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Parkinson's Disease Center at Boston University Medical Center

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Boston University
FROM THE EDITOR

It has been an exciting and busy six months since the release of our first issue of "Progress Notes." The Information and Referral Center has responded to several hundred inquiries of information on Parkinson's disease, especially the new FDA-approved medications Eldepryl (deprenyl) and Permax (pergolide).

I would like to introduce a new resource program available at Boston University Medical Center for people who are inquiring about respite care. Linda Perry, R.N., who is the coordinator of the Parkinson's Day program, will assist individuals and family members in locating respite care services. We are presently completing an assessment of available respite care services in the state. Members of the Massachusetts Chapter of the American Parkinson's Disease Association have identified the lack of affordable respite care as a major problem that needs prompt attention. It is our hope that this program can expand to one which can provide direct-care services. If you have any questions regarding this program, please call the Information and Referral Center at Boston University Medical Center at (617) 638-8466.

Sincerely,
Cathi Thomas, R.N., M.S.
Coordinator of the APDA Information and Referral Center

MEDICAL UPDATE:

The Use of Low-Protein Diet in Parkinson's Disease

by Marie Saint-Hilaire, M.D., FRCPC

Although L-Dopa (usually given in the form of sinemet) continues to be the most important medication for Parkinson's disease, its long-term use is associated with significant complications consisting mainly of fluctuations in mobility. Fluctuations first appear as a gradual shortening of the duration of action of single doses of levodopa with a "wearing off" effect, then progress to rapid, sometimes random, swings, the "on/off" effect. More than 80 percent of patients will experience these complications after more than ten years of treatment with L-Dopa. Recent studies have suggested that these fluctuations are at least partly related to an erratic delivery of the L-Dopa to the brain because they can be eliminated by the continuous intravenous infusion of L-Dopa, producing a stable blood level of the medication.

Competition between L-Dopa and dietary proteins may account for the variations in the clinical response to identical doses of sinemet. This has been confirmed by clinical studies showing that reduction in dietary protein can lessen fluctuations of the blood level of medication when it is taken by mouth, and this has led to a new approach to treating fluctuations: the implementation of a "low-protein diet."

Scientific Basis

Proteins are composed of amino acids, of which a certain class, the large neutral amino acids, interfere with L-Dopa at two levels: the absorption of the L-Dopa from the gastrointestinal tract into the blood, and the passage of L-Dopa from the blood into the brain, where it can be transformed into dopamine to relieve the Parkinsonian symptoms.

Competition between L-Dopa and large amino acids for absorption in the gastrointestinal tract will delay the absorption of L-Dopa and reduce its level in the blood. This will delay the availability of L-Dopa for the brain. In addition, L-Dopa has to compete further with the large neutral amino acids in the blood to cross the blood brain barrier located in the microvasculature of the brain.

The competition between L-Dopa and amino acids coming from dietary proteins may thus account for the variations in the clinical response to identical doses of sinemet. This has been confirmed by clinical studies showing that reduction in dietary protein can lessen fluctuations of the blood level of medication when it is taken by mouth, and this has led to a new approach to treating fluctuations: the implementation of a "low-protein diet."

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the frequency of fluctuations, prolong the "on" time, and even allow a decrease in the total daily dose of L-Dopa. However, the enhanced effect of L-Dopa can also increase dyskinesias and hallucinations.

Clinical Applications
The low-protein diet is an inexpensive and less cumbersome way to decrease the fluctuations in mobility ("wearing off" and "on/off") secondary to L-Dopa therapy than the addition of other medications such as Bromocriptine or Fergolide. If the diet is appropriately followed, the improvement will become apparent within one week. If the patient is fully compliant with the diet and obtains no benefit, the diet can be discontinued after one week. It must also be stressed that this diet does not eliminate all proteins but redistributes them so that the bulk of proteins are taken in the evening. The help of a dietitian may be necessary to determine the minimal amount of protein intake that is necessary every day as well as the protein content of various foods.

In conclusion, the low-protein diet has been proven to be a useful adjunct in the treatment of the motor fluctuations associated with L-Dopa therapy. However, it is important to remember that eating is one of the pleasures of life and following this diet should not completely interfere with the pleasure of dining.

Principles of Application of the Low-Protein Diet
by Linda Perry, R.N., B.S.N.

Administering levodopa therapy (sinemet) away from mealtime is a worthwhile consideration to maximize dose response, given that protein interferes with sinemet absorption, and, consequently, dose effectiveness. At our Center we recommend taking sinemet one half-hour to one hour before meals. Taking this concept one step further, one may consider, with the advice of a physician, the low-protein diet, or more correctly described as the protein-redistribution diet. Research has indicated that many patients improve on low-protein diets and some are able to tolerate less sinemet.

Protein contains essential amino acids which are needed by our bodies to maintain healthy tissue; therefore, individuals normally provide adequate amounts of proteins in their daily diets. Most American diets include protein with each meal (breakfast, lunch and dinner). The United States RDA (Recommended Daily Allowance) of protein intake averages between 30 to 40 grams or more per day, specifically, one half (1/2) gram of protein per kilogram of body weight. The average diet often contains more protein than is actually needed by the body. Likewise, in some instances, diets are deficient in protein.

As previously mentioned in Dr. Saint-Hilaire's column, sinemet is normally administered during the day for symptom relief. The medication may work better in the presence of less protein: therefore, the total daily protein intake required (to maintain health) should be ingested no earlier than the evening meal.

Throughout the day, until the evening meal, all non-protein food items can be consumed. An individual may have as much as desired of any food which contains essentially no protein (trace-protein or low-protein items are acceptable up to 7 grams). At the evening meal, and thereafter, it is advised to consume the recommended daily allowance of protein. There appears to be individual variation in response to protein restriction, so the individual must sense for him or herself what works best. A nutrition book or diet manual which lists protein content of foods may be a helpful tool in menu planning and monitoring daily protein totals.

Discuss the protein redistribution diet with your doctor first before starting, as there may be reasons why your doctor would not recommend this approach.

After strictly adhering to the diet for one to two weeks, you will discover whether it makes a difference. If the diet is not working, simply discontinue using it. Report to your doctor any increase in abnormal involuntary movements should they occur. It is always a good idea to monitor your weight weekly.

To calculate how much protein one requires each day to maintain health (assuming one is within normal weight range), we start by converting our body weight (in pounds) to kilograms by dividing our weight by 2.2. Once we know our body weight in kilograms, we then figure we need one half (1/2) gram of protein for each kilogram of body weight. For example, a 140-pound individual weighs approximately 64 kilograms (140 divided by 2.2). If we know we require 1/2 gram of protein for every kilogram we weigh (and our weight is 64 kilograms), then one can calculate that our body needs approximately 32 grams of protein each day (1/2 of 64) to maintain health.

Throughout the day, an unlimited, unrestricted quantity of the following can be consumed, provided you are on no other dietary restrictions (such as a low-sodium or diabetic diet): coffee, tea, soda, fruit and vegetable juices, all fresh and dried fruits, all vegetables except beans (any kind), pop tarts, onion rings, potatoes cooked any way including french fries. Condiments, spices,
vinegar, butter, margarine, oils and fats (including salad dressings) are also allowed. Sugars, syrups, jams, honey, pickles, olives, hard candies, mints and sherbet are permitted. Graham crackers, soda crackers, saltines, melba toast and shortbreads contain only small amounts of protein. Some types of cereals are low in protein—read the labels and buy cereals that contain less than 2 grams of protein per serving. Eat cereal dry or with non-dairy creamer.

Foods that are high in protein should be avoided until the evening meal. These include all meats, both white and red, including cold cuts, hot dogs and sausage. All dairy products, including eggs, ice cream and cheese, should be avoided during the day along with cakes, brownies, pizza and chocolate.

**Sample Breakfast**
- fresh fruit dish or 1/2 grapefruit with honey;
- low-protein cereal with diluted non-dairy creamer and raisins;
- coffee, tea, juice;
- 6 oz. glass of vegetable or fruit juice;
- 2 latkes (potato pancakes);
- applesauce;
- coffee or tea;
- baked apple with cinnamon, sugar, and butter;
- low-protein cereal;
- coffee, tea, juice;

**Snacks**
fruit rollups, baked apples, pop tarts, graham cracker crust filled with sliced fresh fruit and topped with cool whip, sherbet, ice cream, five pretzel sticks, one slice of low-protein bread with butter, cinnamon or sugar.

**SUPPORT GROUPS**

This column will spotlight one of the 12 Parkinson's Support Groups currently existing in Massachusetts. The remaining 11 will be individually featured in future issues.

**A Visit to the Norwood Hospital's Parkinson's Support Group**
by Cathi Thomas, R.N., M.S.

In October, I had the pleasure of visiting the Norwood Hospital Parkinson Support Group, which meets weekly at the Ellis Nursing Home on Tuesday afternoons. The afternoon was very informative, but more importantly was fun. In attendance were individuals with Parkinson's disease, their family members and people who along the way have assisted the group and have remained active members.

Dorrie Heffernan, along with her husband Ed, shared some of the history of the group with me. When Mr. Heffernan was diagnosed with Parkinson's disease more than ten years ago, Mrs. Heffernan decided to start a group with 14 other families at the Norwood Hospital. They had previously attended a meeting at the South Shore Hospital on Parkinson's disease, and it was from this meeting that they realized the need to start a group in their geographical area.

Over the years, the group has had the support of several wonderful people in leading exercises, playing the piano, assisting with transportation and other important activities to keep things going. The group has made contributions to the national Parkinson's disease organization's funding research, celebrated Parkinson's Awareness Month, visited the governor of the Commonwealth and participated in many events to increase the awareness of Parkinson's disease. However, the most important thing the members of this group have done is offered support and shared personal experiences to many individuals and family members affected by Parkinson's disease.

In my history of working with Parkinson patients, I can recall many acts of kindness generated from this group.

The activities of each group meet-
ing are what keeps people coming back. First, a brief business meeting is held with a report from the officers. Then group members share new information that they may have come upon. This information usually includes a few funny stories and jokes that are enjoyed by all. If a guest is visiting the group, then an opportunity for his/her presentation follows. After this presentation, the group divides in two. Individuals with Parkinson’s disease participate in group exercises, and spouses get together for a short period of personal sharing. I don’t think I have to stress the importance of both of these activities in the successful management of Parkinson’s disease.

The remainder of the two-hour meeting is spent socializing. Mr. Finn plays the piano while everyone joins in dancing—my favorite part. At the end of the meeting, refreshments are served and members depart, sure to return the next week.

For those interested in inquiring about The Norwood Hospital’s Support Group, please contact:

Milton McNeil
President
(617) 782-3993 or

Dorrie Heffernan
(617) 762-2754

If you have questions on any of the other groups please call the Center at (617) 638-8456.

Mass. Chapter News
by Jeanne Murphy

This new year, 1990, is also a new decade for all of us. First, I want to wish everyone a happy and healthy New Year and then share with you the upcoming events planned for the Massachusetts Chapter.

To start the year off, we will be introducing a new fundraising project involving the sale of special note paper designed for the Massachusetts Chapter. Mr. Dick Coldstein, President of the South Shore Support Group, has greatly assisted us with this project. The cards, produced by Success Recognition, will be available for purchase at the end of January. The cards depict a beautiful New England Dock scene and are certain to be enjoyed by many. We will be asking chapter members, support groups, families and friends to purchase these cards to help raise funds for the chapter.

A date has been set for the Parkinson’s Symposium for patients, family members and interested parties. This day-long symposium will be held Wednesday, May 23, 1990 at the George Sherman Union Hall on Boston University’s main campus. This late date was chosen because the students will be gone for the summer and parking will be plentiful. Dr. Ira Shoulson, a renowned specialist in Parkinson’s disease, will present the keynote lecture. Dr. Shoulson is one of the principle investigators who developed the multi-center DATATOP study. This study has investigated the theory that Deprynel (Eldepryl, Somerset) may slow the progression of Parkinson’s disease. In addition, we will have other presentations which will greatly assist individuals living with Parkinson’s disease. We would like this symposium to be very upbeat, with people leaving with very positive feelings. To register for this conference, please call the Information and Referral Center at (617) 638-8456. Tuition will be $15 per person, including lunch. Please make every effort to attend this conference.

Finally, the Fourth Annual Walkathon will be held April 21 at Cleveland Circle. We are desperate for volunteers to help make this walk a success. We are also trying to locate an honorary chairperson to help lead the walk. If anyone has any suggestions, please contact me as soon as possible. Each year the walk gets bigger, but there is certainly room for improvement. Those individuals who participate enjoy the experience!

With best wishes,
Jeanne Murphy

Officers
Jeanne Murphy, President
Suzanne Morin and Midge Stahoviak, Vice Presidents
Robert Sartini, Treasurer
Cathi Thomas, Secretary
Sophia Camann, Chairperson of Fundraising
As the Snow Falls—Don’t You!

The winter months are upon us. Snow and ice accentuate the risk of falling for everyone, so this is a good time to share safety tips to prevent falls.

One symptom that many individuals with Parkinson’s disease experience is postural instability (difficulty with balance). Sometimes this balance problem cannot be alleviated with Sinemet, and, in some cases, the medication may be a contributing cause (presence of involuntary movements).

Listed below are preventive strategies to reduce the likelihood of falling and remember, always ask yourself if it is safe to proceed with whatever activities you are doing.

- Maintain a regular program of exercise. Regular physical activity improves strength, muscle tone, and allows individuals to move easier with less rigidity.
- Keep your environment safe: make sure hallways, stairs and living areas are free of clutter; arrange furniture to allow more room for movement; check that all carpets are secured to the floor; remove throw rugs; keep areas well lit; install grab bars in bathroom, shower and dressing areas; and use a shower seat. Don’t wax floors, and keep outdoor stairs and walkways free from ice. Have a plan for snow removal beforehand.
- Dress sensibly: avoid high heels, backless shoes, rubber-soled shoes, and floppy slippers. Isotoner slippers and shoes with suede traction are great. Do not walk in stocking feet.
- Make life easier for yourself: use a cordless phone; use stores that deliver; attach a basket to your walker; and ask for a helping hand, especially when walking in crowded areas.
- Always use caution when getting up or changing position; use an assistive device when prescribed (cane, walker); remember to stand straight; walk with feet eight inches apart and make U turns; and finally, allow extra time in planning and avoid rushing.

PARKINSON CENTER HAPPENINGS 1989

- **July**
  Marie Saint-Hilaire, M.D., spoke to members of the Emerson Hospital Support Group in Concord, Mass. Dr. Saint-Hilaire also attended the International Congress of Psychiatry and Neurology in Montreal and presented a paper on hallucinations in Parkinson’s disease.

- **September**
  Cathi Thomas and Kathryn Cullen, R.N., M.S., coordinator of the Pawtucket Memorial Hospital Information and Referral Center, attended the Canadian Parkinson Foundation’s annual meeting in New Brunswick, Canada, and presented information on the role of the APDA Information and Referral Centers in the United States.
  Linda Perry, R.N., spoke to members of the North Shore Parkinson Support Group in Saugus, Mass.

- **October**
  Cathi Thomas visited the Norwood Support group at the Ellis Nursing Home.
  Dr. Robert Feldman and Dr. Marie Saint-Hilaire hosted Grand Rounds in Parkinson’s Disease for neurologists, sponsored by Somerset.
  Cathi Thomas presented a lecture on Parkinson’s disease to members of the Graduate Gerontology Nursing Program at the University of Massachusetts.
  Dr. Marie Saint-Hilaire presented a lecture at the Parkinson Symposium held in Tulsa, Okla.
  Linda Perry visited the Cape Cod Parkinson Support Group.

- **November**
  Peter Moshach, Ph.D., presented a lecture on coping with Parkinson’s disease to the Cape Cod Support Group.
  Cathi Thomas spoke to the Worcester Parkinson Support Group.
  Dr. Robert Feldman provided the keynote address to the APDA Parkinson Symposium in Arizona.
  Cathi Thomas presented a lecture to the home-care department at Whidden Memorial Hospital.
  Kathryn Isaac, M.D., presented a lecture to the North Shore Parkinson Support Group in Saugus, Mass.

- **December**
  Dr. Robert Feldman presented a lecture on the management of Parkinson’s Disease at the symposium “Current Concepts in the Treatment of Parkinson’s Disease and Other Movement Disorders,” in Greenwich, Conn.
Progress Notes
A Report from the Parkinson's Disease Center
at Boston University Medical Center
720 Harrison Avenue, Suite 707
Boston, MA 02118-2393