

# Parkinson's Perspective



## Letter from the Medical Director

I learned long ago that Parkinson's disease does not affect just the patient. The importance of the caregiver was brought home to me many years ago when I cared for an elderly gentleman with advanced Parkinson's disease. Both he and his wife were "difficult historians," meaning it was very hard for them to tell me exactly what was going on with his disease.

We admitted the patient to the hospital for our all-day Parkinson evaluation and medication adjustments. Specially trained physical therapists evaluated the patient on an hourly basis throughout the day. We were able to determine exactly how he was responding to the medications, which allowed us to tailor them to his needs. As a result, the patient did much better and was discharged home.

I followed up with a phone call a week later. I was proud of our ability to help him. When I asked how the patient was doing, his wife replied, "Terrible." Quite shocked, I said I would call back. A week later, she again said the patient was terrible. When I asked what was wrong, she said, "He wants to do everything, and he is driving me crazy."

What to do? We were able to get the couple help to come into the home, which resolved the problem. But what if we had been unable to get someone to help the patient's wife? Would we have had to lower his medication, so his increased Parkinson symptoms would slow him down, and his wife could get some rest?

This issue of *Parkinson's Perspective* is devoted to the caregiver. Often, the caregiver is critical to the well-being of the patient. Consequently, the well being of the caregiver is critical as well. In addition to the sheer physical exhaustion that can come from providing care, the caregiver is prone to many other complications. Indeed, a caregiver syndrome is now recognized; caregiver "burnout" is a real danger.

Caregiver burnout is particularly difficult when the caregiver is a family member. On one hand, family members feel a responsibility toward the loved one, but at the same time they may have resentments about the burden that responsibility creates. This is a natural reaction, but if it goes unaddressed, it can cause a great deal of suffering.

How to deal with caregiver syndrome? The first step is to recognize its existence and then to gain knowledge and support to deal with it. Second, share the emotional burden with others. Caregiver support groups can help. Finally, the caregiver should talk with the physician or healthcare professional. Often, misunderstandings or pessimism can unduly worsen the problems.

A handwritten signature in black ink that reads 'Erwin B. Montgomery, Jr.'.

Erwin B. Montgomery, Jr., M.D.  
Medical Director, APDA Information and Referral Center  
University of Wisconsin-Madison

## FROM THE EDITOR

Caregiving can be a stressful job that no one really signs up for. It's a job that you take on when a loved one is diagnosed with a disease that may eventually leave them unable to do certain things. I know it's not an easy task, and I applaud all caregivers. I know this is something most caregivers never thought they would do, but they are doing it because they love the person they are caring for and don't want to give up.

In this issue, we are publishing the stories of a few caregivers, with the hopes that their words will help others in similar situations. We also hope readers will take advantage of the resources and services listed, designed to help caregivers cope with their own stress and take care of themselves.

—Jessica Hahn, Coordinator  
APDA Information and Referral Center

### Here to Serve You!

The American Parkinson Disease Association Information and Referral Center is here to serve you. We have a wealth of information: books from APDA that are available free of charge, a list of Wisconsin support groups, a list of neurologists who specialize in Parkinson's disease, and any information you are looking for about Parkinson's disease. Our mission is "to ease the burden, to find the cure," and that is what we want to do: ease as much of the burden as we can for you. Please contact Jessica Hahn at 608/263-7991 or [parkinsons@neurology.wisc.edu](mailto:parkinsons@neurology.wisc.edu) for more information.

# Caregiving and Parkinson's Disease

## What are some basic things I need to know when helping someone who has PD (Parkinson's disease)?

An individual who has PD and who is on medication will have "on" and "off" times.

**"On" time** is when the individual's medications are working and the person is functioning fairly normally.

**"On with dyskinesia"** is when an individual is mobile but has dyskinesia that may interfere with quality of life.

**"Off" time** is when medications are not working optimally. The individual and the caregiver will need to adjust actions and surroundings to accommodate the person with PD.

There are blank diaries that help you keep track of how PD symptoms reappear after each dose of medicine, so you can report it to the doctor. This information is an important tool to help the doctor adjust medication for optimal disease management.

## What shouldn't I do when assisting a person with PD?

Do not assume that a Parkinson's patient is not listening to you if his or her face remains expressionless and unresponsive. A "flat face" or "mask-like face" can be part of the disease.

Do not assume that a Parkinson's patient is being uncooperative or not paying attention if he or she is slow to follow instructions or to start an activity. This slowness of the thought process and action is part of the disease.

Do not tell a Parkinson's patient to "hurry," because it might slow him or her down.

## What about mealtime?

Because of the varying effect of medication, Parkinson's patients are not always consistent in their ability to do the simplest things. When the medication is working, they may be able to feed themselves. However, if they are unable to feed themselves at the next meal, they are not being uncooperative. This is part of the disease. Patients may be able to do many activities when their medication is working—or "on"—but may not be able to do the very same things when their medication is not working—or "off."

Plan all the important activities—eating, outings, social events—for when the patient is "on."

Always give PD medications on time and at regular intervals. Be consistent. Many people who are on carbidopa/levodopa need to take their medication 30 minutes or an hour before meals or two hours after meals to get the best benefit from the medication. Follow the doctor's orders strictly about timing medication around meals.

## At what point should I ask for outside assistance?

This is one of the most important decisions that can be made about caregiving. Communication with the patient will be key in deciding when it is time to call upon outside help. Do not be embarrassed to ask for help from family, friends, or a professional agency. Outside assistance can come in many variations, from basic cooking and cleaning to in-home nursing.

## Where can I find outside resources?

Agencies that provide live-in and hourly care can be found throughout Wisconsin. For a list of resources, contact the Information and Referral Office: 608/263-7991.

## What about me?

Do not forget to care for the caregiver. Make sure you make time for yourself by taking breaks and pursuing your own life, hobbies, and interests. By taking care of yourself, you will provide the best care for a person with Parkinson's disease.

## What if I need more information about caregiving?

Educational materials are available from the APDA:

"Caring for the Caregiver," APDA Education Supplement #4.

*Compiled by Sylinda Lee with the APDA Information and Referral Center in Utah.*

## Taking Care of YOU: Powerful Tools for Caregiving

It is not unusual for a caregiver to feel overwhelmed, whether you are a beginning caregiver or have been caregiving for awhile, but help is available.

Powerful Tools, sponsored by the Wisconsin Alliance for Family Caregiving and Mather LifeWays, is a program to help caregivers reduce stress, guilt, anger, and depression. It also provides information on caregiving transitions, how to make tough decisions, and how to communicate effectively with family members, medical professionals, and paid help.

Classes are held throughout the state. To find out if a class is being offered in your area, check out [www.uwex.edu/ces/flp/caregiving/education/powerfultools/index.cfm](http://www.uwex.edu/ces/flp/caregiving/education/powerfultools/index.cfm), or contact Jessica at 608-263-7991, who can help you locate a class.

## Wisconsin Family Caregiver Support Program (WFCSP)

A new Web site and toll-free phone number have been established to help family members or friends find resources and services in their local area or elsewhere in Wisconsin. The WFCSP provides supportive services for friends or family who provide care for someone 60 years old and older, or an individual with Alzheimer's disease and related disorders regardless of age. Go to [www.wisconsin-caregiver.org](http://www.wisconsin-caregiver.org) or call **1-866-843-9810**. Please connect with this program if you are looking for assistance, respite, or support.

# Caregiving: Recognizing Signs of Burnout

Caregiver burnout is not something to be ashamed of or deny. Most parents have suffered burnout, either by endlessly walking the floors when a newborn has colic or nightly pacing the floors when a teenager starts dating or driving. Burnout is even more common when you are caring for a loved one who is sick. In most cases, caregiver burnout occurs because the caregiver is trying to do too much or because he or she is trying to do everything alone.

## Common symptoms of caregiver burnout include but are not limited to the following:

- Extreme fatigue or exhaustion
- Feelings of helplessness
- Changes in eating or sleeping habits
- Loss of interest in family, friends, or activities
- Irritability or anger
- Anxiety or depression
- Guilt

Caregivers are often so busy taking care of others that they neglect their own needs. The physical and emotional demands placed on caregivers affect their mind, body, and spirit. The Cleveland Clinic has identified several factors that may lead to caregiver burnout. These are:

- 1. Role Confusion:** Many people are confused when thrust into the role of caregiver. It can be difficult for a person to separate his/her role as caregiver from his/her role as spouse, lover, child, and/or friend.
- 2. Unrealistic Expectations:** Many caregivers expect their involvement to have a positive effect on the health and happiness of the patient. This may be unrealistic for patients suffering from a progressive disease, such as Parkinson's or Alzheimer's.
- 3. Lack of Control:** Many caregivers become frustrated by lack of money, resources, and skills to effectively plan, manage, and organize their loved one's care.
- 4. Unreasonable Demands:** Some caregivers place unreasonable burdens upon themselves in part because they see providing care as their exclusive responsibility. Or, some family members—such as siblings, adult children, or the patient himself/herself—may disregard their own responsibilities and place burdens on the person identified as primary caregiver.
- 5. Other Factors:** Many caregivers cannot recognize when they are suffering burnout and eventually get to the point where they cannot function effectively.

If you are a caregiver, here are some simple, effective suggestions that could keep you from falling into the trap of caregiver burnout.

- **Find a confidant to talk to:** It is best not to choose a family member. Rather, choose a coworker, friend, or neighbor whom you can trust to share your innermost feelings and

frustrations with. Use that person often.

- **Realize that you are not a superhuman:** There are truly limitations to what you are capable of doing. Do not expect to do more than what you can do; do not let others put pressure on you to do more than that.
- **Take care of yourself:** This should not be seen as a luxury but rather as a necessity. If caregivers do not take care of themselves, then they may soon need a caregiver of their own. Appointed caregivers have ended up with strokes, heart attacks, and have even died from not taking care of themselves. Remember what the flight attendant says about your oxygen mask if something happens during a flight: "Put your mask on first before helping someone else with theirs." Taking care of yourself means following a balanced diet, making time for daily exercise, and getting enough rest.
- **Take advantage of friends, coworkers, family members, and anyone else who offers to help:** As a matter of fact, don't just take advantage, but be prepared to have a specific job for that person to do when he or she offers to help. This could be anything from cleaning out the gutters, to sitting with the person you take care of so you can have your hair done, to preparing a casserole so you have something in the freezer when you are too tired to cook. Remember: if they did not want to help, they would not have offered. If they offered and really didn't want to help, then they will probably never offer again, but that is OK too.
- **Look for respite care services:** This can be for a few hours or even a few days. We all need to take a vacation from our every day activities.
- **Don't be afraid to consult a professional:** It is normal to reach a point where you are overburdened. Many caregivers rely on medication, at least for a short period of time, to help "get them over the hump."

Please don't become burned out from taking care of someone. Take care of yourself so that you can have a long, healthy life.

*This article is reprinted with permission from the Tulip Messenger, West Texas Parkinsonism Society Chapter Newsletter.*

## Caregiver Training

Catholic Charities offers classes to help you learn how to care for someone. The classes focus on the practical skills needed to deliver care safely, for you and your care recipient. The six-hour class is offered on an ongoing basis. Classes are held on the near west side of Madison. Call Jean Mueller at 608/833-4800 for more information.

# Parkinson's Disease, Part Two

Parkinson's disease affects not only the person with Parkinson's disease but also the caregiver. Taking care of another person, or being a support system, can take a toll on the caregiver. This has been described as "caregiver syndrome," and there are four symptoms associated with this condition: depression, anxiety, anger, and declining health.

Many caregivers don't realize when something is wrong. They are so involved with taking care of their loved one that they neglect themselves. It's important that family and friends are able to recognize signs of depression, anxiety, anger, or declining health in a caregiver. The American Academy of Family Physicians and the National Center on Caregiving recommend that every caregiver be examined by a doctor for stress and depression. Once a person recognizes there is a problem, she or he can start receiving treatment.

The death rate of affected, untreated caregivers is greater than for non-caregivers. The *Journal of the American Medical Association* published a study by Richard Schulz and Scott Beach (University of Pittsburgh), that stated that elderly caregivers are at a 63 percent higher risk of mortality than non-caregivers in the same age group. A decline in that percentage could be achieved by creating awareness.

Acknowledging and accepting that one has caregiver syndrome is the first step. Treatment options include medication for anxiety and/or depression, talking to a counselor or therapist, joining a caregiver support group, and/or building a social network of people to help when needed. Every caregiver needs to be aware of this syndrome, know what to look for, and take action if symptoms are present.

## There are ways to prevent caregiver syndrome. Some of the things you can do for yourself are:

- Find someone to be with your family member (respite for the caregiver) so you can take some time for yourself. There are many adult day centers, or you can hire a home-care worker to come into your home while you go out for a while.
- Join a support group for caregivers. It helps to talk about your feelings with others who are experiencing similar things and have a network of others who know what you are going through.
- Contact an agency that works with elderly and disabled persons. Don't be afraid to ask for help, and if someone offers to help, take him or her up on it.
- Make a list of things people can do for you when they offer to help, such as making dinner, shoveling snow, cutting the grass, cleaning the house, trimming the shrubs, raking leaves, watching your loved one while you go shopping, changing that burnt-out light bulb, fixing anything that is broken, etc. Share The Care ([www.sharethecare.org](http://www.sharethecare.org)) is a wonderful resource that organizes friends, family, coworkers, faith community, and others who want to help.

Your health is important; it's crucial to take care of yourself.

To receive specific caregiver information for your county, please check out [www.wisconsinicaregiver.org](http://www.wisconsinicaregiver.org).

# Labor of Love

I'm his caretaker . . . and never thought I would be in this position. I married him almost 25 years ago. A big guy, who would start the day about 6 a.m. and still be like the Energizer Bunny at 10 p.m. We worked, we played, had twin girls, had ups, had lots of downs, but there was nothing, I mean nothing, that could have prepared either of us for this.

We were coming into the time of life that was meant to be ours. Enjoying the freedoms of being middle aged, spoiling our wonderful grandkids, traveling when we felt like it, and starting to look forward to our well-deserved retirement. Stop right there. He is retired but was forced by Parkinson's to do so. I continue to work full time in advertising sales; I love my work, but the stress levels can get intense.

Fast-forward to a "normal day." Help my 6'2" husband find his walker and crawl out of bed. He is so tight and stiff, it hurts me to watch him move. He makes it to the bathroom and then to the kitchen. All this takes incredible effort. Pretty soon, the meds kick in, and it gets a little better. Not easy, just a little better. I run off to work, but I'm always thinking about what is going on at home. My daughter has moved back in, which has made it easier, but, at 22, she has her life, too.

The Parkinson's is bad enough, but my husband has the early-onset dementia to go with it. His confusion, depression, lack of expression, and general loss of joy in life leaves me with feelings of loss, grief, anger, guilt, and extreme frustration. I know I need to take care of myself, so I can take better care of him. But, some days, between work; making time for my older children, grandkids, my mother; and taking care of all the things that have to be taken care of . . . I feel like I'm running on empty. Caretaking isn't always a labor of love, sometimes it just seems like labor.

## Mentor Program

Being newly diagnosed with Parkinson's disease can be frightening and confusing for the person with Parkinson's disease as well as the caregiver. We are starting a mentor program to pair individuals up to talk with others who have the disease, as well as their caregivers. If you would like to be a mentor, please contact Jessica at 608/263-7991 or [parkinsons@neurology.wisc.edu](mailto:parkinsons@neurology.wisc.edu).

# The Caregiving Life of Tim Martinson

Caregiving sucks, and so does Parkinson's disease. It is something I didn't think about when I signed that lifelong contract of marriage. On the other hand, Parkinson's wasn't in my wife's life contract either.

Caregiving has been an adventure of many sorts. It has been, at times, economically and psychologically challenging.

We don't know when Parkinson's entered our lives. It was first noticeable sometime before 1997. It was diagnosed 2 to 3 years later and started changing the way we live. By 2003 Linda was in a wheelchair whenever we had an outing. Her stability was affected more than tremors. She would fall down several times a day. She would call me at work several times a day, and it wasn't unusual for me to come home to straighten things out and settle her down. She needed help with many things—her pills would get messed up, the sheets were too heavy, it felt like she needed to go to the bathroom often but didn't really need to, she would get events mixed up, and on and on.

Juggling the need to be there for her and going to work got to be too much. In January 2004, I retired early for my age to be with her. Doctor appointments seemed to be weekly. Not enabling her is a hard thing to do. (Enabling is doing and helping too much with things the patients should do themselves.) It is sometimes much easier for caregivers to just give in and do the little things themselves instead of enduring the pain of watching loved ones struggle. (Little things like buttoning clothes, putting on the seat belt, tying shoes, and folding laundry. I'm not all bad; I helped with these things often.) The worst thing at this point is her anxiety and soft speech mixed with my poor hearing from running heavy equipment all my life.

In the summer and fall of 2004, my wife had DBS (deep brain stimulation) surgery. This has changed our lives tremendously for the better. Very seldom do we need the wheelchair any more. The need for Parkinson's drugs has been reduced, which has reduced some of the side effects of the drugs. Life is a little easier again. With the ability for Linda to contact me by cell phone, I have been able to take on a part-time maintenance job not too far from home, which gives her the secure feeling that I can be home in minutes if need be. My employer (Mennenga Tax and Financial—great people and place) has allowed me to have very flexible hours and has been very considerate of the situation.

I still do most of the housework, like cleaning, dishes, laundry, cooking, and shopping. (It might not be ideal, but it's clean enough. We don't have mice and insects as regular houseguests!)

Some important things to remember: take time for yourself (work is my way of getting away); back off when things get overwhelming; lean on and use your friends if needed; find support groups that can offer many kinds of help; remember that the person with Parkinson's has to interact with others (they need more than just their caregiver).

Don't let me mislead you with the first sentence of this article. Linda and I still love each other. (We just renewed our marriage vows after 25 years.) We will be—or maybe already have been by the time you read this—going on a Caribbean cruise this winter. Caregiving and Parkinson's suck but not so bad we that we can't at least try to enjoy life.

Life goes on. It would be boring if we all knew what lies ahead.

*Peace, Tim*

# Diary of a Mad Caregiver

It was difficult to accept the fact that I am a caregiver. It took a while, because my husband can still do many things in spite of Parkinson's disease, and he takes care of his own personal needs. But, my role has expanded in the years since his diagnosis. A big concern I have is how I will deal with the situation as the disease progresses and my role as a caregiver becomes more demanding. Am I up to the task?

I know a caregiver must take care of herself, and I enforce that with others, but sometimes it's hard to follow my own advice. I do take advantage of support tools available through the Wisconsin Chapter of the APDA and the caregivers' groups. There's an abundance of information resources on Parkinson's and related health issues that we've taken advantage of, and I encourage others to do the same.

We've learned not to be too proud to accept help when offered by family and friends. We're blessed to have wonderful friends who are there when we need them, whether it's to do

a fix-it job around the house, go out for coffee, go fishing, or just listen.

We also educate people about the disease and have found most people don't know much about Parkinson's and related health issues. So, we share what we know to help them understand what's going on.

Let me tell you, the "mad" in the title can refer to anger or mental state, depending on the day. Writing this helped, because it allowed me to express my feelings. It released some of the emotions and reminded me to look at the overall picture and realize what's worth getting aggravated about.

My husband and I take it one day at a time. We don't have a choice in the matter, so we have to deal with it the best we can. Some days are better than others. We're partners, and we're in this for better or for worse.

*Anonymous*

## Greetings

This issue of the newsletter is focused primarily on caregivers, and the Wisconsin Chapter APDA takes this opportunity to thank the caregivers of those who are living with Parkinson's disease. The caregiver—family, friend, partner, or neighbor, whoever you are—is one of the most important elements in the care cycle, and you have to take care of yourself if you're going to continue to fulfill this critical role.

A caregivers' support group meets the second Tuesday of each month at 4 p.m. at 4142 Monona Drive in Monona and is a valuable source of ideas. It's very helpful to have a forum in which to talk about issues and voice your feelings.

We also encourage caregivers to become involved with the chapter as we work to fulfill our mission of easing the burden for Parkinson's patients, families, and caregivers. Meetings are held the second Wednesday of the month at 5:30 p.m. at the UW Hospital and Clinics Neurology Library (600 Highland Avenue, H6/581 CSC). A membership application form is on the next page of this newsletter.

Contact Jessica (608/263-7991 or [parkinsons@neurology.wisc.edu](mailto:parkinsons@neurology.wisc.edu)) or Pam (608/838-8395 or [secretary@wichapterapda.org](mailto:secretary@wichapterapda.org)) for more information.

## Wisconsin Chapter APDA Third Annual Walk-a-thon Sunday, April 6; East Towne Mall, Madison

Walk to raise awareness of Parkinson's disease and raise money for research!

- \$5 per person or \$20 per family
- Registration form at [www.wichapterapda.org/registration](http://www.wichapterapda.org/registration). Advance registrations encouraged.
- Raffle to include autographed Packers football and Badger basketball, Chula Vista Package, and Trek bike
- Appearance by Bucky Badger; face painting; High Energy Mobile DJ Service

Contact Lindsey (608/843-7696 or [lacarlstrom@gmail.com](mailto:lacarlstrom@gmail.com)) or Jessica (608/263-7991 or [parkinsons@neurology.wisc.edu](mailto:parkinsons@neurology.wisc.edu)).

## Lewy Who?

There's an unwelcome member of the Parkinson's community that you may not be familiar with: Lewy body dementia, or LBD, a progressive brain disease that is frequently misdiagnosed. Over 50 percent of Parkinson's patients develop "Parkinson's disease dementia," which is a Lewy body dementia.

Lewy body dementia is the second leading cause of degenerative dementia in the elderly and accounts for up to 20 percent of all dementia cases in the U.S. The symptoms vary from person to person and can mimic other diseases. It's not uncommon for people with LBD to be diagnosed with Alzheimer's, Parkinson's, or similar brain diseases.

Dementia is the central feature of LBD and is accompanied by fluctuating cognition, recurrent visual hallucinations, and/or parkinsonism. Other features that may suggest Lewy body disease are REM sleep behavior disorder, severe sensitivity to certain neuroleptics (medications to treat psychiatric symptoms), or abnormal results on certain brain scans.

Early diagnosis and treatment are important. Parkinson's patients, family members, or caregivers who suspect Lewy body disease are urged to raise the issue with their movement disorders specialist, neurologist, or primary care provider.

The Lewy Body Dementia Association (LBDA) was established by a group of LBD-affected families and caregivers to increase knowledge, share experience, and build hope for others impacted by this horrible disease. The LBD Caregivers' Helpline can be reached at 800-539-9767 or [support@lbda.org](mailto:support@lbda.org). Helpline responders have experience in caring for someone with Lewy body dementia and can provide information and resources.

The Wisconsin Chapter APDA will work to raise awareness of Lewy body disease. To talk about LBD or for more information, contact Pam at 608/ 838-8395 or [secretary@wichapterapda.org](mailto:secretary@wichapterapda.org).

Source: Lewy Body Dementia Association, Inc., LBDA, P.O. Box 451429, Atlanta, GA 31145-9429; [lbda@lbda.org](mailto:lbda@lbda.org); [www.lewybodydementia.org](http://www.lewybodydementia.org).

## Make the Most of Your Brain

Dad was a giver his entire life. He gave money and his time. He drove his truck around the country with a donor sticker on his driver's license. Dad donated blood until he was told, "You are too old." His Living Will specifically stated his request, "I wish to donate any organs and tissue."

But the gift he gave when he died is most inspiring. Dad left us last June, giving his brain tissue to Parkinson's researchers all over the globe. Researchers from Minnesota to Italy, trying to help people with Parkinson's, are studying his brain tissue today.

Dad is helping people he never met, doing his best to help fight the disease. His gift is beyond priceless and is critical in finding the cure.

But, locating a place to carry out his wish was difficult. Running into erroneous and conflicting information almost stopped me cold. As Dad lay in bed during the last few days, I kept trying. At last, I found the Brain Endowment Bank, and my search ended.

The endowment bank's process was clear, concise, and handled in a caring and understanding way. The 20-minute procedure did not affect the visitation or funeral. There was no cost to the family.

According to Dr. Mash, the bank's director, "The most significant discoveries come from the study of the human brain in health and disease. One brain can provide many scientists in academia and industry with specimens for their studies. We have learned more about the human brain in the last 20 years than throughout all of human history."

Dad's wish was to die with dignity, and I believe his gift to others gave him much more. For more information, contact **gdavies@charter.net**. For more information on the UW/VA Brain Bank, please contact Marty Hanfeld at 608/256-1901, ext. 11767.

Source: Brain Endowment Bank, University of Miami, Miller School of Medicine; www.brainendowmentbank.org; http://brainbank.med.miami.edu/; or 1-800-862-7246.

## Don't Let Parkinson's Win

*This excerpt from a letter from a chapter member is shared in the spirit of hope and perseverance.*

We had 53 years of a happy marriage, sharing 30 of those years with Parkinson's. He was diagnosed at age 45, and we had five children, ages 24, 22, 20, 18, and 3 years old. We accepted Parkinson's, and he didn't let Parkinson's define his life, he defined his own life.

We were able to share in our children's graduations. They all married and they gave us 8 grandchildren so far. All the kids were home for Dad when God was calling him home. It gave me so much strength to hear these kids express to Dad and thank him for showing them how to live their lives when some of the roads get rough on your life journey. Dad died at home, just as we had planned, and I was with him at the end."

## Stricker Gift

As reported in the Winter 2007 Chapter News, Greg Kopan competed in the September 2007 Ford Ironman Wisconsin

Triathlon and selected the Wisconsin Chapter APDA to benefit from the event's charitable factor in honor of his brother-in-law, Dale Carlstrom. Kopan's fundraising efforts resulted in over \$5,000 to the chapter, and his determination in the event spurred an additional \$10,000 from Steve Stricker, PGA golfer.

Stricker's contribution is a portion of the charitable proceeds generated from the 2007 Presidents Cup at The Royal Montreal Golf Club in Montreal, Quebec, Canada, which Stricker participated in as a member of the victorious U.S. Team.

The Presidents Cup is a unique golf event in that there is no purse or prize money. Players are not personally paid for their participation, but each competitor is allowed to allocate funds to chosen charitable causes. Stricker, who competed on the U.S. Team for the first time since 1996 and scored three points for U.S. Team Captain Jack Nicklaus, designated the Wisconsin Chapter APDA to receive his contribution.

Thank you, Steve Stricker!

## Support Groups

The chapter sponsors eight support groups in Baraboo, Fitchburg, Madison (3), Stoughton, Sun Prairie, and Waunakee. The Madison groups include one for caregivers and one for young Parkinson's. There has been positive feedback from attendees, and we're anxious to be of assistance to more of you. For more information, contact Jessica (608/263-7991 or parkinsons@neurology.wisc.edu).

# Wisconsin Chapter—American Parkinson Disease Association

P.O. Box 7513 • Madison, WI 53707-751 • 608/263-7991  
chapter@wischapterapda.org • www.wischapterapda.org  
National Website: www.apdaparkinson.org

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Phone: Home ( ) \_\_\_\_\_ Work ( ) \_\_\_\_\_

Phone: Cell ( ) \_\_\_\_\_ E-Mail \_\_\_\_\_

Preferred Method of Correspondence: Email \_\_\_\_\_ Postal \_\_\_\_\_

Patient \_\_\_\_\_ Caregiver \_\_\_\_\_ Other \_\_\_\_\_

Put me on mailing/membership list: Yes \_\_\_\_\_ No \_\_\_\_\_

I would like to be involved with:

Support Groups \_\_\_\_\_ Fundraising \_\_\_\_\_ Walk-A-Thon \_\_\_\_\_ Board \_\_\_\_\_

Membership Drive \_\_\_\_\_ Other \_\_\_\_\_

Membership is renewed annually in September. The optional \$5 membership fee helps the chapter "ease the burden...find the cure."

\$5 \_\_\_\_\_ or Other \$ \_\_\_\_\_ (optional)

Please send application and donations to the above address or call 608/263-7991.

Signature \_\_\_\_\_ Date \_\_\_\_\_

ALL DONATIONS ARE TAX DEDUCTIBLE

## BECOME A MEMBER TODAY!

*The Wisconsin Chapter APDA is a not-for-profit, volunteer organization committed to raising public awareness of Parkinson's disease and dedicated to easing the burden on Parkinson's patients, families, and caregivers.*

### PUBLICATIONS

Use this order form or call 608/263-7991.

\_\_\_\_\_ **Basic Information about Parkinson's Disease**  
(4-page brochure)

\_\_\_\_\_ **Parkinson's Disease Handbook**  
(symptoms, causes, treatment; 40-page booklet)

\_\_\_\_\_ **Be Active** (25-page exercise program for people with Parkinson's Disease)

\_\_\_\_\_ **Be Independent** (32-page booklet on equipment and suggestions for daily living activities)

\_\_\_\_\_ **Speaking Effectively** (34-page booklet on speech and swallowing problems with Parkinson's)

\_\_\_\_\_ **Good Nutrition in Parkinson's Disease**  
(26-page booklet)

\_\_\_\_\_ **Young Parkinson's Handbook** (78-page booklet)

\_\_\_\_\_ **Aquatic Exercise for Parkinson's Disease**  
(20-page booklet for patients and families)

\_\_\_\_\_ **My Mommy Has PD... But It's Okay!**  
(20-page booklet for young children)

## ONLINE

Be sure to check out our chapter Web site ([www.wichapterapda.org](http://www.wichapterapda.org)) for the latest information available from and for the Parkinson's community.

## UPCOMING EVENTS

### Parkinson's Walk-A-Thon Sunday, April 6, 2008

(see previous page for details)

### Shaking Up Parkinson's Disease Luncheon Saturday, April 12, 2008, 10 a.m. – 3 p.m.

AmericInn, 700 Highway 51 North, Minocqua  
RSVP by April 4

Contact: Jessica Hahn ([parkinsons@neurology.wisc.edu](mailto:parkinsons@neurology.wisc.edu)  
or 608/263-7991)

# Valuable Resource Book

Are you looking for resources to help you when things aren't going your way regarding Parkinson's disease? The *Wisconsin Parkinson's Disease Resource Book* is for you. This book covers a wide variety of topics, including listings of attorneys for the elderly, case managers, and Lee Silverman Voice Therapists; Medicare information; and where to find respite care, rehabilitation facilities, neuro-ophthalmologists, and more. To receive a book, please contact Jessica Hahn (see above).

## MEMORY & HONOR

*The following individuals have been recognized through donations to the chapter since the Winter 2007 issue:*

### In Honor of...

Dale Carlstrom  
Sandy Dorshak

### In Memory of...

Annette Barth  
Audrey Frayer  
August Gess  
Michael Jackson  
CJ Kasper  
Eric Konkol

John and Marie  
Marzinski  
Irene Meyer  
Jerry Mauthe  
Rita Pepin  
Helen Quest  
LaVerne Tesch



## Electronic Newsletter

If you would like to receive the newsletter in electronic format, please e-mail [parkinsons@neurology.wisc.edu](mailto:parkinsons@neurology.wisc.edu). Otherwise, it will continue to be delivered via the U.S Postal Service.

*Parkinson's Perspective is published three times a year for Parkinson's patients, their families, and caregivers. It is produced by the APDA Information and Referral Center and the Wisconsin Chapter of the APDA. This issue is sponsored by UCB Pharma. If you no longer wish to receive this newsletter, please call 608/263-7991 or e-mail [parkinsons@neurology.wisc.edu](mailto:parkinsons@neurology.wisc.edu).*

—Jessica Hahn, editor

This newsletter is intended for educational purposes only and should not be interpreted as providing medical recommendations. Patients are advised not to change their treatment without the advice and consent of their treating physician. The editor of the newsletter is solely responsible for its content.



### A Parkinson's Publication

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