

Exercise for People With Parkinson's Disease

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Given the advances in the medical and surgical management of Parkinson's disease (PD), people with Parkinson's disease can live a long and productive life. However, people with PD often experience a gradual decline in mobility over time due to an increase in symptoms such as rigidity, bradykinesia and loss of postural control. This decrease in mobility often leads to a more sedentary lifestyle which contributes to even

greater declines in mobility.

The combination of Parkinson's symptoms and inactivity frequently leads to limited participation in work, social and recreational activities which can negatively impact the quality of life.

People with PD have shown to benefit from

exercise in many ways. Studies investigating the effectiveness of exercise in people with the disease reveal that exercise can lead to improvements in strength, flexibility and cardiovascular fitness. Improvements in these areas minimize the negative impact that Parkinson's symptoms can have on mobility.

As a result, improvements usually occur in walking speed, walking distance, general mobility and health related quality of life.

Exercise has been shown to be beneficial in both the early and late stages of the disease, and getting started early in the process is highly recommended to reap greater benefits.

Animal and epidemiological studies suggest a potential neuroprotective effect of exercise, however, the effect of exercise on disease progression in humans with PD has yet to be investigated.

Although the potential disease modifying effects of exercise are unknown, people with Parkinson's disease can benefit from it and improve mobility despite the progressive nature of the disease.

Components of the program include exercises

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designed to increase flexibility and joint motion, training to improve cardiovascular fitness, strengthening exercises, practicing strategies to improve mobility (e.g. moving in bed and rising from a chair), walking with external cueing (such as a metronome or music to help regulate cadence, step length and speed of walking) and balance training.

The key to success for people with PD is to make exercise part of their lifestyle.

Although short-term exercise can be beneficial, long-term participation in exercise is essential to reap prolonged benefits. People with PD should consult with a physical therapist with expertise in PD who can develop an exercise program targeting the specific problems experienced by an individual. Given the variability in the symptoms of PD, this targeted approach is necessary in order for each person to be implementing the appropriate types of exercises at the appropriate level to optimize the benefits.

Physical therapists can also design exercise programs that can be carried out at home, in a health club or in a group setting. The type of program chosen should be one that a patient will be most successful integrating it into his/her every day life.

It is a challenge for people in the general population to adhere to a regular exercise program. People with PD tend to have even more difficulty adhering to exercise because of problems with fatigue, apathy or depression. For people with these symptoms, exercising as part of a group class, which meets on a regular basis, can help improve participation and adherence.

With an increased body of evidence supporting the effects of exercise in people with PD, it is clear that exercise should be an integral part of the management of people with this disease. Exercise should be recommended at the time of the diagnosis

and referral to a physical therapist with expertise in Parkinson's disease should occur at this time. The patient should follow up with the physical therapist on a regular basis. Changes in the quality of life, mobility, strength, flexibility, cardiovascular fitness, balance and falls should be monitored periodically by the physical therapist using valid, reliable and objective procedures.

This will allow modification and adjustments of the exercise program at regular intervals according to the needs of each individual to optimize mobility and quality of life.

Although much more research is needed to investigate the impact of long-term exercise, it is highly recommended to include exercise in the regular management of patients particularly in the absence of any adverse effects of exercise reported in the literature. ■

New Dosage Strength of Requip® XL™

In April the FDA approved a new 6 mg strength of Requip® XL™ (ropinirole extended-release tablets), offering many patients the option to manage their Parkinson's disease with one or two tablets once daily. The new dosage became available in pharmacies in May.

Requip® XL™ is now available in five strengths (2mg, 4mg, 6mg, 8mg and 12mg), offering physicians and patients a once-daily treatment option that can help reduce the pill burden experienced by many patients.

Requip® XL™ is an extended-release, once-daily formulation that uses a tri-layer tablet for continuous delivery of ropinirole over 24 hours to provide smoother blood levels without the peaks and troughs of multiple daily doses administration.

As Parkinson's disease progresses, patients may experience difficulty swallowing and treatments that can reduce the frequency and the number of pills may provide a convenient option.

Results from a pivotal safety and efficacy trial showed that adding Requip® XL™ to patients' existing levodopa therapy reduced the amount of "off" time by 2.1 hours per day on average, compared to prior treatment. ■





President Joel A. Miele Sr., left, accepts a proclamation from Staten Island, N.Y. Borough President James Molinaro during awareness ceremonies in April.

Dear Reader:

Five-year plans are famous and infamous and usually are underestimated. The most famous, of course, was the one Stalin launched in 1928 in the then-USSR. But national economic five-year plans also have been utilized in China, India, Nepal, Vietnam

and Oman, to name just a few. Closer to home, the MIT Museum has a five-year strategic plan and Alabama has a five-year transportation plan. In Ohio, education is the subject of the Five-Year Vision Ohio Implementation Plan. And, remember the National Institutes of Health initiative called the Five-year Blueprint for Neuroscience Research?

We who are concerned with Parkinson's disease held out such hope when, in 1997 researchers at Robert Wood Johnson Medical center in New Brunswick, N.J. (supported by an APDA grant) discovered alpha-Synuclein, the protein that occurs in Lewy bodies. It was an exciting moment in Parkinson's research, promising better understanding of the etiology and pathogenesis of the disease. Surely a cure could be no more than – you guessed it – five years away.

More than a decade later, through painfully slow progress, we inch closer. Yes, there have been pharmaceutical and surgical breakthroughs. Yes, the current administration in Washington is more science-friendly. But, look what has happened to our economic situation. As we look forward to promising scientific achievements, funding from public and private sources is dwindling, if not disappearing.

Research, especially in an unfriendly economic climate, must be supported and encouraged, for it is the only path to a cure. Young physicians and scientists, many with heavy education loans to pay, should not be discouraged from pursuing a research career path because there is no financial incentive or support.

Supporting the 1.5 million Americans with Parkinson's, a progressive disease, and their caregivers can't be put on hold until the market recovers.

We at APDA have no timetable. We will continue to work until the cure is found, and with your continued support we hope there will not be a need for yet another five-year plan.

Sincerely,

Joel A. Miele, Sr. PE
President

Indiana Law Recognizes Parkinson's Disease as a Line-of-Duty Disability



Law enforcement officers, firefighters and EMS personnel in Indiana who contract Parkinson's disease will now be eligible for enhanced benefits.

Exposure to burning toxic chemicals can bring about early onset of the disease that usually strikes people in their 60s.

Gov. Mitch Daniels signed the law that recognizes Parkinson's as a line-of-duty disability.

The measure officially went into effect on July 1, said Gary Coons, a former Indiana firefighter stricken with the disease at age 33.



In 2005, he was the lead investigator of a large paint warehouse fire. The contents of the building included several paint trucks, painting materials, and solvents, like toluene and he was exposed to many toxins during the three-day investigation.

Since word of his success at the legislative level has spread, he was contacted by fire officials from other states anxious to get a legislative process started in their own states.

(For a profile of Firefighter Coons and his mission to have legislation passed recognizing PD as a line-of-duty disability for emergency responders, see page 5.)■



By ENRICO FAZZINI, DO, PhD

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Q. My husband was recently diagnosed with Parkinson's disease. Is there a test he can take to prove if he really has it?

A. There are imaging studies, which can suggest the loss of dopamine or a change in the metabolism in the brain, but the diagnosis is still based on the presence of bradykinesia and at least one of the following three signs – resting tremor, cogwheel rigidity and gait disorder. MRIs of the brain are preformed in order to rule out any structural lesions such as tumors or strokes.

Q. My wife is 69 years old and has had Parkinson's disease for 13 years. She has recently become more confused and forgetful and her attention is poor. Can she also be getting Alzheimer's disease?

A. Many patients with PD develop cognitive impairments. These impairments are typically attentional and processing impairments. There may also be spatial orientation deficits. What is not seen are the short-term memory deficits characteristics of Alzheimer's disease. There is a form of PD in which dementia presents early; this is known as Diffuse Lewy Body Disease. When dementia is present, it is best to lower or discontinue all

medications except for Sinemet® and to add Aricept® or Exelon®.

Q. Is there any way of slowing down the progression of Parkinson's disease?

A. There are currently no medications which are approved for this purpose, but there is some evidence that the MAO-B inhibitors in particular Rasagiline (Azilect®) may delay the need for starting other anti-PD medications. Dopamine agonists have also been studied to this effect. The problem is that there is no easy and definitive way of measuring the progression of PD.

Q. My uncle has had PD for 16 years and he was recently admitted to a psychiatric hospital for schizophrenia. They said that

the medications caused it and they stopped all of my uncle's medications. His mind cleared up, but he became rigid and unable to move. His wife took him home and the neurologist changed the medication and my uncle is getting better. What happened?

A. Your uncle most likely developed "on/off" fluctuations and needed to be placed on several medications in order to smooth out the effects of L-Dopa, but this eventually built up in his system and led to psychosis. He underwent a drug holiday and now the neurologist is most likely using L-Dopa without other medications. The problem is that soon those "on/off" fluctuations will reappear. If dementia is not present, the only option may be the subthalamic deep brain stimulation. ■

DEEP BRAIN STIMULATION

Medtronic, Inc. announced the U.S. Food and Drug Administration's approval of Activa® RC and Activa® PC, the most innovative deep brain stimulation (DBS) devices available for the treatment of the symptoms of advanced Parkinson's disease and essential tremor. Both Activa RC and Activa PC devices provide bi-lateral stimulation, and offer a more advanced approach to device programming, and additional tools for capturing history relevant to the patient's therapy. New programming options provide greater ability to fine tune the stimulation field and give patients more options to optimize their settings compared to previous DBS devices.



Gary Coons, fire fighter

Firefighter Gary Coons' Efforts Result in Country's First PD Presumptive Law

Gary Coons had always wanted to be a firefighter and really never gave much thought to politics or activism, but now at age 35 he has excelled in all three areas. He also has Parkinson's disease (PD).

After being diagnosed with PD following almost three years of non- and mis-diagnoses, Gary knew his days of fighting fires were behind him. What he didn't know was that he was destined to become responsible for the first law in the country allowing emergency responders afflicted with Parkinson's disease to become eligible for expanded disability benefits.

On May 1, Gary and his wife, Trish, stood with Representative Mary Ann Sullivan and State Senator James Merritt in the Indiana Capitol and proudly watched Gov. Mitch Daniels sign Senate Bill 376 into law. The Indiana Presumptive Law requires PD to be treated as a line-of-duty disability under an emergency responders pension and disability plan, giving them greater benefits than those who incur other types of disabilities. Presumptive legislation links a specific occupation with a disease or condition that has been shown to be a hazard associated with that occupation.

After earning his bachelor's degree from Indiana University-Purdue University at Indianapolis, Gary joined the Indianapolis Fire Department and began a career that would end abruptly when he sustained shoulder and back injuries in the line of duty. He and Trish associated what turned out to be typical Parkinson's symptoms with the series of surgeries he was undergoing. For more than two years he visited doctors and therapists, but the symptoms worsened. No one considered PD in an otherwise young and healthy 30-year-old.

When the diagnosis was made, he began his research and found a 1990 study of Houston firefighters documenting 10 times the incidence of PD in firefighters than in the general population. Further research revealed that PD is considered a rare medical disorder and more likely to be the result of "unusual circumstances" such as toxic exposure. Three years earlier, he had led an investigation of a large paint warehouse fire



Gary, left, poses with Rep. Mary Ann Sullivan and Sen. James Merritt after the bill that would allow emergency responders afflicted with PD to be eligible for expanded disability benefits passed both houses on its way to becoming law in Indiana.

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APDA-funded Research at UCLA Ties Toxin Exposure to PD

The mathematical probability of 30-year-old Gary Coons developing Parkinson's disease was 1 in 100,000. Research has shown, however, that toxicity is the probable cause when Parkinson's symptoms develop rapidly after a probable chemical exposure.

Related research at UCLA's School of Public Health is strengthening evidence of the link between exposure to toxins and PD, especially in the younger diagnosed.

The April 15 issue of the American Journal of Epidemiology published the findings of a team of researchers that provided the first evidence that, as in an-

imal models and cell cultures, pesticides trigger a neurodegenerative process that leads to PD in humans.

The research was conducted by Drs. Sadie Costello, Beate Ritz, Xinbo Zhang and Jeff Bronstein, medical director of APDA's Los Angeles Information & Referral Center, with funding support from the National Institute of Environmental Health Science, the National Institute of Neurological Disorders, and the Department of Defense Prostate Cancer Research Program. APDA provided initial funding to Dr. Ritz, which allowed submission of her application to government agencies for more extensive funding. ■

In the Northeast



New Jersey Chapter president Vicki Collier shows how to make a strike against PD

The **New Jersey** Chapter's "Strike Out Parkinson's Bowl-a-thon" attracted 116 bowlers to Caroliner Lanes, North Brunswick, and raised \$5,000 for programs.

In **Pennsylvania**, Olivia Witt of Southampton decided to have a benefit car wash memorializing her grandfather as her high school graduation project. Her mom, Ali, agreed and the Charles R. Reitenbaugh

Car Wash defied threatening skies and ominous weather reports resulting in more than \$800 to support APDA research and programs. "The weather in the morning was drizzling and cloudy, but we decided to go ahead with it anyway," Olivia reported. About an hour into the event, however, the sun came out, thanks to, according to Olivia, a little bit of help from the honoree. Olivia plans to make this an annual event.

In the West

More than 300 people attended the **Washington** Chapter's Magic of Hope dinner and auction at the Madison Renaissance Hotel on May 9, raising more than \$100,000. The event benefits the chapter's taxi vouch-

er program. Among the evening's highlights was the Dessert Dash, which raised \$5,000. Each attending table took a collection and the tables were called to choose their dessert selection in order of the amount contributed.



Not for the "non-caloric, non-cholesterol" crowd

Albuquerque's KOAT-TV has discovered APDA. **New Mexico** Chapter president Ed Payne and member Brian Trembly were interviewed recently as "local faces" with PD in conjunction with a national broadcast on the disease. I&R Center medical director Pirio Richardson, MD, was included in a segment from the MIND Imaging Clinic at the University of New Mexico Hospital.

They'll be flipping pancakes in Northridge, **California** this fall when the San Fernando Valley Regional Chapter has its first "Pancakes for Parkinson's Breakfast" on Oct. 18. Best-selling author Laura Numeroff ("If You Give a Mouse a Cookie," and "If You Give a Pig a Pancake") will be on hand to sign copies of her books. Rumor is that people are going not only for the great breakfast, or the silent auction but also to see if Ms. Numeroff has a pig in tow for pancakes. Details are on the Web site www.valleyparkinsons.org. ■

Walk-a-thons: APDA's Research Effort

Like a rite of spring, each year APDA Chapters, Information & Referral Centers and support groups around the country turn their efforts to walk-a-thons, the organization's official fundraising event dedicated to research support. Historically these grassroots events contribute half a million dollars to scientific research to find the

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Historically APDA's largest walk-a-thon, the 23rd annual APDA Parkinson Walk-a-thon in Boston, attracted more than 1,500 participants and raised more than \$100,000 for scientific research.



The traditional cowboy parade starts the Truth or Consequences, N. Mex. support group walk-a-thon through downtown.

APDA at the Annual Unity Walk

Springtime found APDA well represented at PD events across the country including the 15th Annual Unity Walk in New York City's Central Park, April 25.

The Unity Walk raised more than \$1.5 million, 100 percent of which goes to Parkinson's research. ■



*Chapter presidents and Information & Referral Center coordinators meet at the APDA booth before beginning the walk. **Front row from the left:** New Jersey and New York coordinators, Elizabeth Schaaf and Linda Chin, RN, (Manhattan) and New Jersey Chapter president Vicki Collier; **Second row from the left:** New York coordinators Eileen Gianetti (Old Westbury) and Mary Ellen Hickman RN (Staten Island), executive director Joel Gerstel, and Virginia and Maine Chapter presidents Melissa Johnson (Southwest) and Mary Sontz. Rhode Island coordinator Mary Ellen Thibodeau, RN, didn't make the photo op, but was also an active participant.*

Walk-a-thons: APDA's Research Effort

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cause(s) and cure for Parkinson's disease, and raise awareness in their locales.

"Walks" vary across the country from the traditional strolls around a park to variations on the theme such as Vermont's rock-a-thon, where rocking chairs replace walking shoes and participants have sponsors support the amount of time they rock. ■



The Ls-Rock On team rocked the most in Burlington, Vt. to become the winners of the Vermont Chapter's 2009 Rock-a-thon.



Melissa Johnson, president of the spanking new Southwest Virginia Chapter, led more than 20 enthusiastic members on their first official trip to participate in the Parkinson's walk. The chapter is the third in the Old Dominion State joining groups in Richmond and Virginia Beach. The Rhode Island and Maine chapters were also well represented.

Young Onset Conference Lists Speakers

APDA and the National Parkinson's Foundation will cosponsor a first collaborative young onset conference, Oct. 23-24, in Dallas. Featured speakers will be:

- J. Eric Ahlskog, MD, PhD, "Partnering with your Doctor to Get the Most from Your Medications"
- Laura Marsh, MD, "Not Just a Movement Disorder: Cognitive Issues in PD"
- David Zid "Delay the Disease: Exercise and Parkinson's Disease"
- Samantha Elandary, CCC-SLP "Parkinson's Related Voice Disorders"
- Melinda Hermanns, PhD "Caring and Sharing"

Registration is \$30 and includes a welcome reception, breakfast and lunch. Visit APDA's young onset Web site www.younparkinsons.org for details and registration. ■



Executive Director Joel Gerstel, Tucson Ariz. Coordinator Cynthia Holmes, and Associate Director for Scientific and Medical Affairs Michele Popadyne, are ready to answer the questions of the American Academy of Neurology conference's thousands of participants in Seattle, Wash.

SCIENTIFIC ADVISORY BOARD MEMBERS MAKE NEWS

**Dr. James Bennett, Jr. Named VCU
Neurology Chairman**

James P. Bennett Jr. MD,
PhD

James P. Bennett Jr., MD, PhD has been named chair of the Virginia Commonwealth University's Department of Neurology and the founding director of the Richmond school's Parkinson's Disease and Movement Disorders Multidisciplinary Research and Clinical Center. Dr. Bennett is a member of APDA's Scientific Advisory Board and the fourth recipient of the George C. Cotzias MD Fellowship to attain the rank of chair of a major U.S. medical school.

The Cotzias fellowship is APDA's most prestigious award given to a young neurologist to encourage his pursuit of research.

Dr. Bennett called his appointment, "an opportunity to pursue a shared vision for improving the lives of people with Parkinson's disease."

Before taking the post on July 1, Dr. Bennett was the Arthur and Margaret Ebbert Professor of Medical Science at the University of Virginia, Charlottesville, where his research was responsible for more than \$15 million in National Institutes of Health grants.

As director of the center, Dr. Bennett will lead a team of physicians that works in partnership with the McGuire VA Medical Center's Parkinson's Disease Research, Education and Clinical Center (PADRECC), one of six such multidisciplinary centers in the United States. The new VCU Parkinson's Center will allow PADRECC's clinical care to be extended to the civilian community. ■

**University of Chicago \$1.2 Million
NIH Grant Based on 2009 APDA
Research Funding**

Un Jung Kang, MD

Un Jung Kang, MD, University of Chicago's Associate Chair of Neurology and Director of the Parkinson's Disease and Movement Disorder Center, has reported that research based upon data resulting from APDA funding has resulted in a \$1.2 million grant from the National Institutes of Health over five years.

The university is one of nine APDA Centers for Advanced Research. The others are UCLA, Boston University and Emory University schools of medicine, the University of Virginia Medical Center, Robert Wood Johnson Medical School, Washington University and the Universities of Pittsburgh and Alabama at Birmingham.

"This is a difficult (financial) time, and I appreciate the support that APDA provides the advanced center very much," said Dr. Kang. "The center's funding has been particularly helpful in these lean times." ■

Firefighter Gary Coons' Efforts Result in Country's First PD Presumptive Law *continued from page 5*

and been exposed to paint chemicals and debris from burning metal over a three-day period. The area had been designated "all clear," and he had not used his SCBA (Self-Contained Breathing Apparatus). It was shortly thereafter that his symptoms began to appear.

"I realized that my Parkinson's disease is not a death sentence, but a life sentence and I must stay active," he said, and has done just that.

Gary founded "Firefighters with Parkinson's Disease," an organization and Web site to educate firefighters and public servants on the dangers of emergency response and to raise funds for research. His efforts on

behalf of emergency responders got the attention of Rep. Sullivan and Sen. Merritt, who shepherded bills through their respective houses, culminating with the new law.

Now that the law has been enacted, Gary has not given up his efforts on behalf of fire safety and education. As the elected trustee of Perry Township, he has guided a tax-cutting merger of the township and Indianapolis fire departments, and is a candidate for the chief planner position for the 2012 Super Bowl.

It is not surprising that Gary Coons has been named one of Indiana's Best and Brightest for two consecutive years – and he's only 35! ■

Train-the-Trainer Program at Boston University

With support from the American Parkinson Disease Association, Inc., an interdisciplinary team from Boston University (BU) and Boston Medical Center hosted its third annual seminar for Healthcare Professionals in March. Participants from New England and beyond attended this 2 ½ day intensive training course to improve their knowledge in the interdisciplinary management of people with Parkinson's disease (PD). Experts in the area of PD presented cutting-edge information on a variety of topics including the effectiveness of rehabilitation, pharmacological management of motor and non-motor symptoms, nutrition, communication and social interaction.

The role of exercise in the management of PD was highlighted by Terry Ellis, PhD, PT, a clinical associate professor at BU. The need for "chronic" exercise programs to manage a chronic condition is gaining support from studies investigating the effectiveness of exercise for people with PD. To provide greater access to exercise programs, the BU team has developed Community Wellness Programs for people with PD. These programs consist of exercises and strategies specifically designed to improve quality of life, mobility and communication in people with PD. Tami Rork DeAngelis, PT, MS, GCS, a physical therapist at the Center for Neurorehabilitation at BU, instructed participants how to implement community wellness programs when they return to their local facilities. "Exercise is an important part of managing PD over the long-term," says Marie Saint-Hilaire, MD, Director of the APDA Center for Advanced Research at BU Medical Center. Cathi Thomas, RN, MS and Coordinator of the APDA Information and Referral Center at BU Medical Center says the goal of the seminar is for participants to bring their new knowledge back to their local communities so that people with PD have more access to expertise and programs to help meet their needs. ■

ANTI-PARKINSON MEDICATIONS INTAKE

A large multicenter study was conducted in Europe, as reported in Vol. 24 of Movement Disorders, to assess medicine-taking habits by Parkinson's patients.

This was a four-week study covering 112 patients in five countries with a disease duration of 7.7 years.

The results can be summarized as follows:

Adherence (doses taken/doses prescribed) **97.7%**

Days Adherence (correct dose days) **86.7%**

Time Adherence (doses taken at correct time) **24.4%**

Fourteen patients (12%) took less than 80% of prescribed doses (suboptimal adherence).

The motor score was significantly higher in patients with suboptimal adherence than in those with satisfactory adherence (29 versus 19).

Drugs prescribed once daily had significantly better adherence when compared with drugs prescribed more frequently. Suboptimal therapy adherence is associated with significant deviation from prescribed levodopa doses, despite greater Parkinson's motor severity. Optimizing oral medication intake has a potential role in maximizing the therapy response in Parkinson's disease. ■

BILLIONS FOR HEALTH CARE TECHNOLOGY

According to the AAN News, May 2009 issue, the new administration in Washington is taking a strong approach to reform healthcare technology in the United States. As part of the larger economic stimulus package passed in February, \$19 billion has been set aside to support the ambitions of Health Information Technology for Economic and Clinical Health (HITECH) Act. Of that amount, \$17 billion will provide incentives to physicians to acquire and use electronic health records and other technology systems. Another \$2 billion will be used at the discretion of the Department of Health and Human Services for standards development, grants, telemedicine, and other improvements.

The goals of the HITECH Act are to expand the standards set by the Certification Commission for Healthcare Information technology and enforce interoperability among the systems and users, ultimately saving the government \$12 billion, maximizing efficiencies, reducing physician costs, and, ultimately, producing savings for consumers. ■

CAREGIVERS and PARKINSON'S DISEASE

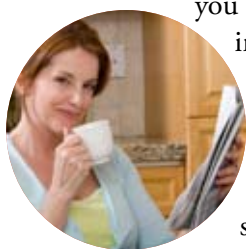
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Caregivers! Between doctor's appointments, therapies and the day-to-day rigors of living with Parkinson's, there is always that person or those people by your side. Your day wouldn't be complete without their faces, and I know you are thankful for their presence in your life, so I am going to "talk" to them!

The caregiver wears many different hats, which can change throughout the years. In the beginning their role can be the cheerleader, the "taxi" driver or the banker. However, as Parkinson's progresses, the caregiver typically takes on more physical roles. Studies have shown that caregivers themselves can become emotionally distressed and are at an increased risk of becoming physically ill. This isn't because they don't love to care for the person – it's simply because they are so busy caring for their loved one that they sometimes forget to take care of themselves! Talk about selfless! The following are some tips to help take care of yourself, while you are taking care of someone else:

HOW TO TAKE CARE OF YOURSELF

1. Try to Identify The Sources of Stress



Being a caregiver can be stressful at times, and you need to be able to recognize warning signs of stress early on before you become overwhelmed. Problems sleeping, increasing forgetfulness, and/or irritability can all be signs you are becoming stressed. If you notice these signs, try to identify the source. Do you have too many things to do? Do you feel you have no control over your life? Once you identified the source, take action at reducing stress by doing something you enjoy. Exercising, reading and yoga are all good ways to have fun and decrease stress at the same time! Also, you can consider using an adult day center where you

can leave your loved one supervised while you spend time by yourself, go out with friends or simply get that grocery shopping done!

2. Plan Ahead

It is very easy to fall into a daily routine, and a lot of times this is exactly what the individual with Parkinson's needs. However, this can become monotonous for a caregiver. It's never a bad idea to schedule future plans to take care of you. Just like you schedule an appointment for a check-up with your physician, you should schedule time to do something you enjoy. You can also schedule time for other people to help you with caregiving in order to give you a break.



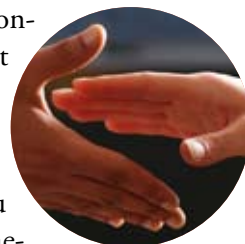
3. Communication

Communicating properly can help to prevent future stress and conflicts. Using "I" instead of "you" can help prevent conflict. For example, saying, "I feel depressed" instead of "You made me depressed," can help prevent people from becoming defensive because they feel like they are being blamed. Also, be clear and direct when speaking. Try to avoid hinting. This will prevent people from guessing what you need, thus preventing future conflicts. Most importantly, always be a good listener.

4. Getting Help

Don't wait until you are exhausted to ask for help. There are many resources available such as community, friends, family, professionals, etc. The following resource list contains just a few of the outside sources of help, or offer a place to start when looking at options.

Prepare a list of things you need help with, so that when some-



one asks how they can help, you can just look at your list. When asking for help remember to be direct and use. “I” For example, “I would like to go for a walk, could you watch grandpa for 30 minutes?” instead of “It would be nice if someone could watch grandpa for 30 minutes.” Remember, although people may see you caregiving, they may not realize that you need help. Never be afraid to ask for help!

5. *Talking to a Professional*

It is important to talk to your physician about any changes in your own health. Mental health professionals are also a great resource for those who are overwhelmed. Don't forget you can also talk to your pharmacist about any changes in your health. A pharmacist can look at your medication list to ensure these changes are not caused by your medications. Certain medications can cause anxiety, confusion, or even a chronic, dry cough.



You may have heard people talk about “caregiver burnout”—this is typically used to describe the caregiver who has become physically, emotionally or mentally exhausted. Again, this isn't a reflection of the person he/she is caring for.

Most of the time it's a reflection of the caregiver simply not paying enough attention to his/her own health. It's important to note that not everyone who is a caregiver will feel burnout. Some

of the signs include:

- Increase or decrease in appetite
- Feeling of hopelessness, lack of energy, or depressed mood
- Sleeping too much or too little
- Difficulty concentrating
- Change from a positive caregiver to an unconcerned caregiver
- Thoughts of death
- Increased alcohol and medication such as sleeping pills, pain pills, etc use

As you can tell, “burnout” is very serious, and requires medical attention. If you, or a caregiver you know, starts to exhibit these symptoms, it's important to intervene as gently and quickly as possible. Caregivers are SO important to the health and quality of life for people with Parkinson's. If you are not the primary caregiver, but know someone who is, it never hurts to ask what you can do to help. Many times just knowing there is someone who can be called on for help can be a big relief. Even little things like buying a gallon of milk on your way to visit can have a huge impact! ■

Web-Based Resources for Caregivers

American Parkinson's Disease Association at www.apdaparkinson.org

Empowering Caregivers at www.care-givers.com

Family Caregiver Alliance at www.caregiver.org

Family Caregiver Support Network (FCSN) at www.caregiversupportnetwork.org

National Family Caregivers Association at www.nfcacares.org

National Parkinson's Foundation at www.parkinson.org

Parkinson's Disease Caregiver Information at www.myparkinsons.org

Well Spouse Organization at www.wellspouse.org

EXTENDED RELEASE MIRAPEX

At the American Academy of Neurology's annual meeting it was announced that in early Parkinson's patients Mirapex® extended release once-daily formulation was superior to placebo and comparable to three-daily administration of the immediate release formulation.

In a double-blind, 18-week evaluation of the once-daily dopamine agonist pramipexole extended-release (ER) was compared to both the pramipexole immediate-release (IR) formulation administered three times daily and to the placebo in 259 patients.

In early Parkinson's disease pramipexole ER was found to be superior (8.1) to placebo (5.1) and to have comparable efficacy (8.4) to pramipexole IR, according to the primary end-point of change in the Unified Parkinson's Disease Rating Scale. In a longer-term study, the efficacy of the ER formulation was maintained between 18 and 33 weeks.

In a switching study in early Parkinson's disease in which patients were monitored prior to and after switching from pramipexole IR to pramipexole ER, the majority of patients (85.5%) switched successfully from one formulation to another. ■

Educational Material

Most APDA publications can be downloaded free from our Web site, www.apdaparkinson.org, publications page.

The new APDA e-newsletter provides timely news about all aspects of PD and a helpful "Tip of the Month." The newsletter is free, and you can unsubscribe any time. Sign up on APDA Web site's home page.

Single copies of the following publications may be obtained free of charge by writing to the national APDA office or by calling 1-800-223-2732, faxing to 1-718-981-4399, or contacting any of the APDA Information and Referral Centers throughout the United States.



BOOKLETS

1. **Parkinson's Disease Handbook** (English, German, Italian, Spanish)
2. **Young Parkinson's Handbook** (English)
3. **Be Active** (English)
4. **Be Independant** (English)
5. **Speaking Effectively** (English)
6. **Good Nutrition** (English)
7. **Aquatic Exercise for Parkinson's Disease** (English)
8. **My Mommy Has PD...But It's Okay!** (English)

SUPPLEMENTS

- **The Family Unit**
- **Hospitalization of a Parkinson's Patient**
- **Fatigue in PD**
- **Healthy Aging**
- **Keys for Caregiving**
- **Neuro-ophthalmology and PD**
- **Medical Management of PD and Medications Approved for Use in the USA**
- **Depression and PD**

WEB SITES

- www.apdaparkinson.org
- www.youngparkinsons.org
- www.apdawest.org
- www.wpda.org

BROCHURES

- A. **Basic Information** (English, Spanish, Chinese)
- B. **Medications to Be Avoided or Used with Caution in PD**
- C. **How to Start a Support Group** (English)
- D. **National Young Onset Center** (English)

DVD

- **Managing Parkinson's Straight Talk and Honest Hope, 2nd Edition**

Materials concerning research in the field of Parkinson's disease, and answers to reader's questions are solely for the information of the reader and should not be used for treatment purposes, but rather as a source for discussion with the patient's health provider.