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Progress Notes: October 1990

Parkinson's Disease Center at Boston University Medical Center

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Boston University
FROM THE EDITOR

Since Fall has arrived, I would like to welcome people back from their summer breaks. I hope the summer was enjoyed by all. I would like to use this column to update a list of available reading materials. I am also happy to report that a close neighbor of ours, Glenna Atwood of Hampden, Maine, has recently completed a book on living with Parkinson's disease. The book is scheduled to be released in February of '91. Our next issue of Progress Notes will feature an article on her book. (From the Editor is continued on page 2.)

MEDICAL UPDATE:

Combatting Sleep Disorders in Parkinson's Patients

by Sanford Auerbach, M.D.

We all have experienced an occasional night of disrupted sleep, and have suffered accordingly as we have tried to get through the following day. Sleep need is universal, the purpose is not obvious although there are many theories which attempt to explain the need and reason for sleep. In the end, the most important observation is that we all need sleep.

Patients with Parkinson's disease are susceptible to a variety of sleep disorders. Insomnia and impaired sleep will decrease the daytime function of the patient, and often times the spouse finds his or her own sleep disrupted. Several factors may contribute to the development of sleep disorders in Parkinson's disease. For one thing, there are a variety of sleep disorders that are simply associated with normal aging.

Normally as we age, our sleep becomes more "fragile"—that is, it becomes more difficult to fall asleep—and we are more likely to awaken in the middle of the night. Other physical changes, such as those that prompt us to go to the bathroom in the middle of the night, further disrupt the quality of our night's sleep. Finally, as people get older, they become less tolerant of sleep deprivation. For example, the daytime function of a 60-year-old person will be more affected by a poor night's sleep than a 40-year-old's or a 20-year-old's functioning might be.

There are certain types of sleep disorders that are directly related to Parkinson's disease or for which patients with PD are at greater risk. This is in part due to the fact that certain brainstem structures affected in Parkinson's disease are also involved in sleep regulation. This might account for the number of changes noted in normal sleep architecture and the disruption of normal sleep rhythms. Motor changes may occur throughout the night. Tremor, for instance, may occur almost anytime during the night, but most especially during stages one and two of sleep. Most importantly, this tremor might disrupt sleep and lead to an unwanted awakening. Early morning foot dystonia, which is often described as a painful cramping sensation, can certainly limit a person's morning sleep. Even more alarming, it has been noted...continued on page 2
From the Editor

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Suggested Reading


From Rage to Courage: The Road to Dignity Walk, by Michel Monnot, St. Denis Press, P.O. Box 442, Northfield, MN 55057.

Parkinson's: A Patient's View, by Sidney Dorros, Seven Locks Press, P.O. Box 27, Cabin John, MD 20818.

A Patient’s Perspective: Living with Parkinson’s Disease, by Jon Robert Pierce, Spectrum Communications, P.O. Box 52721, Knoxville, TN 37950-2721.

Coping with Parkinson’s Disease, edited by Susan B. Levin and Erwin B. Montgomery, MD, Second Edition. Revised by the American Parkinson’s Disease Association I and R Center, St. Louis, MO.

These books, as well as a comprehensive library of newsletters, videotapes, and other materials, are available at the Information and Referral Center. For further information please call (617) 638-8466.

Sincerely,

Cathi Thomas, R.N., M.S.

Sleep
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Sleep disturbance is so important, since the medicines used to treat Parkinson’s disease may keep the patient awake. In addition, too little medicine may cause a person to be rigid or stiff, which may make it difficult to get comfortable and fall asleep.

A common sleep disorder seen in PD is called Obstructive Sleep Apnea (OSA). This disorder is an abnormal breathing pattern which occurs only in sleep. Apnea is a term which means “without breathing.” When muscles relax during sleep, an obstruction or blockage of normal airflow occurs. This problem may be seen in Parkinson patients as well as in other people but is easily treated and diagnosed in a sleep center.

Finally it has been established that patients with PD often may be depressed. Depression in turn may lead to a disruption of sleep. It is important to determine if depression is causing a person’s sleep problems because treatment would be different.

What can be done? Although sleep disruption in PD may be a difficult and complex problem, there is much that can be offered. First, patients should inform the doctor who usually monitors their Parkinson's disease. Often times the doctor may be unaware that a sleep problem exists. In many cases a careful reevaluation of medications and medical problems may reveal a solution. The solution may be as simple as changing the times of medications. Secondly, it may become evident that a person might not be practicing good sleep habits. It is important to avoid stimulants such as caffeine. Do not nap excessively during the day. Participate in an active exercise program every day so that at bedtime you’re ready for a good night’s sleep. Finally, if all measures have been tried without any improvement of sleep, a referral to a sleep disorders center may be necessary. It is preferable that the center have experience in the sleep problems associated with PD. In some cases an overnight sleep study will be helpful.

An overnight sleep study involves spending an evening in the sleep laboratory. The patient will be monitored carefully for brain wave activity (EEG), eye movement (EOG), muscle activity (EMG), breathing activity, and cardiac activity (EKG). After a full night of observation, valuable information can be derived which might be quite helpful in the management of the sleep disorder.

The most important point to remember is that each patient must be evaluated individually. Any or all of the above factors may play a role in sleep disruption of the individual. Indeed there are even other sleep problems which have not been listed in this brief note. Therefore, each problem must be carefully addressed with a good sleep history and medical review.

For further information on sleep problems, please call (617) 638-8466.
Respite

implies only short-term relief from the 24-hour, day-to-day responsibility of caring for another person.

The Parkinson team, under the direction of Robert Feldman, MD, understands the social and supportive needs of patients and family members, and based on these needs, a part-time position of Respite Coordinator has been developed. The position was created to inform families of available services, assess further the respite needs of the Parkinson population, develop programs based on these needs and change the perspective of what respite is all about.

Funding for the respite program has been provided by the Massachusetts Chapter of the American Parkinson's Disease Association. The chapter will support specialized training sessions offered free of charge to individuals engaged by a family for the purpose of respite care. The chapter will also manage monies donated exclusively for respite care which will be granted to families under financial strain in need of services.

A respite care provider might be an individual[s], volunteer or paid, engaged by the spouse or family to manage, in their absence, the personal care and/or supervision of a loved one in the home. It is essential to remember that the family directs the care when respite is utilized. Therefore, responsibilities should be well defined, clearly communicated, and preferably written down. Respite is also provided by health-care centers. Various facilities in Massachusetts, such as nursing homes and some hospitals, offer respite for a fee. These services are usually not covered by insurance. In addition many adult day centers and home health-care agencies provide respite.

When respite care is necessary, accepting it is sometimes difficult. The first experience is usually the hardest for both the patient and family member. Spouses or family members may fear the judgmental attitudes of others or may feel guilty; however, responding to their own needs for more regular support benefits all in the long run! Acknowledging these feelings is a positive step in making a decision to use respite.

Plans in the near future include developing a registry of volunteers and individuals for hire to assist families with respite. Another possible plan is developing a buddy system where two or more families are matched to support each other. Support groups may be able to assist in this area.

How can YOU help? First you can volunteer to fill out a respite survey to help the center understand the unique needs of the Parkinson population. This anonymous questionnaire will assist the center in developing future programs. To obtain this survey either call (617) 638-8466 or stop by the center and pick one up. We appreciate your willingness to do this.

SUPPORT GROUPS

There have been some new additions to the network of support groups in Northern New England. In addition there are a few changes of address and contact persons to report.

New additions

- Pittsfield Parkinson Support Group
  Contact: Rev. Dale Lock
  First Baptist Church
  88 South Street
  Pittsfield, MA 01201
  (413) 445-4539

- New Bedford Parkinson Support Group
  Contact: Mrs. A.P. Wallbank
  155 Shaw Street, Apt. 3
  New Bedford, MA 02754
  (508) 998-8096

- White River Junction Parkinson Support Group
  Contact: Barbara Yacos
  33 Maple Street
  Hanover, NH 03755
  (603) 643-3238

Change of meeting place

The North Shore Parkinson Support Group will change its meeting place as well as its contact person. We are sorry to hear that Mary Unger will be relocating to Tucson, AZ. As many of you know, Mrs. Unger has dedicated many hours in her work with the North Shore Support Group. She has organized and maintained a very large and active group. She has also greatly assisted the center in responding to the many inquiries from patients and family members who live on the North Shore. We wish Mrs. Unger the best and know she will certainly be missed. The new meeting location is at the Trinity Baptist Church, 227 Summer Street, Lynnfield, MA. All are invited to meet on the third Monday of each month at 1:00 p.m.

For information, contact Peggy Besterman, R.N., at (508) 887-2248.

Change of contact person

- Parkinsonian Society of Central Massachusetts
  Contact: Dick Dionne
  P.O. Box 61
  North Uxbridge, MA 01538
  (508) 278-3831

For information on the Parkinson Support Group near you, please call (617) 638-8466.
Mass. Chapter News
by Jeanne Murphy

I would like to welcome everyone back from their summer vacations. I have recently returned from the American Parkinson's Disease Association's Coordinator and Chapter conference which was held in New Orleans in August. The conference was very exciting as well as informative. I was able to meet chapter presidents from all over the country and was excited to learn of the many services and programs underway to help ease the burden and find a cure for Parkinson's disease.

I would like to take this opportunity to thank everyone who participated last April in the Michel Monnot/Sandoz Walkathon. Nationally over $750,000 was raised through many efforts such as ours. This fundraiser increased the number of research grants distributed by the American Parkinson's Disease Association to scientists pursuing a cure for Parkinson's disease.

Locally, our walk was quite successful. Once again we fought the elements of cold and rain but many people came and braved the conditions. We will soon have information on how much money was raised from our area. The walk would not have been successful without the efforts of many. I want to thank everyone for their hard work. It is not too soon to begin thinking of next year's walk, and it is my hope that several walks will take place. To become active with the 1991 walkathon, please call 638-8466 to be on a committee or volunteer in some way. Please call now!

In addition to our walk in Boston, members of the Parkinson Support Group of Cape Cod participated in a local walk which raised several hundred dollars. I would like to thank Mrs. Emilian Perreault (Helen) for her tremendous efforts.

Special thanks to our Walkathon supporters:
Coolidge Corner Clubhouse
Charles Playhouse
John Hancock Financial Services
Ultima Cosmetics

B and D Deli of Brookline
Nick's Comedy Stop
Trophies and Awards
(Mr. John Murphy)
Lorraine and Sam Goldman
(publicity)
Patti Jacobs
(publicity)
Marty Thomas
Edward McCarthy
Dr. and Mrs. Robert Feldman

1990 Parkinson's Disease Symposium
The symposium held at Boston University in May was attended by 300 individuals with Parkinson's disease, family members and healthcare providers. Speakers included Dr. Robert G. Feldman, Dr. Ira Shoulson, Dr. Peter Mosbach, Dr. Wayne Westcott, Dr. Marie Saint Hilaire, Harley Gordon, Esq., Cathi Thomas, R.N., Linda Perry, R.N., and Susan Tiller, R.D. Special thanks to Milton McNeil, Dorothy Halpern, Ida Lovely, Richard St. Jacques, Lorraine Goldman, and Dick Goldstein for their special presentations. In addition I would like to thank Frances Hall and Diane Chenette for volunteering their time to coordinate registration.

Support for the symposium was provided by DuPont Pharmaceuticals, Somerset Pharmaceuticals, Eli Lilly, and the University Hospital. Symposium tapes are available for purchase (see page 5 for order form).

NEW ENGLAND DOCKSIDE

Support the American Parkinson's Disease Association
Here is your chance to support the Massachusetts Chapter of the American Parkinson's Disease Association. The above note card has been custom designed to represent the beautiful geography of the New England area.

For a donation of only $5, you will receive five, 4x5-sized cards with matching white envelopes, sealed with an embossed gold sticker featuring the card's design.

Orders may be placed through any of the Massachusetts Support Groups or through the Massachusetts Chapter of the APDA (see page 5 for order form).

APDA (Mass. Chapter)
720 Harrison Ave, Suite 707
Boston, MA 02118-2393
Tel: (617) 638-8466
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Fill out this order form and enclose it with your check or money order. Make your check payable to the Department of Neurology.

A Videotape of the 1990 Parkinson’s Disease Symposium

To order your videotape please fill out this card and enclose it with a check or money order for $29.95 (this cost includes postage and handling).

Name:__________________________________________________________
Address:________________________________________________________________
Telephone Number:____________________________________________________
Number of Tapes:_____________________________________________________

For either order, send check or money order and form to:

The University Hospital
Department of Neurology
720 Harrison Ave., Suite 707
Boston, MA 02118-2393

APDA (Massachusetts Chapter) Donation “Note Card” Order/ReOrder Form

Fill out this order form and enclose it with your check or money order. Make your check payable to the Mass. Chapter of APDA.

Number of Packages_______ $5.00 per package = _________ Total Donation

Name:__________________________________________________________
Support Group Location:________________________________________________________________
Address to Send Cards:_____________________________________________________

[If Ordering by Mail]:_____________________________________________________

If ordering by mail, please include an additional $1.00 for the first package and 25 cents for each additional package to cover the cost of postage and handling.
Progress Notes

A Report from the Parkinson's Disease Center
at Boston University Medical Center
720 Harrison Avenue, Suite 707
Boston, MA 02118-2393