

The Hagerstown Parkinson's Support Group

Hagerstown, MD and the Four-State Area

Monthly Newsletter

June 2013

Visit Our Website at:
www.fareshare.net/Parkinsons/

Volume 3, Issue 06

[Visit us on Facebook](#)

This Month's Meeting

We had 40 attendees at our May meeting.

Our speaker was Jodi Ramsey of Hospice of Washington County. She explained the purpose of Hospice Care which focuses on palliative or comfort care rather than curative treatment. Hospice providers focus on the person, not the disease, for the last several months of life.

She also explained that Hospice provides counseling and other support for those who are grieving a loved one. This includes a number of targeted support groups.

Ms. Ramsey answered many questions from the group including inquiries about the new medical directive forms called Maryland MOLST. Forms and information are available at: www.marylandmolst.org.

More information on Hospice care is available at 301-791-6360 and at their website: www.hospiceofwc.org.

I want to thank **Dick Naugle** for his inspirational readings and for asking the blessing.

Phyllis Davis won the door prize drawing; it was a \$10 gift certificate to the Western Sizzlin Restaurant and was donated by Paul Romsburg and his family.

June Meeting

MARK YOUR CALENDARS

Join us for our next
Parkinson Support Group Meeting
at the
Western Sizzlin Steakhouse
17567 York Road, Hagerstown, MD
(301) 791-7560

Thursday, June 6, 2013, 11:45 AM.

Our Speaker in June will be

Bailey Vernon
Johns Hopkins University
Educator

Tips and Techniques for Dealing with Stress: [See Page 3](#)

Dance for PD Demonstration Class: [See Page 5](#)

Hospital Dangers: [See Page 5](#)

Upcoming Events

Future Meetings

June 6, Bailey Vernon, JHU Educator
July 11, Becky Dunlop, JHU RN, BSN
August 1, Meritus Pharmacist
Sept. 5, Dr. Samina Anwar, Neurologist
October 3, Bill Bugg, Author
Nov. 7, Steven Ryan, Physical Therapy
December 5, Break Out Sessions

Educational and Other Activities

Caregivers' Breakfast:

Monday, May 20, 2013, 8:30 AM at the Railroad Junction Family Restaurant. Call Art Guyer for information.

Dance for PD Demonstration Class:

The Dance for PD Demonstration Class scheduled to be held at St. Mark's had to be cancelled at the last minute.

We apologize for not being able to reach all of you by email or phone in time. The dance instructor had a family emergency and had to leave town suddenly. We are trying to reschedule the demonstration class as soon as possible.

Continued on Page 2. Please let us know of any events you would like to see publicized.

This publication supports:

The Hagerstown Parkinson's Support Group

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22215 Troy Lane
Hagerstown, MD 21742

The Hagerstown Parkinson's Support Group is supported in part by:



17567 York Road Hagerstown, MD
(301) 791-7560

Stop by for lunch or dinner to support them!

Thanks to Paul Romsburg, his family, and staff of the *Western Sizzlin* for supporting our group. They have done a wonderful job in providing us a place to meet and a great lunch.

UNSUBSCRIBE: If you no longer wish to receive this newsletter, please email: aguyer42@myactv.net

Or call him at: 240-625-2722

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Caregiver's Breakfast.

In April, Dave DeHaven, Ecile Shaw, Peg Hayzlette, Barbara Harrell, Mike Saterbak and Art Guyer enjoyed the Caregivers' Breakfast together.

This month, caregivers will meet for breakfast on Monday, May 20th, at the Railroad Junction Family Restaurant in Hagerstown, at 8:30 AM. We will meet in the private room at the restaurant.

You are encouraged to participate in this if at all possible. Caregivers should call Art at least 24 hours in advance, if you plan to attend or have questions



Homestyle Cooking
(240)-625-9022
808 Noland Drive
Hagerstown, Md
21740

Hours:
Monday-Saturday
6:00 am-8:00 pm
Sunday 7:00 am-3:00 pm

www.railroadjunctionfamilyrestaurant.com

Birthdays

So we can celebrate your birthday at our meetings, we're collecting birthdates (just day and month).

To participate, sign up at the next meeting or contact Art who is keeping a master schedule for the group.

May Birthdays: Robert Dieterich, Elizabeth Malek, Dia Schumacher, Clifton Smith, and Art Guyer.

Strawberry Festival at Homewood:

The Strawberry Festival seemed to be a big success. In addition to Dave & Patsy DeHaven and Art & Doris Guyer, Peg Hayzlett, Doris & Clyde Fearnow, Harry & Phyllis Davis, and Anita & Dick Masters were seen enjoying the beautiful day.

Need Transportation or Just a Break?

Remember, if you need transportation to our meetings or other events, please let us know.

If you would like a couple of hours of free time and we can take your spouse for a short day trip, we will be happy to try to work something out for you.

Give Art a call or send him an email.



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What Is A Caregiver?

*By Ken McKinney
Assistant Facilitator*

Cumberland Parkinson's Support Group

*A Caregiver is patience,
Expressing kindness and love.
A Caregiver is understanding,
And is truly a gift from above.*

*A Caregiver is a partner,
In good times and in bad.
And when there is a special need,
The best friend we ever had.*

*A Caregiver is not just a Giver,
They share our hope and joys too.
So a pleasant smile or a gentle touch,
Is something we can do.*

*God loves a Cheerful Giver,
This we have all been told.
Caregivers receive special blessings,
Whether they are young or very old.*

*You can be a Caregiver.
By just showing that you care,
You can be that special friend,
Just let them know that you are there.*

Reprinted with permission of Mr. McKinney.

In The Hospital?

If you or your spouse, or a member you know is not doing well and/or is in the hospital, please let us know. We like to visit our friends when possible.

Upcoming Events (Cont. from Page 1)

Totem Pole Playhouse Event:

Totem Pole Playhouse, "A Closer Walk with Patsy Cline," Wednesday, June 19th, at 2:30 PM, call 888-805-7056 to check for available tickets.

Summer Picnic:

Thursday, June 20, 2013, at 12 PM in Pavilion #4 in the Martin L Snook Memorial Park, Hagerstown, MD. Fried Chicken, Covered Dish, Dessert and Bingo. See page 6 for more information and directions.

Johns Hopkins Educational Seminars:

Parkinson's Disease 101: For newly diagnosed Parkinson's patients and family. June 10, September 23
5:00 PM – 8:30 PM

Parkinson's Disease 201: For patients diagnosed for at least 5 years, and family. October 28
5:00 PM – 8:30 PM

Deep Brain Stimulation: A session on the innovative technique to provide relief for people with Parkinson's Disease. November 11
6:00 PM – 7:30 PM

Achieving Excellence in Parkinson's Care: Presented with NPF at the Sheraton Baltimore North Hotel, Towson, MD. Saturday, May 18. 9:45 AM – 3:30 PM

For more information on these JHU events, contact **Bailey Vernon** at 410-616-2811 or bvernon1@jhu.edu.

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Tips and Techniques for Dealing with Stress

By Dr. Rita Nachen Gugel

Change is an expected part of our daily lives today. And many times it can be very stressful. Dealing with it so YOU control IT rather than vice versa is an important and positive force in controlling your life. Try a few of these tips:

1. Accept what you cannot change. Take a tip from AA. Change what you can, if it bothers you. But, if you cannot change it, learn to live with it.
2. Face up to your problems. Sort them out, and see which ones are real and which are simply imagined. Deal with them as they are, and not what you think they are.
3. Deal with one problem at a time. Sort out your priorities, and deal with them in the order of their importance to you.
4. Be flexible. Give in once and a while. If you do, others will too.
5. Don't hold all of your worries inside yourself—talk it out. Frequently we swallow our unhappiness (along with candy, cake, ice cream, etc.) because we can't let the problems out. Talk to someone. A burden shared is much less of a burden.
6. Work off Stress. Physical outlets for stress help your body to fight off many of the negative results of stress.
7. Get enough rest/relaxation/sleep. Give your body a chance to recover from day to day. Lack of sleep and rest will only make matters worse for you.
8. Avoid "self-medication." A "spoonful of sugar" may make the "medicine go down," but it does your body no good. Sugar, alcohol, nicotine, and ice cream may all feel good going down, but they make matters worse—from the inside. They add to your body's physical stresses, thus making dealing with external stresses much harder.
9. "Take time to smell the roses." Have some fun. Relax.
10. Think about and do something for others. A little altruism never hurt. It even makes people feel better about themselves.
11. Be the "captain of your ship." If you are not happy with your life, think about what's wrong or missing, and then plan the necessary actions to change it to coincide with your needs and desires for your life.
12. Work on your relationships with those who share your life. Don't hold back your feelings. Share them with your family and friends and co-workers. It can help to decrease tensions.

Art's Note: Much of this can be achieved by attending and participating in your local support group!

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Dance for PD

We will be having a "Dance for PD" demonstration class this summer, at St. Mark's Episcopal Church, 18313 Lappans Road, Boonsboro, MD 21713. Directions are included below. Peg Hayzlett has volunteered to head up this effort and has arranged for this time and location. If the demonstration is successful, we will arrange for the full class schedule. If you have any questions or if you have not signed up at one of our meetings, call Peg at 301-791-0836. As soon as a date has been determined we will let you know.

In partnership with the **Parkinson Foundation of the National Capital Area**, Bowen McCauley Dance is the only dance company in the Metropolitan-DC area to provide Dance for PD -- free weekly dance classes for people with Parkinson's Disease and their care-partners. Besides the health benefits, dance takes the mind and spirit away from the thoughts of disease, disability and social isolation.



In a study of patients with Parkinson Disease, researchers from Washington University School of Medicine in St. Louis have found that those patients who participated in dance classes showed significant improvement in balance and mobility over those who participated in non-dance exercise programs.

Directions:

St. Mark's is located south of Hagerstown, MD, at: 18313 Lappans Road, Boonsboro, MD 21713.

You can reach the Church from I-70 by taking exit 29 and turning south toward Sharpsburg on Sharpsburg Pike (Rt. 65). Drive 4 miles and turn left at the light at Lappans Road (Rt.68). You will see the Church sign ahead on the right.

Prepare to turn right at the Parish House and continue towards the back of the campus for a large parking lot.

For more information and videos go to this link: <http://www.bmdc.org/outreach/dance-for-pd>

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New York Times Article from the New Old Age Blog Hospital Dangers for Patients with Parkinson's

4/17/2013

It was supposed to be a short stay. In 2006, Roger Anderson was to undergo surgery to relieve a painfully compressed spinal disk. His wife, Karen, figured the staff at the hospital, in Portland, Oregon, would understand how to care for someone with Parkinson's disease.

It can be difficult. Parkinson's patients like Mr. Anderson, for example, must take medications at precise intervals to replace the brain chemical dopamine, which is diminished by the disease. "You don't have much of a window," Mrs. Anderson said. "If you have to wait an hour, you have tremendous problems." Without these medications, people may "freeze" and be unable to move, or develop uncontrolled movements called dyskinesia, and are prone to falls.

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But the nurses at the Portland hospital didn't seem to grasp those imperatives. "You'd have to wait half an hour or an hour, and that's not how it works for Parkinson's patients," Mrs. Anderson said. Nor did hospital rules, at the time, permit her to simply give her husband the Sinemet pills on her own.

Surgery and anesthesia, the disrupted medications, an incision that subsequently became infected — all contributed to a tailspin that lasted nearly three months. Mr. Anderson developed delirium, rotated between rehab centers and hospitals, took a fall, lost 60 pounds. "People were telling me, 'He's never going to come home,'" Mrs. Anderson said.

He did recover, and at 69 is doing well, his wife said, though his disease has progressed. But his wasn't an unusual story, neurologists say.

Any older person faces dangers in a hospital, but for people with Parkinson's — largely a disease of older adults — they've proved particularly hazardous. "Patients were telling us these horrendous stories," said Dr. Michael Okun, a University of Florida neurologist and national medical director of the National Parkinson Foundation. "Even in good hospitals. Even in my own hospital."

People with Parkinson's are hospitalized much more frequently than others their age, and their stays last longer. A common reason: "These patients aren't getting their meds on time, and they're not getting the right meds," Dr. Okun said. Some need to take their dopamine-replacing drugs as often as every two hours, a schedule at odds with standard hospital regimens.

Worse, some commonly prescribed drugs — including Compazine and Phenergan for nausea, and Reglan to stimulate bowel function after surgery — actually block dopamine and worsen symptoms in patients with Parkinson's. Then they are at risk for falls and fractures and for aspiration pneumonia.

Moreover, any infection can lead to delirium, because Parkinson's patients have lowered cognitive reserve. But the drug Haldol, which hospitals frequently used to reduce confusion, is also a dopamine blocker. "Haldol is the worst drug you can give a Parkinson's patient," Dr. Okun said. Over all, "it can be a real mess."

With proper treatment, most Parkinson's patients can live long and good lives, "but stressing them with a fall or an infection or anesthesia can make them fall apart," he said, turning supposed in-and-out hospitalizations into weeks of illness and decline. Not everyone is as lucky as Roger Anderson.

What will help, in the long run, is educating hospital staffs about Parkinson's and changing the way they function. And yet — isn't this a sad commentary? — "it's slow going to effect change in the health care system, and in the meantime a lot of people are getting hurt," Dr. Okun said.

So, unfair as it may be to put the onus on patients and families, the foundation is offering a free Aware in Care kit that includes a bracelet identifying the wearer as a Parkinson's patient and fact sheets and reminder slips to hand out to doctors and nurses. "We want to arm people," Dr. Okun said.

The Andersons have used the kit for subsequent hospitalizations and found it useful. And Mrs. Anderson reports that now, years after their three-month nightmare, hospitals actually encourage her to bring along her husband's medications and to administer the pills herself as his schedule demands.

You might argue that the hospital is magnanimously allowing her to do the job its staff is supposed to do, but she's fine with that. It beats the alternative.

— Paula Span

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Summer Picnic

Date: Thursday, June 20, 2013

Time: 12 PM

**Where: Martin L Snook Memorial Park, Pavilion #4
Hagerstown, MD**

Bring a covered dish or dessert and there will be fried chicken.

The cost of the chicken and the fee for rental of the pavilion will be prorated to those attending.

There will be free bingo for all! Everyone should bring one or more wrapped, inexpensive "prizes" for bingo winners. Prizes can be something you want to get rid of or you can pick up some items from a "dollar store."

Directions:

For those using I-81, go East on I-70 at the I-81/70 Interchange

Eastbound on Interstate 70 (from I-81), take Exit 28, turn left on Downsville Pike; turn left at first traffic light. The park entrance is 100 yards past the light, on the left. Follow the park road to the end and the pavilion will be on the right.

Westbound on Interstate 70 (from Frederick), take Exit 28, the park entrance is 100 yards past the first stop light, on the left. Follow the park road to the end and the pavilion will be on the right.

For more information or to make reservations for the picnic, contact:

Art Guyer

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