Kinds of Care

By Diane B. Breslow, MSW, LCSW

Care choices nowadays can be confusing and ambiguous, to say the least. What follows is an overview of the spectrum of care for adults with physical impairments or chronic disease. Although all programs are not specific to movement disorders, all of the levels discussed are potentially appropriate for people with movement disorders.

That said, it is acceptable and recommended that family caregivers ask about a staff’s experience with Parkinson’s and other movement disorders. Family members should also make providers aware of the symptoms and needs of neurologically impaired patients and offer to locate educational materials, speakers, and in-service training for staff.

No matter where your loved one lives or participates in programs such as those described here, he or she should always have a completed Vial of Life form (so-called because some people roll it up and keep it in a bottle in the refrigerator) on their person or in a specified location in their living space. It should contain the following information:

- date
- name, address, phone number
- medications, with dosages and frequency or times
- drug allergies
- medical conditions
- surgeries (including year)
- blood type
- power of attorney for healthcare
- two emergency contacts

The Vial of Life should be regularly reviewed and updated.

ADULT DAY PROGRAMS

Participants in older-adult day programs (also called adult daycare centers) typically exhibit cognitive, social, and/or functional limitations and therefore require supervision and structure. Adult day programs not only benefit the participants but also provide family caregivers a respite.

These daylong community-based social and recreational programs are provided in safe, secure group settings. Most programs offer some health-related services, such as medication reminders. Other features include transportation; lunches and snacks; assistance with or supervision of eating, walking, and toileting; exercise; socialization and peer support; social work services; and on-site or on-call nursing. Services and fees vary by program and location.

REHABILITATION

Rehabilitation therapies can offer safety instructions and help to restabilize functioning, even for a person with a degenerative disorder such as PD. Physical, occupational, and speech therapies can be provided in multiple settings: day treatment centers, the home, inpatient units of rehabilitation institutions, and outpatient centers.

Skilled therapy is prescribed by a physician—in the case of PD, either a movement disorders neurologist or a physiatrist (rehabilitation physician). It is covered by Medicare and private health insurance if the person is
Kinds of Care
continued from front cover

not already receiving insurance-covered therapies in more than one setting at the same time.

**Inpatient rehabilitation:** Large, dedicated rehabilitation facilities offer inpatient as well as all other levels of rehab treatment. Admission is based on the ability to participate in and benefit from daily, intensive, multiple therapy sessions.

**Day rehabilitation programs:** Some rehabilitation facilities offer day rehabilitation in addition to inpatient and outpatient rehab services. A concentrated, somewhat intense community-based treatment program, day rehabilitation encompasses all of the skilled rehabilitation therapies—occupational, physical, and speech. To qualify, a patient must be able to undertake three hours of therapies each day.

**Outpatient therapy:** Since outpatient therapy is provided in a community clinic setting, the patient must be able to leave the home. Sessions of physical, speech, or occupational therapy usually last one hour.

**In-home therapy:** In-home therapy refers to physician-ordered skilled rehabilitation therapy—speech, physical, or occupational—for patients who are homebound. A registered nurse opens and oversees the care. The patient is eligible to also have a bath aide during the course of rehabilitation.

**LONG-TERM CARE FACILITIES**
Long-term care facilities are on a spectrum from most to least independence.

**Continuing care retirement communities:** CCRCs are residential, gate-secured campuses that guarantee lifelong care beginning with independent living (cottages or apartments) and progressing to assisted living and then skilled (nursing home) care. They have substantial entrance fees.

**Independent living:** Independent living is a broad term encompassing senior apartments, active communities, and retirement homes. These buildings are not licensed to provide personal care or nursing services, though residents may contract for private-duty care. These independent-living facilities offer such amenities as 24-hour security, transportation, and activity programs. Retirement homes usually have group dining, but senior apartments and active communities may not.

**Assisted living:** Assisted living refers to a building’s or a specified part of a building’s being licensed to provide personal care 24 hours a day. Trained and certified caregivers assist with daily tasks such as bathing and dressing, escort residents
to meals, set up and dispense medication, and routinely check on residents. Assisted living also provides housekeeping, social programs, and transportation to and from medical appointments, errands, and group outings. Some facilities may offer rehabilitation therapies, hospice care, and specialized care for different disorders.

**Nursing homes:** Nursing homes are licensed and regulated by state and federal governments to provide skilled care from registered nurses and certified nurses’ aides 24 hours a day. Physicians serve as medical directors. Everything from activities to nutrition, personal care, environmental safety, and staff-to-resident ratios must meet state and federal guidelines.

There are levels of care within nursing homes. Some residents require only custodial care—personal care with such activities of daily living as bathing, dressing, and toileting. Other residents require nurses to care for wounds, administer intravenous medications, help with eating, and manage machinery such as a respirator or a ventilator.

Medicare and supplemental insurance policies cover 100 days of nursing home care that results from a hospitalization and meets the criteria for rehabilitation therapies. After the rehab portion, residents pay privately and/or through their long-term care insurance.

**Hospice or palliative care:** Hospice or palliative care is compassionate, supportive, and interdisciplinary end-of-life care for patient and family. It can occur in one’s home, a long-term care facility, an inpatient hospital unit, or a freestanding dedicated hospice building. One must have a physician’s order and an evaluation by the hospice nurse or doctor to qualify. Hospice care is covered by Medicare.

*Over her long career in social work, Diane Breslow, center coordinator and licensed clinical social worker, has been privileged to work in the entire spectrum of care she discusses here.*

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**Helpful Resources**

- Area Agencies on Aging
  www.aoa.gov

- Eldercare Locator
  800-677-1116
  www.eldercare.gov

- Medicare
  800-MEDICARE (800-633-4227)
  www.medicare.gov


- National Association of Professional Geriatric Care Managers
  520-881-8008
  www.caremanager.org

- Social Security Administration
  800-772-1213
  www.ssa.gov

- Veterans Helpline
  800-827-1000
  www.va.gov

**CAREGIVER ASSOCIATIONS**

- Family Caregiver Alliance
  800-445-8106
  www.caregiver.org

- National Alliance for Caregiving
  301-718-8444
  www.caregiving.org

- National Family Caregivers Association
  800-896-3650
  www.nfcacares.org
Neurologists Join Lake Forest Affiliate

Neurologists Charulatha Nagar, Laura Goldstein, and Ian Katznelson recently joined Northwestern Lake Forest Hospital’s new neurology practice, which collaborates with the Northwestern Parkinson’s Disease and Movement Disorders Center.

These physicians provide comprehensive, highly specialized neurological expertise and therapies for patients with Parkinson’s disease and other complex neurological conditions. The Lake Forest practice also offers patients access to related subspecialists, neurosurgeons, and clinical trials in Chicago.

The three physicians, all board certified in neurology, are part of the Northwestern Medical Faculty Foundation and teach at the Feinberg School of Medicine.

Nagar has been seeing patients in Lake Forest for more than seven years. She trained in neuromuscular disorders and clinical electromyography at Washington University in St. Louis and has more than a decade of clinical research experience. She is especially interested in vascular neurology. In addition to her work at the hospital, Nagar counsels stroke victims and their families.

Since 1990 Goldstein has been treating suburban Chicago residents who have a range of neurological disorders. Besides neurology, she is board certified in electrodiagnostic medicine, which evaluates the peripheral nervous system. She graduated from and did her residency at the University of Michigan Medical School before completing a fellowship in clinical electrophysiology at the University of Iowa. Goldstein came to Northwestern Lake Forest Hospital from Northwest Community Hospital, where she was the chief of neurology since 2008 and director of the stroke program since 2007.

Katznelson, a graduate of the Feinberg School, is board certified in clinical neurophysiology and sleep medicine in addition to neurology. He completed his residency at Washington University in St. Louis and trained in clinical neurophysiology at Rush University Medical Center. He brings to his new position nearly a decade of experience, including three years as the medical director of the sleep lab at Resurrection Medical Center.

These physicians are accepting new patients at their office at 800 North Westmoreland Road, Suite 102, Lake Forest. The phone number is 847-735-8550.
Welcome, New Staff

Roneil Malkani, MD
Roneil G. Malkani earned an MD at the George Washington University School of Medicine in 2004. After a postdoctoral fellowship at the National Institute on Aging, he completed a residency in neurology and fellowships in movement disorders and in sleep medicine at Northwestern. He sees patients with movement and sleep disorders. His research focuses on sleep disruption in those with neurodegenerative disorders such as Alzheimer’s and Parkinson’s diseases.

To make an appointment with Dr. Malkani, please call the neurology clinic at 312-695-7950.

Kathleen Nannini-Zaruba, RN
Kathleen Nannini-Zaruba has been a practicing registered nurse for four years in medical/surgical, operating room, and general surgery outpatient care. She comes to Northwestern Memorial Hospital from NorthShore University HealthSystem. She also has experience reviewing short-term disability claims for MetLife; she worked for two large insurance and financial companies before her nursing career.

Nannini-Zaruba has a bachelor’s degree in psychology and a master’s degree in education, with a concentration in counseling psychology, from Loyola University. She received her BSN from North Park University.

Christina Warner
Christina Warner is a clinical research coordinator for the Parkinson’s Disease and Movement Disorders Center. The study protocols she oversees include Phase I, II, and III clinical trials, notably the multisite Parkinson’s Progression Markers Initiative sponsored by the Michael J. Fox Foundation. As a coordinator, Warner facilitates and coordinates multidisciplinary clinical research studies.

Warner graduated cum laude from Knox College with a degree in psychology. She is a founding member and president of the Chicago Mortar Board Chapter.

Emergency ID Bracelets Available to Chicagoans

The Chicago Police Department encourages people over age 60 and people of any age with disabilities to obtain an emergency identification bracelet.

The bracelet contains a confidential code number that is linked to emergency information filed at one’s local police station. If the wearer is injured or incapacitated, authorities may call the phone number on the bracelet to access the information. Not only will prompt, appropriate care be possible, but designated people can be notified in case of an emergency.

Chicago residents should contact their local police station to obtain an application for the bracelet.
First Moving Day Exceeds Fundraising Goal

The National Parkinson Foundation’s inaugural Moving Day Chicago last October raised in excess of $230,000, more than twice the original fundraising goal of $100,000. The Northwestern Parkinson’s Disease and Movement Disorders Center, the only NPF Center of Excellence in Illinois, will use its portion of the proceeds to help establish exercise programs for people with PD throughout the Chicagoland area. Across the country, proceeds will be used to improve the quality of PD care through research, education, programs, and outreach.

Chicago observed Moving Day with a 5K fun run/walk featuring a family-friendly short course and a movement pavilion hosted by Northwestern’s Parkinson’s Center. The pavilion showcased yoga, dance, Tai Chi, and Pilates, all of which have been shown to help manage the symptoms of PD.

Moving Day will return on October 20. Further information is available at www.movingdaychicago.org.
Joanna Blackburn, one of the nation’s few pediatric neurologists specializing in movement disorders, has joined the faculty of the Feinberg School of Medicine to build a multidisciplinary pediatric movement disorders clinic at the affiliated Ann and Robert H. Lurie Children’s Hospital of Chicago. She is an assistant professor of pediatrics at the Feinberg School and a neurology attending physician at Lurie Children’s Hospital.

Movement disorders is a relatively new and growing field of child neurology. In contrast to adults, movement disorders in children may involve an excess of movement. Movements are involuntary and can cause the body to move too much or too little or can impair coordination and balance, interfering with the ability to perform daily living activities.

Blackburn’s specialty is the diagnosis and treatment of pediatric movement disorders such as tics, tremor, dystonia (twisting and repetitive movements or abnormal postures), chorea (brief irregular movements), and ataxia (incoordination). She is board certified in neurology with special qualifications in child neurology.

She received her MD degree from the University of Rochester School of Medicine and did a pediatrics residency at New York University. She completed her residency in child neurology at the former Children’s Memorial and Northwestern Memorial Hospitals in Chicago and a fellowship in pediatric movement disorders at the University of Rochester.

Blackburn is a member of the Child Neurology Society, the American Neurologic Association, and the Movement Disorders Society.
NPF Recommends
Annual Screening for Depression

Following up on the findings of its Parkinson’s Outcomes Project, the National Parkinson Foundation recommends that all people with Parkinson’s get screened for depression at least once a year.

NPF created the project to help researchers identify what treatment and care strategies have the greatest impact on lessening the symptoms of PD. The project found that depression is the number one factor influencing a person’s health.

The project has resulted in a comprehensive database of information on more than 5,000 patients who have been evaluated in a clinic by expert neurologists and followed in 20 NPF Centers of Excellence. NPF is studying the differences in care provided by leading experts.

Since negative mood and depression are the most important factors contributing to the health and well-being of someone living with PD, referring a patient diagnosed with depression to a therapist for treatment is paramount.

“It’s very important that depression is considered just as important as any of the other physical symptoms of Parkinson’s,” said Michael Okun, NPF medical director. “As this report shows, improving mood is one of the most significant ways to address the other aspects of Parkinson’s.”

For doctors, diagnosing depression can be difficult, however, because some symptoms of PD—such as a masked facial expression, sleep problems, and fatigue—overlap with symptoms of depression. In fact, studies show that depression goes unrecognized or undertreated in the majority of people with PD. It is important, therefore, that people discuss even subtle changes in mood promptly with their doctors and understand that depression is a disorder, not a character flaw.

Since PD affects chemicals in the brain that are responsible for the way we feel, depression can be caused by the underlying disease process. Ongoing stress, sadness, and social isolation that result from living with a chronic disease...
can also trigger, or worsen, the condition.

NPF recommends a comprehensive, holistic approach to depression. Treatments with antidepressant medications, independently or in combination with exercise, psychotherapy, and behavioral techniques, are very effective. “Cognitive behavioral therapy—teaching coping strategies, building on self-efficacy, and thinking positively—is a very important part of a person’s overall wellness,” Okun said. “Each individual’s treatment plan should be tailored to his or her symptoms, preferences, and other illnesses.”

As NPF researchers continue to analyze the growing collection of data, they will establish a standard of care that has been “tried, true, and tested” and can inform proactive treatment plans. Ultimately, the purpose of the Parkinson’s Outcomes Project is to help people who have PD to live not only longer but also healthier, more active lives.

The full report on the Parkinson’s Outcomes Project can be found at www.parkinson.org/outcomes.

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**Parkinson’s Disease Classes**

**Integrated Fitness for Parkinson’s**

**Monday, Wednesday, and Friday**

11–11:45 a.m.
Rehabilitation Institute of Chicago Center for Health and Fitness
Call 312-238-5001

**Tuesday and Thursday**

4–5 p.m.
RIC Northshore Day Rehab and Outpatient Center
Call 312-238-5007 or 312-238-5009

**Amplitude-Based Training: Advanced Exercise Class for People with Early-Stage Parkinson’s Disease**

**Time varies by location**
Downtown Chicago, Willowbrook, and Deerfield
Call RIC Center for Health and Fitness, 312-238-5001

**Neurology Arts Lab: Express Yourself through Art and Music**

**Second and fourth Monday**
1–3:30 p.m.
Room Q, third floor, Prentice Women’s Hospital
250 East Superior Street, Chicago
Call 312-503-3320 or email trupti@northwestern.edu

**Integrated Medicine Classes: Tai Chi, Yoga, Positive Psychology**
Call Northwestern Integrated Medicine, 312-926-3627
In the Words of a PPMI Participant

Hi. My name is Dan Rouleau and I am from northern Michigan. Not the northern Michigan you are probably thinking of, such as Traverse City. I’m much farther north than that. I live in the small town of Hancock, located in the Upper Peninsula—420 miles north of Chicago, to be exact.

So, as you can tell, I have a long way to travel to be a participant in the Parkinson’s Progression Markers Initiative, but I would travel that distance 10 times over if it meant finding a cure for Parkinson’s disease.

After being diagnosed with Parkinson’s, I enrolled in the PPMI study in July 2012 and have had nothing but a positive experience so far. The people within the study at Northwestern Memorial Hospital—Karen Williams, Christina Warner, and Dr. Tanya Simuni—have been great to work with. I feel like I am part of a team, working together for a common goal.

Teamwork is something that I am very familiar with. This winter is my 18th year coaching high school hockey. Being part of the study gives me hope that PD will not determine when I have to stop coaching, but rather that I’ll retire on my own terms. I have always loved to play the game of hockey, starting when I was 4 years old, and began coaching youth hockey at the age of 23. It has always been a big part of my life.

Now, since joining the PPMI, I am part of a much bigger team against an opponent we would all like to beat!
study to assemble a population of sufficient size to draw meaningful scientific conclusions over time and try to develop better ways to measure the progression of PD. The information gathered will be critical to the future development of new and better treatments for PD.

In the observational study, participants will undergo numerous tests and assessments of bodily processes related to PD but will not receive an experimental drug or treatment. The study will use a combination of imaging techniques; collection of blood, urine, and spinal fluid; and clinical tests.

For more information, please call the center’s research team at 312-503-0755.

Reported by the Project Management Office, Feinberg School of Medicine
Movement Disorders Clinical Trials For information on participating in any of the following movement disorders clinical trials, please call 312-503-0755.

EARLY PARKINSON’S DISEASE
PPMI Study The objective is to identify clinical, imaging, and biologic markers of PD progression for use in clinical trials of disease-modifying therapies. The study is recruiting PD subjects diagnosed within the last two years who are not currently taking medications and do not require therapy for at least six months. It is also recruiting non-PD subjects, especially males under age 65, as controls. Funded by the Michael J. Fox Foundation.

FS-Zone The primary objective is to assess the impact of pioglitazone (Actos) on the progression of PD in order to determine whether to proceed with further study of this agent. Funded by the National Institute of Neurological Disorders and Stroke.

ADVANCED DISEASE
Amantadine This study is looking at the potential benefits of the FDA-approved medication amantadine on freezing of gait. Patients are required to be both on and off medication. Participation includes four clinic visits and one telephone interview.

Selegiline The purpose is to measure the efficacy of Selegiline in reducing fatigue symptoms in PD patients. Participation requires three days at the clinic and telephone calls.

SLEEP DISORDERS IN PARKINSON’S DISEASE
Circadian Rhythms in PD This study is looking at how the biological clock works in patients with PD. Sleep patterns, daytime sleepiness, and melatonin blood levels are being examined. Participation lasts two to six weeks and includes one or two three-night sleep studies. Participants are compensated for their time and travel. Funded by the Paul Ruby Foundation for Parkinson’s Research.

CERVICAL DYSTONIA
CD-Probe This observational study is designed to capture current diagnosis and treatment approaches for CD and their effects on patients’ quality of life. Patients are asked to complete questionnaires during four clinic visits and two telephone interviews after Botox injections. Funded by Allergan.

CD-FLEX The purpose is to evaluate whether short, flexible dosing (6 to 10 weeks) of Xeomin is more effective than long, flexible dosing (90 days to 16 weeks). Patients are asked to complete questionnaires during 10 to 12 clinic visits. Funded by Merz.

Consider making a personal contribution to research by participating in a clinical trial. Clinical research may lead to the discovery of new possibilities in the control or the delay of Parkinsonian symptoms. All study-related care is provided at no charge. For information about participation in clinical trials, please contact the Movement Disorders Research Office by phone at 312-503-0755, by fax at 312-503-0787, or by email at parkinsons@northwestern.edu.

The Parkinson’s Disease and Movement Disorders Center participates in preclinical and clinical research in order to extend the knowledge and treatment of movement disorders. Recognized by the National Parkinson Foundation as a Center of Excellence, the center’s multidisciplinary group of neurologists and neurosurgeons are continuously engaging in cutting-edge research.
NPF Town Hall Meetings: 
Achieving Excellence in Parkinson’s Disease

Did you know that the largest clinical study of Parkinson’s disease is currently being conducted by the National Parkinson Foundation?

NPF’s Parkinson’s Outcomes Project was designed to study how the best care affects real people with Parkinson’s disease, at every stage of their disease. NPF is studying more than 6,000 people with Parkinson’s in 10,000 clinical evaluations and counting.

More than ever before, this project is helping us to understand how expert care changes the lives of people with Parkinson’s throughout the course of their disease.

As this project grows, NPF is traveling around the country to explain and discuss findings from the study with the Parkinson’s community. To date, key findings include the importance of treating depression (see page 8), the impact of differing approaches to Parkinson’s care at different NPF Centers of Excellence, the importance of exercise, and the processes by which this project arrived at these findings.

JOIN US TO LEARN ABOUT THIS EXCITING RESEARCH
Come to one of the NPF Town Hall Meetings scheduled in the cities below to learn from the researchers and to take part in the search for better therapies.

What are we learning?
- Even the best doctors sometimes treat Parkinson’s differently, and those differences provide lessons for everyone.
- Depression is a much more important problem than previously thought, but there are things you can do to feel better.
- Often doctors and patients don’t know what to expect. Are you doing well or could you be doing better? We are shedding new light on this.
- How is exercise helping people?
- Can we understand the importance of a great care partner? What makes it hard to be a care partner? How can we make it easier?

Although attendance is free, seating is limited and an RSVP is required. To RSVP, please call our helpline at 800-4PD-INFO (800-473-4636) or visit www.parkinson.org/townhall. For more information on the Parkinson’s Outcomes Project, visit www.parkinson.org/outcomes.

Chicago  April 6
Baltimore  May 18
Gainesville, Florida  June 4
Portland, Oregon  Fall (date TBD)
Boston  Fall (date TBD)
Kansas City, Kansas  Fall (date TBD)
Support Group Attends Show about PD

A private performance of the one-man show *Side Effects May Include* was offered to Parkinson’s Center’s Support Group members, families, and friends at the Greenhouse Theater in Chicago in January.

*Side Effects May Include* was written by former Seinfeld writer Marc Jaffe and Broadway playwright Eric Coble. It is a funny and touching true story about Jaffe’s journey with his wife as she experiences early-onset Parkinson’s disease. *Side Effects May Include* is being offered to theater groups around the country. Ten percent of ticket sales go to the charity *Shaking with Laughter* in support of the Michael J. Fox Foundation.

Holiday Celebration Features Center Volunteer’s Jazz Quartet

Parkinson’s Center volunteer Peter Kim (at right in photo) and his quartet performed at the center’s annual year-end celebration in December before a packed audience of Parkinson’s Center’s Support Group members, families, and friends. The quartet played a medley of jazz and holiday songs.

A monthly program hosted by the center, the support group offers dance and exercise therapy, lunch, and a presentation relevant to both those living with Parkinson’s disease and their caregivers.

For more information about the support group, please call Trupti Patel at 312-503-3320 or visit [www.parkinsons.northwestern.edu/support_groups.html](http://www.parkinsons.northwestern.edu/support_groups.html).
WE’RE GRATEFUL FOR SUPPORT

Recent philanthropic successes are benefiting the cooperative efforts of researchers, educators, and clinical caregivers at the Northwestern Parkinson’s Disease and Movement Disorders Center.

For the second year in a row, the center’s advisory council has funded competitive grants for junior investigators conducting Parkinson’s research. Two researchers have each received a grant of $25,000 from the advisory council, a collaborative effort of Northwestern Memorial Foundation and the Feinberg School of Medicine Development Office.

The Paul Ruby Foundation for Parkinson’s Research contributed $100,000 to a formal grants initiative to support Parkinson’s research projects through Northwestern Memorial Foundation; more information is available at www.paulrubyfoundation.org. In addition, the annual Sub5 Century Challenge bicycle ride, last held in September 2012, contributes to the foundation’s support for Parkinson’s research.

We are grateful for the generous efforts of volunteers, donors, and thankful patients, many of whom are members of our advisory council. All gifts play a direct and significant role in the center’s ability to offer a wide variety of services to patients and families and to pursue cutting-edge basic and clinical research.

If you have an interest in becoming involved with the advisory council, or in making a gift to support Parkinson’s research or clinical care at Northwestern, please contact Jorie Parwani of Northwestern Memorial Foundation at 312-926-4198 or Barbara Monroe of the Feinberg School of Medicine at 312-503-0761.
Calendar

LAKE FOREST PARKINSON’S DISEASE PATIENT AND FAMILY SYMPOSIUM
Saturday, May 4, 9 a.m.–12:30 p.m.
Northwestern Lake Forest Hospital
660 North Westmoreland Road, Lake Forest
Call 312-926-8400

PARKINSON’S DISEASE ANNUAL PATIENT AND FAMILY SYMPOSIUM
Saturday, October 19, 9 a.m.–12:30 p.m.
Northwestern Memorial Hospital
251 East Huron Street, Chicago
Call 312-926-8400

MOVING DAY CHICAGO
Sunday, October 20, 9 a.m.–12:30 p.m.
Lincoln Park Grove 2, Chicago
Call 312-505-7602
www.parkinson.org