's team name and stepped forward to visit with us. Thanks to the Iowa APDA office for providing the materials.

I was there with Paul, Jeff, and Jim as we struggled to challenge ourselves and perhaps stave off aches and pains during the week to ride tandem bikes, speak about Parkinson's, our conditions and involvement – showing others what we have been able to do for awhile at least.

I was there to ride on the back of a tandem, demonstrating Dr. Albert's findings that exercise can help suppress Parkinson's symptoms for while.

I was there to be interviewed, to speak for me and other Parkinson's disease patients, when the crew from NBC Nightly News joined for us for interviews, filming and learning about

Pedaling For Parkinson's and Dr. Albert's findings and that forced exercise helps reduce the symptoms of Parkinson's for a time.

I was there when we spent a night in the Darling home. He is a scientist in Iowa City studying Parkinson's and exercise and oxygen's part in helping the body. Maybe there is a place for me in the study.

I was there to help and give support to a friend who had a difficult time finishing one day's trip. We are reminded that we can't do all that we used to do and there's more to strength than what's shown in muscles.

I was there to visit with a high school student, a fine young, who was on his first RAGBRAI as the support driver.

Looking back as I regain some strength, I think of Aesop's tale about the hare and tortoise. The steady stick-to-it turtle and the high speed rabbit that failed to out-travel the turtle. Well, I was indeed the slow turtle, and often felt my tale's outcome would end in turtle soup pot-cooked! But then maybe not as my new pace gives me a chance to look around, visit and be there for someone else.

So, I have traveled with Dr. Jay Alberts and his Pedaling For Parkinson's team. This year's included Dr. Alberts' family, friends, fellow-workers and we Parkinson's patients from several states and Germany. We came together to help with the mission to raise awareness about Parkinson's and to raise funds to battle the disease and help patients and families who have been touched by it. Looking at the week, we can say, "Mission accomplished!"

In closing, when asked, "How was RAGBRAI? I have to say it was difficult, by far more work than fun. However, I was in the right place at the right time to be of help. Will I do it again? Yes, if God plans it.



William Hinkle is co-facilitator for the Dike support group with his wife, Corrine. If you are interested in speaking with William or additional information on the Pedaling for Parkinson's Team call 319.989.2110.





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Parkinson Disease Information & Referral Center

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WHAT IS APDA?

The American Parkinson Disease Association, Inc. was founded in 1961 to “ease the burden and find a cure” for Parkinson’s disease. Headquartered in New York, the organization focuses its energies on research, patient services, education and raising public awareness about the disease. The 2007-2008 APDA budget for research is more than \$3.5 million plus the funding of 9 Centers for Advanced Research. \$2.6 million is provided for patient services, including 62 regional Information & Referral Centers and the APDA National Young-Onset Center. Each year the APDA Scientific Advisory Board reviews grant applications and submits recommendations for funding researchers whose work shows promise for making scientific breakthroughs or finding improved treatments for Parkinson’s disease. The APDA national office also coordinates the efforts of 56 chapters and 250 affiliated support groups across the nation.

PD101- JUST DIAGNOSED

Parkinson’s disease (PD) is a progressive degenerative neurological disorder affecting more than 1.5 million Americans.



PD101-Just Diagnosed

Free session for recently diagnosed patients and families. Have you or a loved one been diagnosed with Parkinson’s disease within the past two years? If so consider attending a free information seminar at Iowa Methodist Medical Center.

Tuesday, October 21, 2008
5:00-7:30pm
Iowa Methodist Medical Center
1200 Pleasant Street
(Hill Auditorium)

To register or for additional information call
515.241.6379 or 877.872.6386
Email
erwinjs@ihs.org