

The Informant

Newsletter of the American Parkinson Disease Association

Information & Referral Center at Iowa Methodist Medical Center

Winter 2006

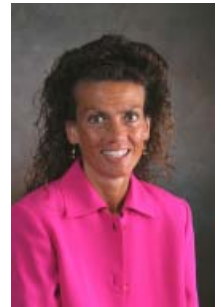


Tips for the Holidays for People who are Memory Impaired or Have Behavioral Difficulties

Lynn K. Struck, M.D.

Neurologist, Iowa Health Physicians, Medical director of the Information & Referral Center, Iowa Methodist Medical Center

With the holidays approaching, it's important to remember that individuals with memory impairment or behavioral difficulties do not always feel comfortable at large family gatherings. There are several things that can be done to make the situation more comfortable for these people, especially during the holiday celebrations. Here are some suggestions for helping those with memory impairment/behavioral difficulties to get the most enjoyment out of holiday family gatherings.



1. Plan ahead. If the individual is vulnerable to over stimulation, limit activities or length of time in which he or she is included. For example, don't let dinner continue for hours.
2. Establish a quiet room so the family member can step out of the hustle and bustle for a calm moment.
3. Budget in nap time, especially if the individual is accustomed to daily naps.
4. Assign a family member to be a companion to the individual for that day to monitor how he or she is doing and make sure that he or she feels comfortable.
5. If the gathering is in the home of a person with memory impairment or behavioral problems, do not rearrange the furniture. This can be a source of confusion and anxiety.
6. Do not put out a lot of finger foods, like sweets, especially if the individual has a problem with impulse control. This can lead to sugar-induced hyperactivity or an upset stomach.
7. Eliminate alcohol consumption, which can provoke bad behavior or interfere with medications.
8. Break down complicated tasks and involve the individual in simple, helpful, preparation tasks, such as greasing one of the cooking pans or peeling potatoes. This aids self-esteem and helps him or her feel a sense of contribution to the celebration.
9. Engage everyone, including the memory-impaired individual in reminiscing. Often, someone with memory problems can recall the past but forgets recent events or conversations. By getting him or her to talk about the past, younger family members can hear about their roots. In addition, the memory-impaired person will feel validated for his or her perspective on family history.
10. Avoid criticism that can embarrass or shame the individual, such as saying, "Don't you remember ...?"
11. Be sure to follow the individual's regular schedule of medication.
12. If traveling by air, plan on how much time you will need – then double it. Rushing is very stressful for everyone. Be careful that airport services such as wheelchair accommodations might be in short supply during the heavy traffic at the holiday season.
13. Above all, be sensitive and loving.

– These tips are from Daniel Sewell, M.D., Director of the Senior Behavioral Health Unit, University of California, San Diego, Medical Center.

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The material in this newsletter is presented solely for the information of the reader. It is not intended for treatment purposes, but rather for discussion with the patient's physician.



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& Referral Center
Iowa Health - Des Moines
1200 Pleasant St., E-524
Des Moines, IA 50309
Toll free: 877/872-6386
Fax: 515/ 241-6393
E-mail: erwinjs@ihs.org

**Information & Referral Center
Coordinator**
Sam Erwin

Medical Director
Lynn K. Struck, M.D.,
Neurologist, Iowa Health Physicians

APDA-Iowa Chapter
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Iowa Chapter APDA
PO Box 507
Waukee, IA 50263
www.apdaiowa.org

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**From the Coordinator of the APDA Information & Referral Center,
Iowa Methodist Medical Center, Des Moines – Sam Erwin**



Being a part of a statewide organization gives me an opportunity to meet so many people. From meeting Nicole at a recent Parkinson's Action Network (PAN) conference, to standing with Sherry in Burlington at a health fair, playing with the Des Moines Area support group, having lunch with Jerry and Linda to hear about their Santa Fe experiences, being with Deb through the deep brain stimulation (DBS) procedure, being in the room with Michael J. Fox and so many of you, and receiving notice on Dot's death in Davenport, we're brought together through the pages of this newsletter.

Your willingness to share your stories and successes is a wonderful gift to everyone. As the holidays begin never forget that people invite you to their celebrations because of who you are and how much you give them when you are in their presence. Thank you for a wonderful year.

From the Iowa APDA Chapter President – Barbara Moore

I have been asked several times about my thoughts on what Mr. Limbaugh shared with the world regarding Michael J. Fox's Parkinson's symptoms.

At first I was in shock that anyone could say something like that and not take into account the hurt and anger that people suffering with PD and their families would experience.

Then I thought, I wish that he were right. Wouldn't it be absolutely wonderful to be able to leave the symptoms of PD at one's home or office. Just picture being able to drive home safely, hug your children and your spouse all without losing your balance trying to do so. But it is not true what Limbaugh accused Michael J. Fox of – which was faking the severity of his PD symptoms. I wish it were, but it is not. Michael, just like all PD patients has to get in his vehicle and go home where he will fight a host of other symptoms such as legs cramping, insomnia, feet that feel like they weigh 100 lbs each, getting stuck in bed and not being able to turn over or get out.

You know, if anything, Mr. Limbaugh, Michael downplays his symptoms. PD patients and their families and caregivers need HOPE, and Michael gives us HOPE and reality. This HOPE comes from our scientists and physicians exploring all the options for a cure. This can be done, but not if we do not even try.

This discussion should not be a political one. Our politicians need to have some faith in the American public that we will not let research get out of control.

Oh, oh, oh – I only wish that Mr. Limbaugh were right, and that we're all faking our symptoms.

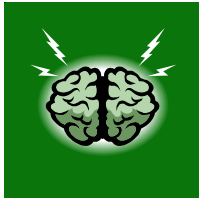
And Michael – thanks for all you do – you have our entire support.



Deb Wityk, membership secretary, left, and Barbara Moore at the Des Moines appearance in October of Michael J. Fox. See page 5 for Deb's story.

If you'd like to get involved in the Iowa APDA Chapter, contact Barbara Moore, via e-mail at souner13@aol.com, or write to Iowa APDA, PO Box 507, Waukee, Iowa 50263.

Brain Fitness



Memory is a skill that can be sharpened and improved at any age. Forgetfulness isn't a hopeless problem that comes with aging. Give your mind a regular workout with these thought-full exercises.

- **Focus.** Pay attention and concentrate-it helps you remember.
- **Say it again.** Repetition helps cement thoughts in your mind
- **Tell Tales.** Telling your life stories-even "tall tales"-can improve your memory.
- **Write It Down.** Putting it in writing reinforces the thought in your mind.
- **Play Games.** Challenge your mind-do word searches, crossword puzzles, or play trivia or jeopardy games.
- **Fantasize.** Using your imagination stimulates your memory.
- **Learn New Tricks.** Take up a new hobby, learn computer skills, or study a foreign language. Learning new concepts improves your ability to reason and solve everyday problems.
- **Follow a Scheme.** Organize your life-keep a calendar or date book, make lists and check them often.
- **Munch Memory Foods.** Fruits, vegetables, and grains are rich in antioxidants (vitamins A, C, & E, plus selenium)-great fuel for your mind!
- **Tune Into Music.** Melodies can nourish both your brain and soul. Try some complex Mozart for a real boost.
- **Get Moving.** Experience life to its' fullest-indoors and out. Regular exercise improves the oxygen flow to your brain.

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Happy to be Over the Hills

by Linda Jordening

In September 2006, the Iowa APDA Chapter coordinated a hiking tour for Parkinson's patients. Working through The World Outdoors, an outfitter, arrangements were made for a six-day hiking tour originating from Santa Fe, N.M., Sept. 11.

Several inquiries about the trip were received by Sam Erwin, Iowa APDA Information and Referral Center, but only three people made the trip – Jerry Kemperman and his friend Betsy Wallace, who does not have PD, but provided moral support for the first part of the tour, and me.

This is my perspective of the trip, which I found to be a wonderful experience. It has been nearly six years since I was diagnosed with PD. I've always been athletic and now, faced with unfamiliar and unpredictable physical limitations, I wanted to see how my body would respond to the travel and exercise involved in the trip. I estimate that I hiked about 25 total miles, and Jerry covered about 30 miles.

Day 1: We departed with our guides, Ann and Ryan, for Tent Rocks Kasha-Katuwe National Monument, the site of tent-shaped rocks formed by wind and water-eroded volcanic pumice. Our first day was "only" 3 miles of trail with an elevation change of 600 feet. It soon became apparent that Jerry, a retired forester, would be able to provide us with interesting information about plants and trees we passed on the trails. We returned to the Alameda Inn that evening to enjoy dinner together at a nearby restaurant. I felt really good physically, which calmed my concern about not having done enough pre-trip conditioning.

Day 2: We departed for the Santa Fe Ski Basin located in the rugged Pecos Wilderness, beginning our hike on the Puerto Nambe Trail at an elevation of over 10,000 feet. We climbed to an open meadow close to tree line where we ate lunch (packed and served by our guides) and enjoyed the view of Mount Baldy Peak. We hiked about 4.5 miles with an elevation change of 600 feet.

I didn't get as fatigued as I thought I would, but noticed on the trail that I got off-balance a couple of times in terrain that hasn't bothered me in the past. I was glad I had brought a walking stick with me, as Jerry (who is also a very experienced outdoorsman) had recommended. My leg and arm muscles were still feeling pretty good by the end of the day.

Day 3: After breakfast, we left Santa Fe and headed for Bandelier National Monument, beginning our day's hike from Burnt Mesa, where we left Jerry and Ryan to hike along 7.5 miles of trail from the Mesa down into Frijoles Canyon, an elevation loss of about 1,500 feet. I opted for a shorter hike of about 5.5 miles with Ann. We spent time exploring the Ancestral Pueblo dwellings before again joining Ryan and Jerry. The average elevation of the area is 7,000 feet.

We stayed the third night at the Abiquiu Inn, not far from Los Alamos. My stamina was better than I had expected, but I was still glad I had opted for the shorter hike. I was tired enough to sleep well, but not plagued by stiff muscles ... yet.

Day 4: We drove to Kitchen Mesa, a country with steep, multi-colored cliffs that inspired painter, Georgia O'Keefe. We hiked through this beautiful area to a summit overlooking a valley. The most challenging portion of the hike for me was a "rock scrambling" section along the trail. It was a short, steep climb over large rocks in order to continue up the trail. My balance wavered briefly at one point, but Ryan grabbed my daypack and with a small tug, helped me regain my footing.

Continued on page 4

Parkinson Disease Support Groups

If you are interested in forming a support group, or we are not listing your support group please contact the American Parkinson Disease Association Information and Referral Center, 1.877.872.6386 for information

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Happy to be Over the Hills –Continued from page 3

After I reached the top, I felt so glad that I had tried and succeeded. Since my PD diagnosis, I treasure small victories more than ever.

We lunched at Echo Amphitheatre, a natural hollow of sandstone. We then traveled across the valley to Taos where we explored art galleries and picturesque shops before dinner. We hiked about 4 miles, plus whatever we walked in Taos. By the end of the day, my quadriceps felt a bit stiff from the downhill hiking we had done. Even so, I rested well that night.

Day 5: We left Taos and headed for the Taos Ski Valley in the Sangre de Cristo Mountains. It was cloudy, cold and drizzling by the time we reached Bull of the Woods Trail. Again, we had two options for distance and Jerry and Ryan took the longer 7-mile hike while Ann graciously accompanied me on the shorter 4-mile hike. The alpine trees sheltered us from some of the rain, but the footing was muddy and slippery, so my eyes were more attentive to the trail than to the trees and sky.

We came to a high meadow area and a small lake where the sign said, “Elevation 11,040 feet.” From that vantage point, we could see glimpses through the clouds of Wheeler Peak, New Mexico’s highest, at 13,161 feet. It was beautiful, and I tried to capture some of the grandeur with my camera.

Our descent was on the same trail, an estimated elevation loss of 1,500 feet. At the end of the hike, when my muscles

were still warmed up, my legs felt weary, but they didn’t bother me much. However, when we got back to Taos, I winced while getting out of the van – my muscles stiffened during the ride. The real test came later when we were preparing to leave the restaurant, as I stood, I walked stiffly for a few steps before I could straighten up completely. I mentally asked myself the familiar question, “Is this a symptom of my PD, or am I just that out of shape?”

Day 6: The morning of our final day was bright and sunny. We went to the Wild Rivers Recreation Area where we hiked into the deep gorge of the Rio Grande River Canyon. Our guides took us along the river to a spectacular view of the point where the Red River and the Rio Grande come together. We then climbed 800 feet to the rim of the canyon where we ate lunch. The hike was a little over 4 miles, a steep climb back to the top, and I stopped frequently to catch my breath.

At each rest point, I looked down into the valley to appreciate how far we had hiked. Perhaps there is a metaphor here: Each of us facing life with Parkinson’s can look back down at the low point in the valley that represents our diagnosis. As we make the climb to a full life that includes managing our disease, it is well that we occasionally stop and look at how far we have come.

Jerry and I would like to thank the Iowa Chapter of APDA for honoring a grant request to financially support this trip. Also, thanks to Sam Erwin for her assistance in planning, communications and fundraising that made this trip possible.

Finding a Path that's Right for You

Deb Wityk, membership secretary for the Iowa Chapter of American Parkinson's Disease Association, was diagnosed with Parkinson's disease (PD) in June 1995. In October 2006, she started the procedure known as Deep Brain Stimulator (DBS). This is her story.

This is not the clinical story of how DBS is performed or what happens. This is the story of the process that allowed me to open my mind and heart to a procedure that can buy me more time until there is a cure for PD.

I can still remember that day in June 1995 when I took my first Sinemet, and I could move my stiff, rigid body with ease for the first time in several years. It felt like a miracle. After many years of adjusting my medications to make my "cocktail," it now contains Sinemet, Comtan, Amantadine and Mirapex.

In October 2004, I was without these medications due to an emergency hospitalization, resulting in some serious additional complications. This was in part due to the loss of my neurologist and my search for another, which brought me to Dr. Lynn K. Struck in December 2004. At my first meeting with her, she asked if I had considered DBS as a possible symptom relief. My immediate thought was, "Why would I let a doctor drill holes in my head and hot wire my brain?" Smart response, at that moment, but oh, so true for me later.

When attending the World Parkinson Congress in February 2006, I consciously avoided the sessions discussing DBS. I was not open to that information. Yet, throughout the congress, I continually had conversations with individuals who had gone through the procedure with positive results.

I entered a drug study because my dyskinesias had become more debilitating after more than 10 years on Sinemet. However, the drug study proved to be unsuccessful in controlling my dyskinesias. I was discouraged and needed some hope. In June 2006, I attended the annual seminar in West Des Moines where two individuals discussed with Dr. Struck their DBS procedures and the positive results.

I am always cheering for others to be open to different ideas or to be open to change in their life. Now it was time for me to do the same. Finally persuaded, I contacted Dr. Struck's office to say "yes" to DBS. After two additional appointments with a surgeon and a psychologist, the date was set for Oct. 3, 2006.

It was time for me to prepare. I reached out to my family, friends and support group. As I shared with them the details of the procedure, there was obvious hesitation and fear for my welfare. However, they soon realized that I had made the decision to proceed, and they embraced me with their love and prayers.

While meeting with my healing touch practitioner, I developed an outcome vision of this procedure for myself. I was informed about the surgery, risks and benefits. I was honest about my periods of anxiety, and while I had a sense of humor, I also had an ease to cry. I listened to people's concerns but in the end, I did what I needed to do for myself. In that visualization, the outcome was to be great.

Admitting my fear and anxiety about going through the procedure, I designed a vision that would come to mind when needed. My vision is a green, grassy, hilltop meadow bathed in sunshine with two little girls – Miss Hailey Mae and Little Laura Ruth, my grandbabies, dancing and singing with me. There are also some additional children without faces – grandbabies scheduled to be born in March and April. The people who prayed and held me in a space of healing, my family and friends, join us. We are filled with joy as we laugh, sing and dance in a prayer of thanksgiving.



I have just finished the second phase of the two-part procedure. The first phase occurred on Oct. 3. With the help of my thanksgiving vision to calm my fears, on the surgical table in Omaha, having been off my meds for 12 hours, I was uncomfortable – cramping, stiff and rigid. I was able to move my fingers and felt my body relax without those drugs. It felt wonderful. I cried with joy at that miracle.

On Oct. 12, the second surgery was performed to connect the leads and put in the power pack. I got to sleep through that, although I was off my meds again. I'm on my way to bionic! Waiting to be programmed and switched on feels like an eternity.

How did I go from not being open to this procedure to actually lying awake as a drill makes a hole in my head? For me, the power of prayer and openness to what is best for me were the answers. To understand that and to be able to continue to do what I love and be there for my family, I said yes to DBS. And as my fortune from a recent Chinese meal said so well, "Everyone around you is rooting for you. Don't give up!"

Deb is scheduled to be "turned on" in late November. For more information about DBS, check with your physician, and log on to www.newhopeforparkinsons.com.

Thank You to Our 2006 Donors

The contributions of our donors make this newsletter and the other services provided by the chapter and the Information and Referral Center possible. Your generosity is genuinely appreciated, and it helps to "Ease the burden and find a cure."

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You can make contributions to the Iowa Chapter by sending a check made out to Iowa Chapter APDA to APDA, PO Box 507, Waukee, Iowa 50263.

Your donations are used for the purchase of books and other resources, support for PD support groups, staffing of the Information and Referral Center at Iowa Methodist Medical Center, and operating expensed for the Iowa chapter, as well as research funded by the national APDA office.



Dot A. Christiansen, PD Support Group Facilitator, Passed Away

Dot A. Christiansen, 67, of Bettendorf died on Tuesday, November 7, 2006 at Trinity Terrace Park Pathway Hospice. Dot was born October 23, 1939 the daughter of Thomas and Dorothy (Hymes) Harmon. She was united in marriage to Jerry Christiansen March 26, 1975,

in Moline, IL. He preceded her in death in 2001.

Those left to honor her memory include her stepdaughters, Ruth (Byron) Buck, of China, Natalie (John) Crose, Orion; sisters, Della Hogan, California, and Dixie Leslie, Georgia; 2 brothers, Tom and Ted Harmon, both of Missouri; 9 grandchildren, Britt, Brianna, Alysabeth, Byron, Christian, Daniel, Breslin, Brenden and Braylin.

The American Parkinson Disease Association, Inc., was founded in 1961 to "ease the burden and find a cure" for Parkinson disease. Headquartered in New York, the organization focuses its energies on research, patient services, education and raising public awareness of the disease. The APDA national office also coordinates the efforts of chapters and information and referral centers across the nation. In 2004-2005, the APDA budget for research was more than \$2.5 million, plus APDA funded eight advanced centers for PD research. Annually, the APDA scientific Advisory Board reviews grant applications and recommend funding for researchers whose work shows promise for new breakthroughs or improved treatments.

National American Parkinson
Disease Association
135 Parkinson Avenue
Staten Island, NY 10305

APDA Activities Around Iowa



Left to right, back row, Ruth Newton, Sam Erwin, and front row, Sherry Engberg and Jo Hamilton spread awareness of APDA and Parkinson's disease at the annual Burlington Health Fair.

For more information about APDA and support groups around Iowa, contact the American Parkinson Disease Association Information and Referral Center.



Marcia Hurley supports her group by leading exercises at the Des Moines Area support group meeting.

*Happy Holidays to you and your family from the
Iowa Chapter of APDA and the
American Parkinson Disease Association Information and Referral Center.*



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Parkinson's Disease Information and Referral Center
1200 Pleasant Street - E-524
Des Moines, IA 50309

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