

The American Parkinson Disease Association

SPRING 2003 NEWSLETTER

The American Parkinson Disease Association

A Quarterly Newsletter © 2003
by The American Parkinson Disease Association, Inc.

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Early PD Stages Reflections

I am a pastor and two years ago, while on vacation from my parish, I noticed a faint weakness of my right hand at breakfast. Some weeks later, I went to my computer and typed in "Parkinson's" on the internet. When I read about the symptoms, I diagnosed myself correctly. I began to recall occasional, faint and fleeting indicators such as a slight hand tremor in the middle of the night, the voice trailing off at the end of a sentence, reversing letters while typing. Soon afterwards during my annual physical, I voiced my suspicion to the doctor who tactfully suggested some other explanation. As a precaution, though, he sent me to a neurologist who promptly confirmed my suspicion.

I immediately began taking medications and visiting the new physician for checkups. When I asked the prognosis, he said he would know better in a few years. That was encouraging!

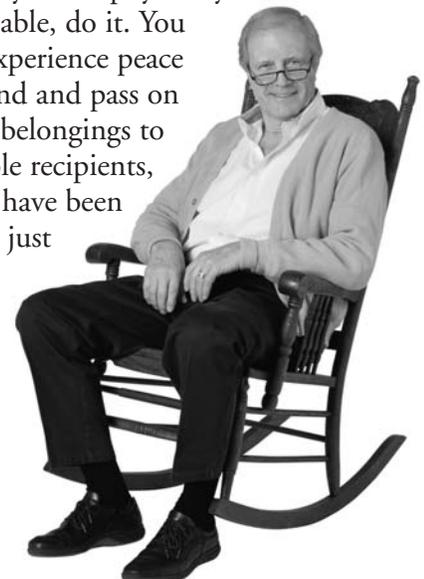
The next obvious challenge was "to tell or not to tell." I quietly shared the news with the family and a few close friends. Since I displayed no observable signs, there was no need to inform the parishioners. Why burden them when I'm the one who has been ministering to them for nearly fifty years in their heartaches? Besides, I trust, I have been in their prayers anyway.

The typical fatigue, nevertheless, has

demanded some adjustment. I've started eliminating outside commitments, such as giving a talk on one of my specialties. Besides a regular noontime nap, I sometimes need a mini-nap early in the evening. Early rising requires these daytime breaks. I'm eating properly and exercising as usual, too. Oh yes, I've started attending a monthly support group. For decades, I've been involved in other such groups in various capacities. Now I'm a participant-recipient myself and I firmly believe in them.

Beyond staying in control and adjusting as much as possible, one has also to take a realistic look at the future. Many in the general population are collectors, and now is the time to make decisions. Granted, it's sad to part with valuables accumulated over decades, but it must be done.

While you are physically and mentally capable, do it. You will experience peace of mind and pass on some belongings to suitable recipients, and I have been doing just that.



Aging is a degenerative process that starts in adulthood, accelerates in mid-life and shifts into fast-forward after age 50.

The good news is that current research shows we can dramatically slow down the aging process by consuming a variety of specific foods and supplements.

The most compelling theory of why we age centers on free radicals. These are highly reactive molecules in the body that emerge as a result of breathing, eating, physical stress and exposure to the sun and pollutants such as cigarette smoke. Free radicals constantly attack and damage our body cells and as this damage increases, it promotes cancer, declining immunity and memory loss.

The antidotes to the damage caused by the free radicals are chemicals called antioxidants. They can be found in foods and in vitamin supplements. Antioxidants neutralize the free radicals and delay aging, decreasing the cellular and body destruction.

For slowing the aging process the dieticians recommend five or more servings of fruits and vegetables a day. This is the most important thing you can do to stall the aging process, since such foods provide the greatest amount and widest range of known and unknown antioxidants. ■

This article was abstracted from the Vermont Parkinsonian, October 2002.

PRESIDENT'S MESSAGE



Dear Readers,

The American Parkinson Disease Association continues to meet, in these most demanding times, the challenge to provide support, and encouragement to those individuals with Parkinson's disease and their families.

As we move forward with initiative and determination, APDA proceeds with extensive research efforts at an energized pace. In today's unparalleled medical environment, we continue to augment these research endeavors, to develop the best approaches for prevention and treatment of this disease.

As we look to the year unfolding before us, to our mission and our responsibility to support the community, APDA continues to examine new ways and means to meet the charge of service to all Parksonians. We constantly consider new avenues to provide necessary meaningful information, and through funding efforts, to continue critically essential research.

In this on-going effort, all scheduled events, plans, developing cooperative partnerships and corporate initiatives, outlined in my address to you last fall, are on schedule.

Operations throughout the APDA national support network of Chapters, Information and Referral Centers, headquarter administration and affiliated support groups continue to strengthen those in most need. In this regard, I look forward to joining with our national support network team of Chapter volunteers, I & R Center personnel, Advisory Board members, and headquarter staff at our annual APDA National Conference and Symposia to be held July 30th to August 3rd in Portland, Maine.

Our continuing efforts and resolve are made possible with your support, your guardianship and perseverance; for these efforts and more, I sincerely thank you.

Sincerely,

A handwritten signature in black ink, appearing to read 'Vincent N. Gattullo'. The signature is fluid and cursive, with a large, sweeping initial 'V'.

Vincent N. Gattullo

Choosing a Nursing Home

For many families it comes a time when the members realize that a father, mother or another loved one will be best off in a nursing home, where the specialized needs of older age can be best met. The process of finding a nursing home is not only difficult for you, but for your loved ones as well; in many cases, their lives will be dramatically altered. This article hopefully will help people in making the best possible decision when selecting a long term facility.

Inquiries: a loved one is a special individual with specific interests and needs, all of which should be reflected in the nursing home you and your family select. Options must be well researched with every family member having a voice; once the decision is made ask your doctor, hospital discharge planner or social worker to provide you with a list of qualified nursing homes.

Most nursing facilities offer more than one level of care, specifically a "skilled" care section and an "intermediate" care section. Before choosing a nursing home, you should try to visit several potential facilities. During the visits, the family members should tour the facility with a staff member and feel free to ask questions. It is a good idea to take notes during this exchange, so you can later compare your impressions on each facility you visited.



Cost: when looking for a nursing home, compare room rates and additional costs. Always ask what is included in the cost of the room. A low per-day rate may increase significantly when one adds the costs for such things as medication, administration and personal care. The harsh reality is that sometimes the decision will be based on what you can afford, therefore, it is important to know up front what the total cost of care will be, and what help is available through Medicare, Medicaid or Veteran's benefits. When comparing prices, be aware that most, but not all facilities, are obligated to accept patients who qualify for Medicaid, however, the number of Medicaid beds in each facility may be limited and the names of potential future residents may be placed on a waiting list.

Location: location is another important factor to consider when choosing a nursing facility, as distance may affect how frequently family members and friends are able to visit. Also important is the overall physical setting. Does the center offer gracious living in a home-like atmosphere with quality color-coordinated furnishings and surroundings? Is the environment clean, odor-free and have well groomed, attractive lawns and grounds? Does the facility meet your personal standards for cleanliness and neatness? Does the facility

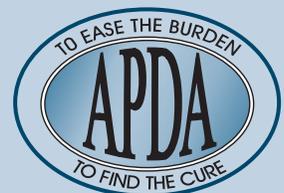
Awakening in the middle of the night and not being able to fall back to sleep is usually caused by aging.

When you find yourself awake at 3 a.m. do not become angry. Anger only excites you, preventing sleep, instead, fix your mind on a single relaxing image, for example visualize a flickering candle. If you are still awake after 30 minutes, go to another room. Watch an old movie on TV, or read a book or magazine. When you feel sleepy, return to bed. If sleep still eludes you, go back and read some more.

The following preventive steps can also help you:

1. Eliminate daytime naps if they have become a habit.
2. Do not go to bed too early. This only increases the chances of insomnia.
3. Set your wake-up alarm an hour earlier than usual. This makes you more tired for the following night. Advance the alarm by 15 minute increments until you are sleeping through the night. Then slowly extend your sleep period until you are back on a normal schedule. ■

Adapted from the January 2003 issue of the Vermont Parkinsonian



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Medicare Coverage for Brain Stimulation

Medicare has announced it will cover Parkinson's disease or essential tremor treatments with Activa® Therapy. This therapy uses deep brain stimulation technology from Medtronic, Inc., to reduce some of the motor symptoms of the two most common movement disorders.

Activa® Therapy uses Medtronic's "brain pacemaker" technology to control some of the disabling motor symptoms of these movement disorders. Many private insurers already cover the expenses of the treatment, and more are now anticipated to follow suit. ■

Treatment of Drug Resistant PD Tremor

In a study reported in the *Journal of Neurology, Neurosurgery and Psychiatry*, Dr. O. Pogarell studied 84 patients with optimally treated early and advanced Parkinson's disease (PD), with drug resistant tremor. The journal reported that an average patient dose of 4.1 mg pramipexole (Mirapex®) administered daily gave significantly better results than the placebo. ■

Choosing a Nursing Home *Continued from Page 3*

meet or exceed local, state and federal fire safety requirements? Are there lounges for family visits and socialization? Is the resident's room adequately lit? Can the residents provide their own decorations, furniture, telephones and televisions?

Meals: mealtime is usually a highlight of each day in the facility. Most nursing homes will be glad to show their menus for the month and talk about the time allocated for each meal, arrangements for special diets, and assistance available to residents who can't feed themselves. Ask to tour the kitchen to determine whether it is clean and whether the cooks and servers are wearing gloves and hairnets. Make sure that the food is prepared in a way your loved one would enjoy, and served in a pleasant atmosphere. Find out whether meals are delivered to residents who are unable to eat in the dining room.

Medical care: patient care is an essential component of nursing home care and you should not hesitate to ask questions about it. Who comprises the treatment team, and how involved are residents in their care? Are there licensed physicians and nurses on duty around the clock or are they only available by phone? Are sick patients treated on the premises or are they quickly transferred to a hospital? How close is the nearest hospital? Are other medical services like dentistry, podiatry, speech therapy, physical therapy or occupational therapy available? If so, what is the frequency of these sessions? Are personal physicians granted privileges in the facility? How experienced and compassionate is the staff in regard to treating patients suf-

fering from stroke, Parkinson's disease, Alzheimer's disease, joint replacements, bone fractures, and related illnesses?

Accreditation: every nursing facility you consider must have a current license from the state and have an internal assurance program in place. Facilities certified by Medicare and Medicaid should be able to produce a copy of the state certification survey conducted yearly. With respect to security, are visitors required to sign in before they enter the premises?

Solicitation: is solicitation allowed within the facility? Are the residents notified if there is a visitor to see them? Are there security guards and/or cameras at the front desk? Is there a guard on duty around the clock? To better ensure the safety of your loved one, it is important to ask questions about the employees of the facility, specifically the screening process in hiring them. Far too often, these questions are not asked because they may seem insulting.

Please remember that the safety of your loved one is at stake.

Choosing a nursing home is in no way an easy decision. In fact, it may be one of the most difficult decisions you ever make. The selection of a nursing home is best made by visiting the facility and by asking questions, and then more questions. Do not accept advice blindly. A lack of planning and preparation could lead to a rash decision and grave consequences. ■

Abstracted from Eckman on Elder Law, January 2003 issue.



In 1975, when the Relaxation Response was first introduced, it explained how people could use a series of exercises to relax and improve their health. Since then there has been much research on this topic that has yielded some remarkable findings.

When we are under stress, our bodies release certain hormones and chemicals that increase breathing rate and muscle tension. If you are constantly under stress, the reaction could result in any number of physical and emotional symptoms, including head aches, stomach aches, and anxiety. There is also evidence that chronic stress can lead to, or worsen, certain illnesses. Everyone possesses an inborn bodily response that is called “The Relaxation Response”. This response decreases metabolism, heart rate, blood pressure, etc.

The Relaxation Response can help you unwind whenever you are feeling stressed, or prevent stressful feelings from occurring in the first place. The following steps are helpful:

- ◆ Sit comfortably, with your eyes closed.
- ◆ Relax your muscles and breathe deeply using your abdominal muscles, not just your chest muscles. Place one hand on your abdomen, just below your rib cage. As you breathe in, you should feel your hand rise.
- ◆ Silently repeat the word “one” as you slowly exhale, or simply focus just on your breathing.

- ◆ If you have any intrusive thoughts, don’t worry, just return to your deep breathing.

By performing this exercise for 10 to 20 minutes once or twice a day, you’ll immediately begin to feel calmer and better equipped to deal with the hassles of everyday life.

Although the original guidelines for the relaxation response suggested that people repeat the word one as they exhaled, it was since found that this response can be elicited in many ways.

Some people prefer to say a prayer as they exhale or words such as peace or serenity. Still others who are simply too fidgety to sit still and meditate can use jogging to elicit the response.

As you jog, focus on the cadence of your feet, left, right, left, right, rather than repeating a word. While most runners experience a high during their third or fourth mile, those who use the Relaxation Response often reach that high during their first or second mile. You can enhance your experience by using imagery or visualization after you have elicited the Relaxation Response.

Imagine a tranquil scene, such as a beach you once visited, a perfect sunset over a lake, or a crystal-clear stream. By doing so, you will feel the same peace and quiet you experienced when you actually were in such a setting.

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Deep Brain Stimulation Alert

The Food and Drug Administration (FDA) recently issued an alert after having received reports of deaths of patients with implanted deep brain stimulators who had received diathermal therapy.

This therapy uses shortwave, microwave or therapeutic ultrasound to deliver “deep heat” to body structures. It is used by physical therapists, chiropractors, nurses, dentists and others to promote wound healing after surgery or to relieve swelling, pain and stiffness in muscles or joints.

The treatment can be hazardous to patients with deep brain stimulators which involve the implantation of electrodes into the brain to treat neurological ailments such as Parkinson’s disease. Diathermy may cause implanted electrodes to heat up excessively, damaging the surrounding brain tissue.

Patients with any sort of implanted metallic lead are at risk of serious injury when exposed to shortwave or microwave diathermy. This is true even if the implanted device is not turned on, and even if the lead is no longer connected to an implanted system.

The FDA urged doctors who implanted or monitor the leads or systems to caution their patients against receiving shortwave or microwave diathermy therapy. The agency also stressed that healthcare professionals who use such therapy should ask patients about whether they have implants. ■

TEN ADDITIONAL RESEARCH PROPOSALS APPROVED BY APDA FOR FISCAL YEAR 2002-2003

At a recent meeting the APDA Executive Committee approved to support the following five Medical Student Summer Fellows (\$4,000. per each grant):

Brett Bordini,
at the University of Wisconsin Medical School, Madison, WI,

Maher Khan,
at the Chicago Medical School, Chicago, IL,

Elise Malechi,
at the University of Maryland, Baltimore, MD,

Eleanora Marnes,
at the Finch University of Health Sciences, Chicago, IL,

Mark Richardson,
at the Medical College of Virginia, Richmond, VA.

Three research grants were awarded to **Bari Hoffman Ruddy, Ph.D.**, University of Central Florida, Orlando, FL, **Vernice Jackson-Lewis, Ph.D.**, Columbia University, New York, NY and **Rawindra Singh, Ph.D.**, University of Massachusetts, Worcester, MA.

Two research fellowships were also awarded to **Yoshirori Kawazoe, Ph.D.**, Baylor College of Medicine, Houston, TX and to **Jillian Prestopnik, Ph.D.**, New Mexico VA Medical Center, Albuquerque, NM ■

Relaxation *Continued from Page 5*

At the Mind/Body Medical Institute, the Relaxation Response was integrated with three other important self-help therapies — exercise, nutrition and cognitive work. Combined, they provide a potent tool to manage stress and improve health.

We know that regular exercise strengthens your body, helps you maintain a healthy weight, relieves both physical and mental tension and improves your mood.

It is however important to check with your physician before starting any program.

Because of jam-packed lifestyles, many of us tend to eat on the run. We emphasize that in addition to exercising regularly, eating a healthy diet is fundamental for improving health and preventing the progression of certain chronic medical problems.

Eating habits however are deeply ingrained and can be difficult to change.

Start by asking yourself how you view food. Do you view eating as a way to alleviate stress? If your answer is yes, you probably need to learn how to deal more effectively with the stressors in your life. Do you eat because

you are bored? If so, try to find other, more positive ways to fill your empty hours, such as exercise, reading or hobbies.

What you think and say to yourself over the course of the day has a profound effect on your emotions and physical well-being. Many of us think endlessly about our problems and concerns and don't give ourselves the chance to take action of effectively work through them. Some of our internal chatter focuses on ourselves. This can simmer over into our impressions of others or life in general. When we send ourselves negative messages, we threaten our psychological and physical health. You can improve your well-being by recognizing and changing your negative self-chatter.

If your feeling tense, anxious or upset for any reason, breathe deeply, to interrupt your thought pattern. Identify the negative thoughts and challenge them with evidence to the contrary. If you constantly criticize yourself, learn to dispute your negative reactions. Rely on humor to defuse stressful situations.

If you can find humor in even the most upsetting predicaments, you will feel better instantly. ■



questions & answers

Enrico Fazzini, D.O., Ph.D

Asst. Prof. Neurology New York University, N.Y.

Q: I have had restless leg syndrome (RLS) for many years and now am taking carbidopa/levodopa 25-100 mg to reduce night leg movement since Aug. 2002. Recently I am experiencing spells also in the daytime when sitting.

Can you send me some information about RLS and Parkinson?

A: Restless Legs Syndrome is best treated with a dopamine agonist such as Pramipexole (Mirapex) or Ropinerole (Requip). These medications are longer acting than the carbidopa/levodopa you have been taking and would also be more effective.

Q: What tests can I have my doctor do to determine if I have any of the four genes that pre-determine if I may have inherited Parkinson's from my mother? She is 81, I am 61. I have had depression & insomnia for years, I've been on 100 mgs of Doxipin & 2mgs of clonapezen to help the depression & insomnia for several years. A sleep study was done a few years ago on me

& I was told that I had restless leg syndrome. My voice is also becoming impaired. I have no volume & when I'm tired, my voice shakes. What can I do now to prevent the symptoms from becoming worse?

A: Even if it was known that you had a strong genetic predisposition for developing PD, there would be little that you can do to prevent the development of PD. Having said that it might be advantageous to take coenzyme Q10 (1200 mg/day) and selegiline (5mg twice a day). These compounds may delay progression of PD.

Q: Has anyone yet developed a way to give medicines for PD through a skin patch?

A: There is a large clinical trial underway testing a dopamine agonist that is delivered by skin patch. The medication is smoothly delivered over 24 hours and should decrease the fluctuations in response to L-Dopa that many patients experience. I am now conducting this study in New York. Information regarding the study and updates from the Academy of Neurology meeting this month can be obtained from my web site www.theparkinsondoctor.com.

Pfizer Share Card

The Pfizer for Living Share Card, was launched in January 2002. It is part of Pfizer's commitment to provide qualified Medicare beneficiaries without prescription drug coverage with simple and convenient access to the medicines and healthcare information they need.

The Pfizer Share Card program enables Medicare beneficiaries to purchase up to a 30 day supply of most Pfizer prescription medicines for a flat fee of \$15 per prescription. In addition to the \$15 prescription, Share Card members have access to a 24-hour call center with live operators to learn about other health services and benefits for which they may be eligible. The Share Card is accepted at most participating pharmacies throughout the United States including major chains with no enrollment fee.

Information on availability and applications for Share Card are available by calling 1-800-717-6005 and or www.pfizerforliving.com. ■

Information on Parkinson's Disease

Single copies of the following publications may be obtained free of charge by writing to the national APDA office or by calling the toll free number 1-800-223-2732 or Fax 1-718-981-4399.

EDUCATIONAL BOOKLETS

1. **Basic Information about Parkinson's Disease**
4 page brochure (English, Chinese, Spanish)
2. **Parkinson's Disease Handbook**
Symptoms, causes, treatment, 40 page booklet (English, German, Italian, Portuguese, Spanish, Russian)
3. **PD "n" Me-Coping with Parkinson's disease**
70 page booklet (English)
4. **Be Active** — A suggested exercise program for people with Parkinson's disease, 25 page booklet (English, German, Italian)
5. **Be Independent** — Equipment and suggestions for daily living activities, 32 page booklet (English, German, Italian, Spanish)
6. **Speaking Effectively** — Speech and swallowing problems in Parkinson's disease, 34 page booklet (English)
7. **Good Nutrition in Parkinson's Disease**
26 page booklet (English, Italian, Swedish)
8. **Young Parkinson's Handbook**
78 page booklet (English)
9. **How to Start a Parkinson's Disease Support Group**
24 page booklet (English, Italian)
10. **Aquatic Exercise for Parkinson's Disease**
A 20 page booklet for patients and their families (English)

EDUCATIONAL SUPPLEMENTS

Hospitalization, Helpful Hints, Living Will, Oral Health Care, The Family Unit, Helping Your Partner, Nursing Homes, Long Term Care Insurance, Recreation and Socialization in Parkinson's Disease, Comtan Questions & Answers, Use of Comtan in the Treatment of Parkinson's disease, PD and The Emergency Room

CARELINK

(A cooperative APDA - GSK project)

You can now contact the APDA Information and Referral Center closest to you by dialing the toll free number 1-888-400-2732

APDA WORLDWIDE WEB SITE

www.apdaparkinson.org for PD, I&R Centers, Chapters, Support Groups, Education and Information Material, Meeting Dates, Publications, Medical Abstracts, Video Library, Udall Bill, etc.

WORLD PARKINSON DISEASE ASSOCIATION WEB SITE

www.wpda.org/ A weekly updated source of world news

DEEP BRAIN STIMULATION FOR PARKINSON'S DISEASE

A clinical trial of deep brain stimulation (DBS) for Parkinson's disease (PD) is underway in a new collaborative agreement between the National Institute of Neurological Disorders and Stroke (NINDS) and the Department of Veterans Affairs (VA). A total of 316 patients will participate in the study, which is taking place at six locations around the country. NINDS, is providing \$7 million for the 5-year trial.

Interested parties can contact the location closest to their residence for further details:

University of California
at San Francisco, CA
tel. (415) 221-4810 ext. 2488
Medical College of Virginia
at Richmond, VA
tel. (804) 828-5235
Baylor College of Medicine,
Houston, TX , tel. (713) 798-4773
University of California,
Los Angeles, CA
tel. (310) 794-7239
Oregon Health Science University,
Seattle, OR, tel. (503) 494-7950
University of Pennsylvania,
Philadelphia, PA
tel. (215) 829-7181 ■

The material contained herein concerning the research in the field of Parkinson's disease and answers to readers questions are solely for the information of the reader. It should not be used for treatment purposes, but rather as a source for discussion with the patient's own physician.

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