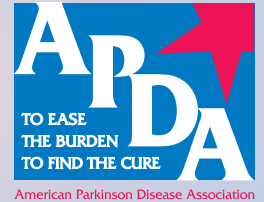


Parkinson's @ Us

Newsletter

Spring 2010



**A Publication of the American Parkinson Disease Association
Information and Referral Center at Emory University and the APDA Georgia Chapter**

THE FAMILY UNIT AND PARKINSON'S DISEASE

R. Malcolm Stewart, M.D.

Introduction

Parkinson's disease (PD) is an unwanted intruder and a potentially strong and disruptive force which can upset the emotional and economic relationship in the family. Recognizing that PD has an impact far greater than on the individual alone can help marshal the needed resources to ease the burden for the individual and family alike and foster a sense of cooperation and adaptive behavior.

Function of the Family

The word family brings forth a special image and feelings about self and relationships to others who are closely bonded with shared experiences. When functioning well, the family promotes the welfare and wellbeing of its members. When an illness such as PD strikes, these family relationships may become stressed. How the individual and family weather the storm depends on how healthy the relationships were prior to the onset of the disease. The outcome depends on the severity of the disease, the personalities of the affected individual and other family members, the degree of interdependence and integration of the family, the cultural background and the ability to adapt and adjust to new circumstances.

Reaction of the Patient to Illness

Each individual has a unique personality and coping style and will react to illness differently. Normal emotional feelings occur in response to illness and

include anger, guilt, resentment and minor depression. Adaptive behavior includes acceptance of the situation and appropriate attempts to regain control of an overwhelming situation individually or by seeking outside support.

Maladaptive behavior can emerge and includes denial of the situation, major depression and withdrawal and inappropriate overcompensation. The amount and quality of socialization with others may also be severely affected.

When early symptoms of PD begin to emerge, they may be misinterpreted or attributed to aging and depression. The lack of motivation, decreased desire of activity or decreased ability to concentrate may be noted first at work by a supervisor or at home by a spouse. When confronted with a concern about decline in performance or productivity, the patient may become defensive or exhibit denial. Some individuals always need to be in control and will look at any attempt to question their ability or to help them as an attempt to control them or, at very least, an unpleasant reminder that something is wrong with them. Rather than being grateful, the patient appears hostile and upset.

Alternatively, some patients become more dependent on others and will accept any and all help gratefully to the point of becoming increasingly more dependent and eventually helpless. Understanding

Continued on Page 6

PRESIDENT'S CORNER

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404-728-6552

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Lynn Ross
LMSW
Editor
Linda McGinn, R.N.
Copy Editor

Dear Friends,

First, I would like to send out a very big thank-you to a dear person and devoted board member, Carol Palmer. Carol has served on the board for over 6 years and most recently as president of the board. She is stepping down from the board and we will REALLY miss her! As most of you know, serving on the board is a VOLUNTEER position so we are especially grateful for all her hard work and efforts. Of course, we want her to continue to be involved in our activities whenever she can.

The new year begins with fresh enthusiasm and lots of new ideas. Despite the sluggish economy and resulting slowdown in fundraising, APDA has not had to cut any of our current programs. And we are even working on providing new services to our members!

In addition to the Caregiver Time-out and respite programs, we are offering some exercise programs and potentially some new dance programs to PWP. Learn more about those programs on our website.

As always we ask that you keep us in mind for donations. Our annual fundraiser is coming up March 13-15, 2010 at Smoke Rise Country Club. We need your support!

Finally, thank you to all who have given of your time and talent to help APDA Georgia—whether as a board member, a support group participant or a helper at our educational meetings!

Best wishes,

Annemarie Schwarzkopf
President
Board of Directors
APDA Georgia Chapter
www.apdageorgia.org

AMERICAN PARKINSON DISEASE ASSOCIATION

Support Group Meetings in Georgia and South Carolina

ATLANTA

APDA Educational Meeting
Clairmont Oaks
441 Clairemont Avenue
Decatur, GA 30030
3rd Saturday, 10:30 AM (Aug-May)
Lynn Ross LMSW 404-728-6300

Atypical Parkinsonisms (PSP, MSA, CBD)
Caregiver Support Group
Wesley Woods Health Center
1841 Clifton Road
Atlanta, GA 30329
3rd floor conference room
2nd Saturday, 10:00AM– 11:30AM
Lynn Ross LMSW 404-728-6300

People with Parkinson's PWP Group
Westminster Presbyterian Church
1438 Sheridan Rd. NE
Atlanta, GA 30324
3rd Tuesday, 1:00 PM
MaryAnne Brawley (770) 554-4193

Atlanta Veterans Medical Center
10th floor, room 110
1670 Clairmont Road
Decatur, GA 30033
1st Tuesday, 1:00- 2:15PM
Conetta Sam 404-321-6111 x7121

ATHENS

Athens Council on Aging
135 Hoyt Street
Athens, GA 30606
4th Monday, 2:30 PM
Chris Hill (706) 549-4850

BLAIRSVILLE

The Cadence Bank
Blairsville, GA 30512
2nd Wednesday, 3:00PM
Paula Wilde (706) 745-6594
Peter Schultze (706) 745-9171

CONYERS

Remington House
4th Wednesday, 4:00 PM
Anna Thomas
(770)787-1796
ajones3302@amedisys.com

DOUGLASVILLE

Wellstar Medical Center
8820 Hospital Drive
Douglasville, GA 30134
1st Tuesday, 2:00 PM
Larry Hennessy (770) 949-9467

DUNWOODY

EARLY ONSET PD GROUP
Dunwoody Baptist Church
1445 Mt. Vernon Road
Atlanta, Georgia 30338
3rd Tuesday, 7:00 PM
Eileen Piasecki (770) 837-9545

Dunwoody United Methodist
1548 Mt. Vernon Road
Dunwoody, GA 30338
2nd Monday, 7:00PM
Barbara Bean 770-394-0675, ext. 119

FAYETTEVILLE, NEWNAN, PEACHTREE CITY

Towne Club
201 Crosstown Road
Peachtree City, GA 30269
4th Tuesday, 7:00 PM
Pam MacAllister (770) 487-4444
Betty Fry (770) 631-2665

GAINESVILLE

St. Paul United Methodist Church
404 Washington St., First Floor
Gainesville, GA 30501
First & Third Thursday, 11:00 AM
Dean and David Poole (770)967-0161

AMERICAN PARKINSON DISEASE ASSOCIATION (CON'T)

Support Group Meetings in Georgia and South Carolina

GAINESVILLE

Lanier Village Estates
4511 Misty Morning Way
Apt 2118
Gainesville, GA 30506
2nd Friday, 11:00AM
Ruth Pearce (770)718-9752

GRIFFIN

Spalding Regional Medical Center
601 S. 8th Street
Griffin, GA 30224
3rd Thursday, 2:00 PM
Liz Tarleton, (770)233-2001

KENNESAW

Kennesaw United Methodist Church
1810 Ben King Road
Kennesaw, GA
2nd Tuesday, 7:00PM
Juna Crane (770)499-8594
junacrane@comcast.net
Maureen Demianyk (770)499-2365
mdemianyk@hotmail.com

LAWRENCEVILLE/ GWINNETT

Glancy Rehabilitation Center, Mango Room
3215 McClure Bridge Road
Duluth, GA
2nd Friday, 1:30 PM
Sharon Hansen (678)312-6175
shansen@gwinnettmedicalcenter.org

MACON

Medical Center Wellness Center
3797 Northside Drive
Macon, GA 31210 (Sept.-May)
3rd Thursday, 2:30-3:30PM
Caregivers 1:30-2:30PM
Mary Michael Atkinson
(478)746-9401 x211

ROME

Fifth Avenue Baptist Church Fellowship Hall
416 North 5th Avenue
Rome, GA 30165
1st Tuesday from 6:00pm - 8:00pm
James Trussell 706-413-3264
james@gaparkinsons.org

ROSWELL

Roswell United Methodist Church
814 Mimosa Blvd.
Roswell, GA 30075
2nd Sunday (Aug. – May), 4:00 PM
Robin Cleveland, (678)-819-3915
rcleveland@visitingangels.com

TIFTON

LeRoy Rogers Senior Center
315 West 2nd Street
Tifton, GA 31794
2nd Tuesday, 2:00 PM (Sept-May)
Linda Boyette, R.N. (229) 388-1888

CAREGIVER SUPPORT GROUP

Well Spouse Association
4th Monday 7-8:30pm
atlantawsa@gmail.com
www.freewebs.com/atlantawsa

SOUTH CAROLINA

ANDERSON, SOUTH CAROLINA
AnMed Health Rehabilitation Hospital,
1 Springback Way
Activity Room
3rd Thursday, 2:00 PM
Katherine Vickerman (864)332-2850

CHARLESTON, SC

Bon Secours, St. Francis Hospital
2095 Henry Tecklenburg Drive,
Rm 1
West Ashley, SC 29414
2nd Sunday at 2:30 pm (except July)
Gretchen Huff 843-297-1122

AMERICAN PARKINSON DISEASE ASSOCIATION (CON'T)

Support Group Meetings in Georgia and South Carolina

GREENVILLE, SC

John Knox Presbyterian Church
35 Shannon Dr., Greenville, SC 29615
3rd Thursday, 2:00 pm (Jan-Nov)
Sandi Holmes 864-609-1793
www.parkinsonsupport.org

HILTON HEAD, SC

HiltonHead Regional Medical Center
25 Hospital Center Blvd.,
Hilton Head Island, SC 29926
3rd Tuesday, at 1:00 pm
Mary Ann Burgeson 843-757-3776

LANCASTER, SC

Covenant Baptist Church
165 Craig Manor Road
4th Tuesday at 3pm
Janice Broach 803-285-2014

MYRTLE BEACH/ MURRELL'S INLET, SC

Waccanaw Community Hospital
Hwy 17 Murrell's Inlet
2nd Thursday, 7:00PM
Elaine Casavant (843) 650-8756

ROCK CITY, SC

HealthSouth's Cafeteria
1795 Frank Gaston Boulevard (behind Piedmont Medical
Center) Rock Hill, SC 29732
3rd Wednesday, 1:30 P.M.
Valerie Badanich 803-517-4586

SPARTANBURG, SC

Ballet Spartanburg building of the Chapman Cultural
Center,
200 E. St. John Street
2nd Thursday, 1:30-3:00
Ethel Perricone (864) 597-1150

COLUMBIA, SC

Lexington Medical Park Auditorium
2720 Sunset Boulevard
West Columbia, SC 29169
3rd Sunday 3:00PM (July-May)
Dottie Gantt (803) 604-0061
lakeside@att.net
www.columbiaparkinsonsupport.org

COLUMBIA, SC (Northeast)

The Waterford at Columbia,
9370 Windsor Lake Blvd.,
Columbia, SC 29223
4th Thursday, 12:30 pm
Paulette L. Freeman, BSW
803-296-3102

NORTH CAROLINA

Asheville Chapter
1st Tuesday 10:30-12:00PM
Care Partners Health Services
Seymour Auditorium
Lisa Laney-Kendrick, MSW
828-277-4886

If there is not a support group in your area and you would like to start a support group,
contact the Information and Referral Center at 404-728-6552

THE FAMILY UNIT AND PARKINSON'S DISEASE (CON'T)

R. Malcolm Stewart, M.D.

the basic personality of the individual permits a better selection of the appropriate approach to that person.

Reaction of the Spouse (Caregiver)

Just as the patient has a unique personality, so does the spouse. The major coping style of the spouse will color the reaction to the illness. At an early stage of illness, before PD is recognized, the spouse may respond by becoming overprotective and may overwork to the point of exhaustion. On the other hand, the spouse may feel overwhelmed and try to avoid the situation as much as possible. Generally, because PD strikes older people more frequently, the spouses have bonded together for a sufficient time to remain supportive of each other. New research strongly suggests that spouses of individuals with chronic health problems often develop significant health problems of their own related to long term caregiving. As a caregiver it is important to take care of one's self and maintain their own health.



Adjustments of Spousal Roles

The occurrence of PD may cause a power shift in the spousal relationship and require an adjustment of roles. This change may unfold smoothly or may be a source of strife, depending on pre-existing family dynamics and whether or not the disease affects a currently employed breadwinner. Most healthy marriage relationships incorporate a degree of independence coupled with a mutual sharing. Other less adaptive relationships include: a) a mirroring type in which the spouses are inseparable without outside interests apart from each other; b) a satellite type in which the family activity all revolves around a certain person like the spokes of a wheel around the hub in a somewhat authoritarian manner; c) the marriage of convenience in which the individuals coexist deriving a measure of companionship and economic benefit without strong bonding. If the sharing model exists, understanding or mutuality can overcome the usual conflicts, which flow from change in independence to dependence, without increasing either guilt or resentment. The other models are less adaptive when the relationships are destabilized. In the satellite model, one spouse may not be able to cope with the new found authority and responsibility and is unaccustomed to making decisions, while the other has been accustomed to giving orders, but not taking them. In the mirroring type, the inability of one spouse to keep up with the other alters the relationships and forces the spouse either to give up his/her favorite pursuits or establish new relationships, which have been avoided in the past. In the marriage of convenience, the pair may simply drift farther apart.

Outside Resources

The successful resolution of the effect of PD on the family involves utilizing resources outside the nuclear family that may include the extended family, friends, church or synagogue, the physician, support

THE FAMILY UNIT AND PARKINSON'S DISEASE (CON'T)

R. Malcolm Stewart, M.D.

groups and national organizations. In utilizing these resources an informed patient and family will be more successful in understanding the proper expectations concerning prognosis and rehabilitative efforts.

Friends play a particularly important role in the life of the Parkinson's patient. Many patients tend to lose initiative and withdraw from their circle of friends. "I can't play cards because the shaking gives away my hand." "I don't want anyone to see me this way." If the friends can get past the excuses, and drag the patient out of the closet", both will be better for it. Obviously, judgement in matching the activity to the patient's condition is needed to foster a sense of enjoyment, achievement and success.

The physician has a special relationship, which is more than prescribing medication. Through good rapport and honest communication, he/she can convey a realistic expectation tempered with encouragement and hope for the future. The physician can help the patient evaluate the advantages and disadvantages of available options, such as physical therapy and new pharmacological and neurosurgical advances. Again the individual styles of the physician, the patient and the family will affect the relationships. Many physicians will bring the family into the room with the patient during the examination and evaluation to facilitate communication and to insure that instructions are clearly understood. Physicians need to be prepared to answer sophisticated questions and sometimes be able to say "I don't know." All in all the physician can be a coach for the patient and family to encourage the greatest independence possible and provide a stabilizing force to help the family cope.

The family should develop a relationship with a local support group. This action permits the development of relationships outside the family including social

interaction, physical conditioning and emotionally corrective experiences. Some patients do not want to know too much about PD, to see someone worse than themselves, or have others see them.

Their wishes should be respected, but alternative approaches should also be explored. The support group is a tremendous source of information about the disease itself and ways of coping with it. Affiliation with a national association, such as APDA, provides yet other resources.

APDA is focused on finding a cure by funding research projects and the Information and Referral Centers to support the patients and caregivers through education. For the listing of a center in your area, you can call the APDA national office. APDA has two special Centers – one dedicated to support armed forces veterans, (Tel. No. 775-328-1715) and one to support Young-Onset Parkinsonians, (Tel. No. 877-233-3801).

Furthermore, through the Internet, at www.apdaparkinson.org, APDA provides current information which is actively pursued by patients and families alike.

Conclusion

Even though PD can affect the family unit negatively, a well planned, active approach with good communication and cooperation of everyone involved will foster a spirit of hope and ease the burden for those who walk this path.

The information contained in this supplement is solely for the information of the reader. It should not be used for treatment purposes, but rather for discussion with the patient's own physician.



We're Sharing the Health with a new Complimentary Exercise Class:

Exercising Control

Meets on the second and fourth

Thursday of every month.

Upcoming Class dates:

February 25 • March 11 & 25 • April 8 & 22

11:00 am

Belmont Village Senior Living

5455 Glenridge Dr., N.E.



Recent research has shown that exercise can have a positive effect on Parkinson's Disease.

Learn more about the overall benefits of physical activity as you participate in Belmont Village's complimentary new Parkinson's Exercise Class.

Class will be led by Certified Personal Trainer, Kirsten Magee. Kirsten has a Master's degree in Exercise Science from Georgia State University and more than 14 years of experience as a personal trainer. Her desire to create an exercise class for those with Parkinson's was inspired by working with her father-in-law as he dealt with the disease.

Join us today for a better tomorrow.

Receive a free gift on your first day of class! Reservations required.

Please contact Kendall Crye at 404-252-6271
or kcrye@belmontvillage.com for enrollment information.

www.belmontvillage.com   PC Lic 60030281 ©2010 Belmont Village, L.P.

Exercising Control over Parkinson's Disease

A CELEBRATION OF DANCE

Hosted by Georgia American Parkinson Disease Association
and Madeleine Hackney

Sunday, April 11, 2010

1:00 p.m.-3:30 p.m.

Academy Ballroom Atlanta

800 Miami Circle, NE

Suite 140/150

Atlanta, GA 30324



Suggested Donation: \$10 per couple (proceeds go to Georgia APDA)

Come celebrate with us at this special event that will include:

- A brief presentation of the benefits of dance for those with PD
- A beginner-level dance lesson
- Performances (tango, waltz, foxtrot and more) by professional dancers
- Open dance floor with DJ

For more information please call Kathy Edwards at 404-325-2020.

SIT AND GET FIT IS NOW STAND UP!

From sitting to standing, this exercise program is changing directions. It will now be a light to moderate intensity exercise class for seniors, including those with Parkinson's disease or muscular disorders. This class will emphasize posture, balance, coordination, strength, and flexibility in a relaxed environment. The class will meet at University Heights Methodist Church, 1267 Balsam Drive, Decatur, GA 30033 on Tuesdays from 11:30 am – 12:15 pm. Cost is \$90 for nine sessions. Call Kirsten Magee for more info, 678-592-6801 or email at kdafitness@hotmail.com.

NAC RELEASES 2009 CAREGIVING IN THE US SURVEY

The National Alliance for Caregiving, a non-profit coalition of national organizations focusing on issues of family caregiving has released the 2009 Survey Caregiving in the US. The survey is the most comprehensive examination to date of caregiving in America. To read an informative and realistic look at this growing population go to www.caregiving.org.

"Driving Parkinson's Away"

American Parkinson Disease Association Georgia Chapter

What: Saturday Night - Gala Dinner (Cocktails, Dinner, Live and Silent Auction)

Monday Noon Tee Time - Golf Tournament and Awards Dinner

When: March 13 & 15, 2010

**Where: Smoke Rise Country Club
4900 Chedworth Drive
Stone Mountain, GA**

Why: To benefit the American Parkinson Disease Association in Georgia.

**For details go to the website www.apdageorgia.org
Or call 404-325-2020**

STAFF CHANGES

Dear APDA family,

It is with much excitement and trepidation that I am announcing my departure from the APDA I&R center at Emory University. On November 1st, I officially passed on the reins to Lynn Ross, LMSW. Emory has offered me an opportunity to enhance medical care of the Parkinsonian by accepting the new position as Coordinator for the Comprehensive Care Clinic within the Department of Neurology Movement Disorder Clinic. I will continue to work closely with the Parkinson population through my current research projects and in my exciting new role within Emory. I have enjoyed and appreciated working with the PD population for the last 6 years and will continue to volunteer my services.

Lynn Ross joins the APDA family with vast knowledge of Movement Disorders. She has assisted with the I&R center during my recent maternity leave and is well trained on how the center functions. Please give Lynn a warm welcome.

Sincerely,

Mary Louise Weeks

Dear APDA family,

Mary Louise gave me a brief introduction in her message, but I want to tell you a little more about my experience with the Department of Neurology at Wesley Woods. I am not new to the Movement Disorders program, having worked in the position of social worker for over two years. In that capacity, I work with all the neurologists assisting patients and their families with information regarding resources and services available in our service area and beyond. The role of coordinator for the APDA I&R center will be an extension of what I am doing now and I look forward to serving our PD patients and their families. I will be happy to provide you with the latest information on resources, research, and education in the area of PD. I look forward to hearing from you and I hope to meet you at our monthly educational meetings and the other events in the PD community. I can be reached at 404-728-6552 or 404-728-6300 and my email is slross@emory.edu.

Warmest regards,

Lynn Ross



American Parkinson Disease Association
Information and Referral Center
at Emory University
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Atlanta, GA 30329

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MARK YOUR CALENDAR!

Upcoming APDA events:

The next Educational Meetings are located at Clairmont Oaks in Decatur, GA

March 20, 2010

Depression, Anxiety, and Sleep Issues in PD by Roza Adamczyk, M.D.

April 17, 2010

To be announced

May 15, 2010

Gentiva Safe Strides Program by Emily Pullen, MPT

There will not be an educational meeting in June or July

Educational meetings will start at 10:30am. Please come prepared with your questions.

OTHER EVENTS:

October 15 – 17, 2010

2010 Southeastern Parkinson Disease Conference
Sheraton Gateway Hotel
Atlanta, GA



This newsletter made possible by an educational grant from TEVA Neuroscience

DISCLAIMER

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