



Young Parkinson's Handbook

A Guide for Patients and Their Families



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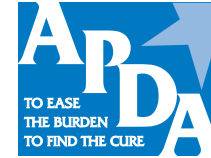
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This handbook is a guide for Parkinson's disease patients and their families and is not intended as a substitute for medical diagnosis and treatment.

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A Note from the Editors

We believe it is essential for young people with Parkinson's disease and their families to have updated information about the unique aspects of young onset Parkinson's disease. It is that belief which led to the publication of this new edition of the *Young Parkinson's Handbook*. This book was written with the goals of answering your questions and providing information that will help you navigate your way through the maze of medical, psychological, and financial issues you and your family may encounter. It is our hope that you will be able to use this handbook as a reference, and return to it again and again as you explore different subjects over time.

As you read this handbook, keep in mind that Parkinson's disease affects each person differently. Because the information presented is meant to be broad and inclusive, and because symptoms vary from person to person, not all information will apply to you or your current circumstances.

We want to thank all of the authors who devoted their time and expertise to this publication. Their dedication to the PD community, particularly to young people and their families, made this resource possible.

A special thank you to Arlette Johnson who, after being diagnosed with PD at a young age, led the way in supporting young people with PD by conceiving and editing the first APDA *Young Parkinson's Handbook* and establishing the first Young Onset Information and Referral Center. Today, APDA is proud to have the only National Young Onset Center with a full-time director dedicated solely to supporting young people whose lives are impacted by Parkinson's disease.


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Part I

Learning the Basics

Whether you are newly diagnosed, have been living with Parkinson's disease for some time, or know someone who is affected by it, we hope you will find this summary of "the basics" helpful. By developing an understanding of what is happening in the body and the brain, the available treatment options, and some of the unique features of having this disease at a young age, you will have a better foundation for making important healthcare decisions now and in the future.

What is Parkinson's Disease?

By Michael Rezak, MD, PhD

Parkinson's disease (PD) is a movement disorder that is caused by the deficiency of a substance in the brain called dopamine. Dopamine is a neurotransmitter that is produced by cells (neurons) in a region of the brain known as the *substantia nigra*. When approximately 60-80% of the dopamine neurons are lost, motor symptoms of PD begin to emerge. Although we know that PD symptoms are caused by a depletion of dopamine in the brain, we do not as yet fully understand what mechanisms or conditions cause the degeneration to occur.

The diagnosis of Parkinson's disease is made on clinical grounds, meaning that the person is examined by a physician who determines whether the following cardinal features of the disease are present:

- Tremor at rest (tremor when the limb is not in use)
- Bradykinesia (slowness)
- Rigidity (stiffness)
- Loss of postural reflexes (balance problems)

Not all of these features need to be present to make the diagnosis. Currently, there is no definitive test for Parkinson's disease. Instead, there are a series of physical and cognitive assessments used by your healthcare team to determine the diagnosis and rule out the existence of other conditions that may have symptoms similar to those of PD.

It is now known that Parkinson's disease can encompass more than just motor symptoms. In some people these non-motor symptoms may affect quality of life more than the motor symptoms. They can include sleep problems, pain, loss of sense of smell, cognitive and psychiatric symptoms, and problems with blood pressure, bowel and bladder function, and sexual functioning. In a recent neuropathological study, it appears that changes in other parts of the brain may predate the loss of dopamine neurons in the substantia nigra. This could possibly explain the fact that many patients may have loss of sense of smell, sleep disorders, depression and other symptoms well before their motor symptoms begin. Currently, these changes often associated with Parkinson's disease are being further investigated in the hope of discovering ways to predict who is likely to get PD and how to prevent it.

Although the neuropathology and most clinical symptoms are the same at whatever age PD develops, there are some unique characteristics and treatment strategies that require consideration when PD occurs at an early age.

What is Young Onset Parkinson's Disease?

When Parkinson's disease is seen in individuals under the age of 40, it is called "young onset" Parkinson's disease (YOPD). However, the age range considered young onset varies somewhat depending on the source.

It is estimated that approximately 10% of the 1.5 to 2 million people with PD in the United States fall into the YOPD category, strictly defined as occurring between the ages of 21-40. The number of cases may actually be much higher than 10% of the PD population because Parkinson's disease is often overlooked as a possible diagnosis in younger patients. As a result, many young people travel a circuitous route in order to attain eventual diagnosis. Although the diagnosis is not a welcome one, for many young people it ends a lengthy process of referrals to a variety of medical specialists searching for the cause of their symptoms. Once the diagnosis is made, some express relief that this was "not just all in my head," and that they now have a name and medical treatment for what they have been experiencing.

Although both environmental and genetic causes for YOPD have been implicated, it appears genetics may play a greater role in the development of PD in those with young onset than in those with later onset. A number of genes have been identified as possible players in the development of PD, but more research is needed to determine how each of these genes specifically functions (see *Genetics* section).

Unique Characteristics of YOPD

There are some physical, emotional, and social characteristics as well as medical management implications that are unique to YOPD:

Dystonia Symptoms in up to half of those with YOPD begin with *dystonia*, an uncontrollable stiffness or cramping of a muscle group or limb. A cramp or ache in a specific area of the body, commonly in the foot or shoulder, is a very common initial symptom of young onset PD. Individuals often report “early morning dystonia” which may interrupt sleep.

Dyskinesia and Motor Fluctuation There is a greater tendency in young people to develop dyskinesias (involuntary body movements) and fluctuations in movement over time when taking the PD medication levodopa.

Disease Progression Recent data has shown that those with young onset PD tend to have a more slowly progressive course and a smoother course of the illness than their older counterparts.

Cognition (Thinking) Problems with dementia appear to occur less frequently in younger patients.

Emotional and Social Issues YOPD occurs at a time when young people already have a very full life. Managing career and family obligations along with the stress associated with the presence of a chronic disease can prove to be a challenge to all members of the family. For some, the most difficult aspect of YOPD is an uncertain future. Questions abound, such as: Will I be able to continue working? What kind of medical bills can I expect? Will I still be able to function as a nurturing parent and spouse? Fortunately, due to its typically slower progression and the considerable number of medications now available for the control of symptoms, many young people find they are able to continue the work, social, and recreational activities they enjoy for many years.

Coming to terms with the diagnosis and challenges of the disease over a lifetime can be difficult. The patient and his or her family members are likely to experience a wide range of emotions as they try to manage this unexpected change in their lives. Many find a sense of support when they are able to communicate with others who are living with YOPD. Young onset PD support groups, online discussion groups, and various programs offered by the APDA and other Parkinson’s organizations offer the opportunity to meet and to share

information and resources with other young people and their families. Professional counseling can also be very beneficial. Individual counseling can provide a private place to talk about the impact PD may be having on you and your family, and family counseling can facilitate better communication between all family members and help everyone develop healthy ways of adapting.

Medical Management

Currently, no treatment has been shown to definitively slow or stop the progression of PD. Instead, therapy is directed at managing the symptoms of the disease. Treatment typically includes the use of medications and surgical intervention. Other treatment approaches include physical therapy, occupational therapy, speech therapy, and general lifestyle modifications such as diet and exercise.

Principles to be considered with regard to the medical management of Parkinson’s disease are as follows:

Symptomatic Treatment Treatment usually begins when the person with YOPD feels that his or her symptoms are affecting motor or social functioning to the extent that the ability to enjoy a meaningful quality of life or maintain employment is being compromised. Treatment is typically focused on the most bothersome symptoms, and medications can often be targeted to particular symptoms, such as management of tremor.

Levodopa Currently, levodopa is considered the most effective drug for controlling the symptoms of Parkinson’s disease. Levodopa is modified by brain enzymes to produce the chemical dopamine, which the brain needs to properly control muscle movement. When there is a deficiency of dopamine, it negatively affects motor functioning and results in the symptoms of PD. While almost all people with PD will be taking levodopa at some point, its use should be delayed for as long as possible, particularly in young people. This is because the length of time levodopa is taken has been shown to be related to the development of motor complications, such as excessive movements (dyskinesias) and motor fluctuations. Once introduced, levodopa should be utilized at the lowest doses possible when: 1) an inadequate response is obtained with other medications, or 2) side effects are encountered with other medications at doses required to achieve the necessary response.

Other PD Medications Because long-term use of levodopa at high dosages often leads to movement complications that can be difficult to manage, many doctors are now using a number of other medications which can be used alone or in combination with levodopa to treat PD symptoms. MAO-B inhibitors, anticholinergics, amantadine, and dopamine receptor agonists (such as Mirapex® and Requip®) may be used prior to the introduction of levodopa, and are often adequate to treat the early stages of PD for a number of years. Dopamine receptor agonists behave like dopamine but are not as potent as levodopa and are not converted into dopamine as is levodopa.

Fortunately, we are witnessing the continual development of new drug therapies for the treatment of both the motor and non-motor symptoms of PD. For the most up-to-date information on available medications, contact APDA's National Young Onset Center.

Regular Exercise A consistent exercise program, based on one's ability level, should be incorporated into the treatment regimen of each patient in order to maintain flexibility, mobility, and general well-being. Patients can develop an exercise program on their own or with a physical therapist. Many find that attending general or PD-specific exercise classes is also helpful.

Rehabilitative Therapy Adjunct therapies, such as physical therapy, can address gait and balance issues. Speech therapy (such as the Lee Silverman Voice Treatment) can be used when symptoms are troublesome or as an early intervention.

Surgical Intervention

For most people with Parkinson disease, levodopa and other medications are effective for maintaining a good quality of life. However, when medication adjustments do not continue to improve mobility or if PD medications cause significant side effects, surgical treatment may be considered. Many people with YOPD have experienced a positive response with Deep Brain Stimulation (DBS) surgery. This procedure involves inserting a thin metal lead into a targeted area of the brain. The lead contains four electrodes. A wire, attached to the lead, runs down the neck under the skin to a computerized pulse generator. This computerized device is implanted under the skin in the chest, much like a pacemaker for the heart. Electrical impulses from the electrode silence the parts of the brain that produce movement problems resulting from dopamine loss, and can decrease motor fluctuations and markedly reduce dyskinesias. DBS surgery

does not destroy brain tissue; therefore, if newer, more promising treatments develop in the future, the DBS procedure can be reversed. Although most patients still need to take medication after undergoing DBS, many find that they are able to significantly reduce the amount of medication they are taking because of the decrease in PD symptoms. The amount of symptom reduction varies from patient to patient.

The availability of DBS represents a major milestone in the treatment options for Parkinson's disease. When choosing a center for DBS surgery, look for one with an experienced DBS team. There is a learning curve in successfully implanting the DBS device, and you should seek a center that has performed the surgery many times (contact APDA's National Young Onset Center for local resources). Criteria for patient selection may vary somewhat from center to center. Although the procedure is not without some small risk, appropriate patients can gain significant improvement. Research has shown that earlier intervention provides a more robust benefit, and that activities of daily living and quality of life can be measurably improved. Furthermore, it appears that younger patients may benefit more from DBS than older patients.

As with any treatment decision, it is important to discuss the potential risks and benefits of DBS with your doctor.

Choosing Your PD Doctor

When seeking neurological care, it is best to seek a physician who has an understanding of the unique requirements of the young PD patient. This usually means a neurologist who has pursued specialized training in movement disorders. Movement disorders specialists work extensively with PD and other Parkinson's-like illnesses. Having someone who has this knowledge base as your treating physician will help you maximize symptom control while minimizing complications of treatment which ultimately translates into long-term maintenance of functional independence.

The Genetics of Parkinson's Disease: Why, What and How

By Andrew Singleton, PhD

Genetics is a rapidly evolving field of study, and each new discovery gets us closer to being able to answer the questions below more thoroughly and accurately. Given the pace at which new discoveries are continually being made, it would be advisable to supplement the information below with the most recent data available.

Why Study the Genetics of PD?

There are several basic ideas underlying the investigation of genetics in Parkinson's disease. The first is that identifying genetic mutations that cause PD allows researchers to make models of the disease both in cells and in animals. By studying these models we can gain insight into the molecular and cellular basis of the disease. All of this is ultimately aimed at developing a therapy that halts or reverses the disease progression, not just one that treats the symptoms.

A second key outcome of genetics work is that it allows us to identify people who are at risk for the disease. From a clinical research perspective, having a pool of individuals who we think are at greater risk for PD, but who do not yet have the disease, is incredibly valuable. It allows us to study these people over many years, with the aim of defining symptoms that help predict the onset of Parkinson's disease years before any movement problems are felt by the patient. Early identification of the disease will be critical in the effective application of disease modifying or preventative therapies.

What Have We Learned?

Given that so much emphasis has been placed on identifying genetic changes that underlie PD, what have we found? In 1997 researchers were able to identify the first genetic mutation to cause PD in a gene that produces the protein alpha-synuclein. This was a monumental discovery because it showed that the genetic study of PD was possible.

A month or two later, alpha-synuclein was found to be a major component in the development of Lewy bodies (the neuropathological hallmark in PD) in the brain of all PD cases, not just in familial forms as was previously thought.

This discovery provided researchers a target for working out the process of cellular degeneration and dysfunction involved in Parkinson's disease.

This initial finding has been followed by the discovery of four other genes that can cause PD when mutated:

- PRKN (also called parkin)
- DJ-1
- PINK1
- LRRK2 (also called dardarin)

Thus far the two most common genetic causes of PD are mutation of parkin and LRRK2. Though these are still relatively rare, Parkin mutation appears to be responsible for 20% of young onset PD where patients have a strong family history of disease and onset occurs below age 30. Mutation of LRRK2 seems to be responsible for approximately 2% of typical late onset PD. These discoveries have allowed researchers to delve deeper into the mechanisms of the disease to get a more cohesive picture of PD and a better understanding of the genetic similarities and differences between young onset and later onset PD.

What is the Role of Genetic Testing?

Genetic testing is commercially available for several of these genes; however, young people should weigh the usefulness of these tests in their own situation by consulting with their healthcare provider. On a personal level, a positive result can provide a "reason" for disease and this may be of some comfort. It is also important, however, to consider several limitations of these tests:

- In most cases the results of these tests are negative or equivocal (meaning that something was found but its significance is unknown).
- There are certainly more genes and more mutations yet to be identified, so lack of a positive result does not mean there is not a genetic basis to disease.
- These tests in general do not assess the whole gene or all of the possible mutations.
- As yet a positive test result does not effect treatment and provides little additional information on prognosis.

The question of whether Parkinson's disease can be inherited is still being studied. While the risk to first-degree relatives of a person with Parkinson's disease varies from study to study and from country to country, present findings indicate that first degree relatives of an affected individual are between 2.7 and 3.5 times more likely to develop the disease than individuals without a family history of PD.

Genetic counseling of affected individuals and their family members should be done on a case-by-case basis. Any person wishing to seek testing should talk with his or her primary care physician or neurologist and seek genetic counseling prior to any testing.

How Do We Move Forward?

We are entering a new age in the field of genetics. The tools to find genes that underlie disease have become more sophisticated and more readily available. We are in a better position than ever to eventually predict those who are at risk of developing PD. These advances in genetics can also help us create a reliable prognosis following onset that can be instrumental in predicting a response to treatment. The successful application of these techniques requires the participation of patients and their family members. Participation might include such activities as enrolling in a research study, becoming a vocal supporter of research, or raising funds for research. Patients and their families should also seek out reliable information about genetic advances in the treatment of PD in order to stay educated. Only through a cooperative effort can we, as a community, move forward to realize a cure for PD.

Part II

Understanding Your Brain

When we think about Parkinson's disease, we tend to think of motor symptoms such as rigidity and tremor, probably because these are the symptoms that are most noticeable. However, PD is a neurological disease with both motor and non-motor symptoms that stress your brain and your psyche in all sorts of direct and indirect ways.

Because PD limits one of the key neuro-transmitters, dopamine, which regulates a number of different and competing things throughout your brain, it can lead to a range of behavioral, psychological, and cognitive (thinking) changes. This can result in a number of different problems including sleep disorders, depression, hallucinations, impulsivity, and changes in memory and thinking. These different symptoms may be either consistent or sporadic; they may be bundled together or present separately. Before reading on, remember, these are possible problems, not inevitable ones.

Sleep Difficulties

By Thomas Freedom, MD and Johan Samanta, MD

For most people, night is a time of rest and renewal; however, for many people with Parkinson's disease nighttime is a struggle to get the rest they need. For young people in particular, lack of sleep can create additional stress by affecting job performance, concentration, interest in social activities, or ability to fulfill parenting and other daytime family responsibilities. PD chat rooms on the Internet are busy during late night and early morning hours, attesting to the fact that sleep disturbances are prevalent in the PD population.

The amount of sleep an adult needs varies from person to person, but most people need between seven and nine hours of sleep a night. Normally, a healthy young person should fall asleep within 15 or 20 minutes. One or two awakenings may occur, and as long as one falls back to sleep in a few minutes, this is normal. One study found that people with PD averaged just over five hours of sleep and woke up twice as many times as did adults of similar age without PD. Difficulty falling asleep, staying asleep, or early awakening with difficulty falling back to sleep may be signs of sleep problems or sleep disorders. These problems can be related to any number of medical conditions, including PD, or to psychological problems including depression or anxiety.

The reasons for nighttime difficulties are multiple and complex and, until recently, were not well understood. Following are some of the most common sleep disorders that result in decreased sleep. Fortunately, many sleep disturbances can be treated successfully. Sometimes, treating the Parkinson's disease will result in improvement in sleep.

Insomnia

Many people have difficulty falling asleep or staying asleep, awaken early and are unable to fall back to sleep, or perceive their quality of sleep as poor. When one or more of these features is present, we call this insomnia. Insomnia is a common complaint of people with PD and can be caused by both the disease itself and certain PD medications. Insomnia can have a measurable effect on daytime functioning or general well-being and can contribute to daytime sleepiness, lack of attentiveness, and irritability. Some features of PD such as difficulty turning in bed, pain, early wearing off or ineffective response to PD

medications, involuntary movements, dystonia (severe muscle contraction) or urinary frequency may also disrupt sleep.

Treatment of insomnia begins with learning good sleep hygiene, but may also include cognitive behavioral therapy (done by specially trained professionals) and use of medications. Depression, which is common among Parkinson's patients, can also contribute to insomnia. An antidepressant or sedative may improve sleep. However, studies have shown that practicing good sleep hygiene habits and taking measures to promote relaxation before bedtime can often work better than sleeping pills.

Sleep Fragmentation

Sleep fragmentation or frequent awakening is probably the most common nighttime complaint in PD. This type of sleep disturbance may be associated with a greater susceptibility to medication-induced hallucinations as well as excessive daytime sleepiness. Sleep fragmentation is best treated by the use of the long-acting sedative clonazepam (Klonopin®) taken at bedtime. Clonazepam, rather than being immediately sedating, tends to help regulate sleep and allow for a more normal nighttime sleep pattern. Treating the excessive daytime sleepiness which often goes hand-in-hand with sleep disturbance is also an alternative. Changing medications (as many of them can cause sedation when taken during the day or disrupt sleep patterns when taken at night) or adding a stimulant medication can also be effective.

People with sleep disorders should be exposed to as much light (preferably real daylight) and physical/mental stimulation during the day as possible because these things can improve many sleep issues without medication. Light is an important synchronizer of the sleep-wake cycle, and many people with PD have reduced exposure to bright light. Physical and mental activity stimulates the alerting and wakefulness centers in the brain and increases blood and oxygen flow to the brain.

Excessive Daytime Sleepiness

Daytime sleepiness can occur for a variety of reasons and is not necessarily related to sleep disturbances, age, duration of the disease, treatment, or motor disability. Sometimes the medications used to treat PD can cause people to feel sleepy. Impaired driving due to sleepiness has been reported with the

use of certain medications, particularly some dopamine agonists. Patients may not be aware of sleepiness prior to a “sleep attack.”

Sleep Apnea

Sleep apnea (or obstructive sleep apnea) is the most common sleep-related breathing disorder. An apnea is a pause in respiration due to obstruction in the upper airway or decrease in respiratory effort. Features of sleep apnea may include loud snoring, choking, or gasping or gurgling sounds and may result in morning headaches from fatigue. If left untreated, this condition can affect blood pressure and may raise the risk for stroke or heart disease. Sleep apnea can be treated by weight loss, avoiding certain positions in bed (particularly sleeping on the back), avoiding alcohol, and treating allergies, nasal congestion, and esophageal reflux. The most common treatment is the nightly use of continuous positive airway pressure (CPAP). A CPAP device (which fits over the mouth and/or nose while sleeping) provides a continuous flow of air through the upper airways, preventing obstruction and improving oxygenation during sleep. Polysomnography (a sleep study) is used to confirm the diagnosis of sleep apnea. Some people benefit by using an oral appliance made by a dentist and worn at night. Sometimes surgery on the nasal passages or throat can be of benefit.

REM Behavioral Disorder

REM (rapid eye movement) sleep is a normal stage of deep sleep where the bodily muscles, with the exception of eye movements and breathing, are paralyzed (muscle atonia). There can be brief twitching, but most movement cannot occur during this stage of sleep. Loss of REM “paralysis” can occur in PD resulting in movements during REM sleep. REM behavioral disorder (RBD), often described by patients and family members as “thrashing about” in sleep or “acting out” of dreams, is a result of impaired sleep paralysis. It is more frequently encountered in males with PD than females. Patients often describe vivid dreams that can range from friendly and pleasant to quite menacing and frightening. To avoid possible injury, it may be advisable for the bed partner to sleep in a separate bed during this type of sleep disorder until adequate control has been attained in the person with PD. Fortunately, REM behavior disorder responds to medications in the majority of patients. Individuals with newly diagnosed PD who have RBD symptoms often report resolution of this sleep disturbance when they begin treating their PD with dopaminergic medications.

Restless Legs Syndrome

Restless legs syndrome (RLS) is a relatively common disorder in PD. It can be associated with disrupted sleep and daytime sleepiness.

RLS has four features:

- There is a desire to move the limbs, usually associated with discomfort.
- The symptoms begin or worsen during inactivity or rest (lying, sitting).
- Symptoms are partially or totally relieved by movement (walking or stretching).
- Symptoms are worse in the evening or at night.

Certain medications such as antidepressants and antihistamines may worsen RLS. Adjusting or adding certain types of PD medications can improve the condition.

Nighttime Urinary Frequency

Nighttime urinary frequency is common in PD patients and can be the result of a dysfunction of the autonomic nervous system. It is characterized not only by increased urinary frequency but also an increased sense of urgency, particularly at night. In new cases, other treatable and potentially serious causes, such as infections or prostate difficulties (in men), should be ruled out first. Several medications are available to address simple nighttime urinary frequency. If the problem persists, a formal urologic evaluation may be necessary.

Diagnosing and Treating Sleep Disorders

Sleep disorders are best diagnosed in one of the many sleep disorders centers found throughout the country. The best centers are accredited by the American Academy of Sleep Medicine (AASM) and have staff with specialized training in the diagnosis and treatment of sleep disorders. In addition to evaluating patients, these centers perform specialized diagnostic sleep tests during overnight sleep studies. The nocturnal polysomnogram (PSG), or overnight sleep study, is the most widely used tool for diagnosing sleep disorders.

Once the diagnosis is determined, a treatment plan is recommended, usually by a sleep specialist in consultation with the neurologist. Behavioral techniques such as optimizing sleep habits (sleep hygiene), adjusting medications (both to optimize sleep and minimize daytime sleepiness), and treating underlying sleep disorders are usually recommended.

While the causes of nighttime difficulties in PD are varied and often complex, it is important to know that potential solutions do exist. Below are some general tips for getting a good night's sleep.

Sleep Hygiene Tips

Sleep hygiene refers to the behaviors and habits we can control that affect our body's day-night cycling and our readiness to go to sleep or to be alert at a given time of day.

- Try to maintain consistent sleep and rising times with a goal of spending at least 7 but not much more than 8 hours in bed each night.
- Preserve the bedroom for sleep and avoid activities right before bedtime that may stimulate wakefulness.
- Don't exercise within 4 hours of going to sleep.
- Allow about 4 hours after a large meal before going to bed.
- Avoid caffeine for 6 to 8 hours before retiring.
- If alcohol is consumed, use only moderate amounts.
- Limit fluids at least 4 hours prior to bedtime
- Do not take over-the-counter or prescription sleeping medicines without consulting your doctor. Some may cause a worsening of sleep problems.
- Consult your physician regarding timing of evening PD medications and use of time-released medications or appropriate long-acting administrations.
- If unable to fall asleep within 30 minutes, get out of bed and sit quietly, listen to soft music, read or engage in other relaxing activity until feeling sleepy; then go back to bed.
- Remedies such as a warm glass of milk, a massage, and an expression of affection may be helpful. A hot shower or bath can also promote relaxation.
- Consider seeing a counselor or therapist to discuss issues that may be causing stress or anxiety.

Depression

By Laura Marsh, MD

Most people experience feelings of depression periodically. Depressed emotions are normal, particularly in the event of loss. The changes in physical functioning associated with PD can be experienced as "a loss," and this can, in turn, precipitate feelings of depression. However, for people with PD, depression is often more complex because it can also be part of a variety of psychiatric conditions related to the underlying brain changes in PD.

Depressive Emotions and Depressive Disorders

In general, the term "depression" refers to an emotion characterized by sad and unhappy feelings. However, it is not uncommon for people to use the term depression somewhat loosely, when they are really experiencing a range of other emotions including feelings of anger, disgust, anxiety, apathy, fear, or tiredness. The key features of a "depressive disorder" are a sad mood and/or the inability to enjoy or be interested in activities that would ordinarily be pleasurable. In addition, the sad feelings are usually persistent and pervasive. For example, having to stop working because of PD can be an understandable cause for feelings of sadness and discouragement. However, in the absence of a depressive disorder, the person is able to continue to pursue and achieve satisfaction from other activities; the sadness does not color virtually all aspects of life.

In depressive disorders, continuous negative thoughts, especially about oneself, or morbid thoughts about death (especially one's own), and excessive and inappropriate feelings of guilt are very common. While it may be normal to feel guilt over past mistakes, sadness over losses, or resentment because of the impact of PD on daily functioning, in the setting of a depressive disorder these feelings become a preoccupying source of distress. There may be significant anxiety as a feature of a depressive disorder, although anxiety disorders are fairly common in PD and can also be present independent of depressive disturbances.

Both general feelings of depression and PD-related depressive disorders often involve similar cognitive and physical symptoms.

Cognitive symptoms can include problems with:

- concentration
- attention
- multi-tasking
- slowed thinking

Physical symptoms can include:

- fatigue
- low energy
- slowed movements
- aches and pains
- decreased appetite
- sleep disturbances

Many of these symptoms also occur in PD without an accompanying depression, but they tend to be worse when the patient has an untreated depressive disorder and may lead to an increased level of disability. In fact, when patients describe a degree of disability that is far greater than their motor examination suggests, it is important to look for signs of a depressive disorder. Successful treatment of depression can improve thinking deficits, fatigue, and slowness. Patients are also better able to pursue regular exercise and other compensatory strategies (such as monitoring the pace of daily activities) that can maximize functioning.

One important clue to the presence of a depressive disorder is the inability to effectively respond at an emotional or behavioral level to life's challenges, including those brought on by PD. Many people think that mood disorders result from a lack of coping skills or weak character, but this is not true. With PD (or any chronic illness), successful coping and adaptation are virtually impossible in the face of an untreated mood disorder. Individuals who are ordinarily resilient and resourceful when faced with adversity will often say, "I keep trying, but I just can't keep my chin up." Recognition of this state may be more difficult for those who normally cope well. These individuals are likely to try their best to carry on with daily activities despite their untreated mood disorders.

Treatment

When identified and properly diagnosed and treated, most depressive symptoms can be treated successfully, providing patients with improved quality of life and reducing disability.

The combination of psychotherapy and medication has been shown to be the most effective treatment for depressive disorders. Antidepressant medications are generally indicated when depressive disorders persist and are contributing to significant distress and dysfunction. Once a depressive disorder is treated, the person is usually better able to face the challenges associated with PD, respond to encouragement, develop ways to compensate satisfactorily, and take advantage of new opportunities. In fact, such changes are often taken as signs that the mood disorder is responding to treatment.

It is important to know that an underlying diagnosis of depression in PD can be missed because many of the symptoms of depression are also common symptoms seen in PD (for example, lack of facial expression or extreme fatigue). Therefore, clear descriptive communication with your doctor about how you are feeling emotionally is essential so the doctor can then determine why these feelings might be occurring and provide proper treatment.

Thinking and Memory

By Zoran Grujic, MD and Michael Mercury, PhD

People with Parkinson's disease may experience changes in how their brain processes information. Young people often find that staying focused and multi-tasking are more difficult for them and that their memory is not as good as it used to be. Typically, three areas of thinking are impacted in Parkinson's disease: memory, speed of processing information, and executive functioning. Any changes in mental functioning are often best evaluated by neurologists and neuropsychologists associated with memory and cognitive assessment centers.

Memory

In general, normal memory consists of three components: encoding, storage, and retrieval. People with PD are typically able to learn (encode) and store new information. The problem in PD lies, instead, with the retrieval of newly presented information.

Specifically, when someone with PD tries to remember something, they may not be able to spontaneously recall the information. They may think that they have forgotten what they had learned. In most cases, what is happening is that the information is in the memory stores; however, the individual is having problems accessing the information. If the person is given cues or reminders he or she will usually be able to "remember" the information.

Not being able to spontaneously recall can lead to feelings of anxiousness and frustration, compromised attention, and difficulties with initial learning and recall. Additionally, people with PD have a greater risk for clinical anxiety and depression which can further impact memory. Treatment of these conditions can enhance the ability to encode, store and retrieve information.

In today's technology-centered world, use of Palm or Blackberry devices allow someone with retrieval memory problems to be cued for important events in an efficient and developmentally appropriate manner. A key point here is that in PD, people are not actually forgetting, even though it may appear that way. Being aware of how the recall process is impacted, and learning how to modify behavior to maximize recall, can be very helpful.

Speed of Processing

Speed of processing refers to how quickly the brain is able to process and use information. Diminished speed of processing may result in an individual

remembering something better after some time has elapsed, than when trying to recall it immediately. Speed of processing can impact several areas of thinking by compromising a task that one can otherwise, intellectually, do appropriately. For example, extra time may be needed to accomplish certain tasks such as balancing a checkbook or giving a presentation at work. "Thinking on your feet" when asked a question may present a challenge. It can be reassuring to remember that it is the speed of processing, not intelligence, that is being affected.

Executive Functioning

Executive functions include cognition (thinking) and behavior. Cognition involves problem solving, organizing, planning, and being able to shift easily between tasks (e.g., multi-tasking). Behavior involves modulating actions in response to social cues. People who experience problems with executive functioning may have difficulty making decisions or completing projects at work (cognition) or may act out in impulsive ways (behavior). Problems with behavior may result in actions that are interpreted as more extroverted, with individuals more prone to say exactly what is on their mind. In extreme cases, individuals can have difficulties controlling impulses which can lead to embarrassing or dangerous situations (e.g., inappropriate remarks, high-risk behaviors such as gambling). The impulses can be difficult to control even though, intellectually, the person knows the appropriate way to behave. These behaviors are not conscious choices people are making. Some medications used to treat PD symptoms as well as the progression of the disease may be contributing to the behaviors (see *Impulsive Behaviors* section).

Treatment

Cognitive and memory decline in people with Parkinson's disease is often misinterpreted as laziness, carelessness, or willful lack of cooperation and participation in activities of daily living. This is usually not the case. It is important to discuss any changes in memory, thinking, or behavior with your physician as early as possible so an appropriate course of action with regard to assessment and treatment can be determined.

Treatment decisions for memory loss associated with PD are based on several factors including the degree of memory loss, the severity of the PD motor deficits, and other medical conditions the person may have. As with any other chronic disease, it is important to look for potential causes other than

PD that may account for changes in memory. Medical problems such as infections, sleep disorders, vitamin deficiencies, and medication toxicity can also lead to confusion and memory loss.

Mood disturbances such as depression or anxiety can cause significant problems with attention and also need to be recognized as potential causes of a decline in mental functioning. Treatment choices for anxiety and depression include psychotherapy and medications. Psychotherapy can be helpful in reinforcing the fact that the person with PD is not “forgetting,” and can provide support and direction in developing compensatory strategies.

At this point in time, there are no pharmacological therapies that have been approved by the Food and Drug Administration (FDA) for the treatment of “simple” memory loss or executive dysfunction associated with PD. However, the FDA has approved rivastigmine (Exelon®) to treat Parkinson’s-related dementia. Exelon® is an acetylcholinesterase inhibitor. It increases a chemical in the brain called acetylcholine which is involved in memory processing. The B vitamins (B12, B6) and folic acid may have a role in decreasing the risk of developing a dementia by lowering a chemical in the blood called homocysteine. High levels of homocysteine have been associated with arteriosclerosis and memory loss. Regular physical exercise has also been shown to delay the onset of dementia. Studies have also found that keeping one’s brain active in intellectual and social activities delayed the onset of memory loss or decreased the risk of developing Alzheimer’s disease. These studies seem to confirm the idea: “Use It or Lose It.”

One question which often arises is whether cognitive changes inevitably lead to dementia. Dementia is defined as a disease of the brain in which at least two areas of cognitive functioning (e.g., memory, executive functioning) are impaired. Activities of daily living must also be compromised by these changes to qualify for a diagnosis of dementia. In Parkinson’s disease, cognitive changes do not inevitably lead to dementia. In fact, it is believed that dementia occurs less frequently in individuals with young onset Parkinson’s disease. However, if you feel you are having difficulties in any of these areas, memory assessment clinics are available in many hospitals and can be helpful in determining the cause(s) and prescribing treatment for changes in memory or cognitive functioning. Movement disorders centers may also be able to provide referrals for appropriate evaluations.

Impulsive Behaviors

By Gregory Pontone, MD

For a small percentage of people, the use of particular PD medications may contribute to a type of distressing behavior that involves tendencies toward impulsiveness.

Gambling, sex, and shopping are all within the normal repertoire of human behaviors. However, between 9-14% of people with young onset Parkinson’s disease develop problems related to these and other activities during the course of treatment. Pathological gambling, hypersexuality, excessive shopping, and other behaviors that people have difficulty controlling are collectively called impulse control disorders (ICDs) by doctors and researchers.

Impulse Control Disorders

Impulse control disorders encompass a number of behaviors in which a person fails to resist the drive to act in ways that are distressing and can potentially lead to social, occupational, or financial problems. Although gambling, shopping, and sexual behaviors have been the most frequently reported to doctors, behaviors like skin picking, punding (intense fascination with a repetitive activity), and compulsive eating have also been described. Occasionally, ICDs will be a completely new behavior. For example, a person who never gambled before begins taking weekly trips to the casino. However, most often, ICDs represent an intensification of previous behaviors. For example, a woman who enjoys collecting art-deco lamps suddenly goes out and buys 15 lamps in one day for a two bedroom condo.

Sexual ICDs vary from person to person but represent a deviation from the individual’s usual sexual activity in frequency, intensity, or context. Hypersexuality can start as intrusive thoughts or urges and trend into inappropriate remarks or acts. Some patients may begin to use pornography, patronize prostitutes, or develop a pattern of recurring behavior that involves unusual and socially unacceptable sexual practices (paraphilias) such as sadomasochism or exhibitionism.

Identifying ICDs can be difficult because the behaviors are often done in private and hidden out of shame or embarrassment. Symptoms of depression, irritability and appetite disturbances may be associated with the presence of these behaviors. Affected individuals may be disinhibited, often acting without

thinking of consequences or doing or saying things that are not usually said or done in public. Often individuals will have more than one impulse control problem concurrently. Family members and individuals close to the patient sometimes detect a problem when repeated, unexplained withdrawals of money occur, as in the case of gambling or shopping. Hypersexuality is often detected when an individual spends increasing amounts of time on the Internet, looking at pornography, or soliciting sex in “chat rooms.” However, many ICDs go unrecognized for an extended period of time because the behaviors are diverse and the affected individuals often minimize or downplay their involvement in the behaviors.

Even when recognized, ICDs can cause tension between the affected person and his or her family and friends. When confronted, individuals will often deny that the behaviors are a problem. Efforts to stop or reduce the frequency of the behaviors sometimes result in a pattern of remitting and relapsing behavior. For example, after a month-long cessation of all gambling activity, the affected individual goes to the casino and spends a month’s salary. The constant “push-pull” between the urges produced by the ICDs and the efforts of family members to stop the behaviors often results in strained relationships.

Treatment

The treatment of impulse control disorders in PD is challenging because the medications that are needed to treat the movement disorders associated with PD are often the precipitating agents of ICDs. At this time, there is no clear way to predict which patients will develop ICDs. Research findings suggest that young onset PD patients on dopamine agonist therapy (i.e., Mirapex®, Requip®) may have an increased risk of developing ICDs. In addition, PD patients who have noticed increased difficulty with mental tasks such as sequencing, multi-tasking, and organization (sometimes called “executive dysfunction”) may also be at increased risk for ICDs.

Stopping PD medications altogether in order to treat an ICD is not practical. However, stopping or reducing the dose of the suspected agent often helps. Usually, when a dopamine agonist is suspected of contributing to an ICD, the patient can be switched to levodopa. If the agonist was added to levodopa to improve movement, options include using a higher dose of levodopa or using other medicines or methods to prolong the effectiveness of the levodopa dose.

Many patients report rapid cessation of ICD symptoms and behaviors after they stop dopamine agonists. When stopping the offending antiparkinson medication is not effective or not an option, adding low dose quetiapine (Seroquel®), an antipsychotic, often has a clear effect on helping the patient resist impulses.

Behavioral interventions are especially important in the treatment of ICDs because they can prevent some of the adverse consequences of such behaviors. Behavioral interventions can include limiting bank account access in the case of gambling and shopping. Restricting the use of the Internet and video player can help in some cases for hypersexuality. For some ICDs, self-help groups, such as 12-step gambling groups, can also be helpful.

Once an impulsive behavior is recognized, the first and most important step a patient or family member should take is to inform the patient’s physician. Most neurologists are now aware of the association between PD medications and ICDs, and can provide treatment or make the appropriate referrals for treatment. Stopping or changing medication doses without the guidance of a physician can produce unwanted side effects. It is also important to confirm that the impulsive behaviors are not occurring in the context of a psychiatric disorder (i.e., bipolar disorder) which, if left untreated, could lead to further impairment of functioning. Once identified, most ICDs improve or remit with appropriate treatment within a matter of weeks.

Psychological Impact

By Marc Slutsky, MD

For people with Parkinson's disease, symptoms such as slow movement, soft or slurred speech, or lack of facial expression can have a powerful psychological impact. When tremors are your predominant symptom, hiding them often becomes the usual first response, and others may react by looking away. Difficulty moving can easily lead to withdrawal and exclusion and then to isolation. If speech becomes difficult, you may avoid conversation, and others may think your silence means you don't understand what they are saying. When your face is not expressive, people act as if you don't have emotional responses.

These experiences play a significant role in how you see yourself, how you express yourself, and how you expect others to see you. They often define how friends and family view you and interact with you. What you and your friends and family think about the disease can influence how you treat each other and behave together. Understanding this can lead to adaptation that will make life fuller.

Psychological Considerations

There are three basic perspectives to consider when thinking about the psychological impact of Parkinson's disease:

The first is that every individual has a life-long personality which remains with him or her. You and every one of your family members and friends have a personality that is uniquely yours, and you have most likely become accustomed to interacting with one another in particular ways that take one another's personality into account. Some people are impulsive, others are compulsive; some are prone to anger, others to sarcasm, and some will get depressed when they are disappointed. Parkinson's disease is a stressor that will bring about responses consistent with a person's overall personality. For example, someone with a dependent personality may find it easier to become "a patient," and to receive care, than to become a "care-giver."

The second perspective is that unlike strokes or degenerative diseases, which destroy parts of the nervous system, Parkinson's primarily interferes with the speed and effectiveness of brain functioning in ways that can prevent different parts of a coordinated action from working well together. This means that a Parkinson's patient has to work with great concentration to accomplish what

other people would do without thinking. This can become incredibly tiring to the patient and extremely frustrating to anyone interacting with him or her. It is much easier to be empathic with someone who has absolute limitations as with a stroke, than with someone who presents his or her limitations inconsistently. It is not unusual for a person interacting with a Parkinson's patient to assume that the patient is creating his or her symptoms deliberately because the symptoms are not present at all times.

The third perspective is that Parkinson's impacts the brain directly and can lead to certain symptoms that resemble other psychiatric syndromes. One symptom that can be particularly disturbing is hallucination, seeing or hearing what is not really present. Unlike serious mental illness, in Parkinson's disease people may often be aware they are hallucinating. PD hallucinations are usually visual in nature. Rarely, patients may have auditory (hearing things or voices) or tactile (feeling things, like bugs crawling) hallucinations.

Most often it is the antiparkinson medications that induce hallucination. If you experience hallucination, consult your doctor to determine if your PD medications are contributing to this problem and should be reduced or discontinued. If motor function is severely compromised by reduction in antiparkinson medications, antipsychotic medications may be used to relieve the hallucinations. Some antipsychotic medications such as haloperidol (Haldol®), chlorpromazine (Thorazine®), fluphenazine (Prolixin®), perphenazine (Trilafon®), thiothixene (Navane®), and thioridazine (Mellaril®) should never be used in PD, because they can potentially result in serious medical side effects. Instead, the newer "atypical" antipsychotic medications, particularly quetiapine (Seroquel®) and clozapine (Clozaril®), should be used because of their decreased occurrence of undesirable side effects. However, risperidone (Risperdal®) works similarly to haloperidol and should be avoided in PD.

Understand and Accept the Use and Disappointment in Medicines

The more scientists understand how the brain functions, the more complicated the situation appears. The very neurotransmitter that works to stimulate the brain one way also works to push it the reverse way. Medicines used to treat Parkinson's add to the complication. Every one of them alters the presence of the neurotransmitters everywhere in the brain. Often, the very

medicines that are supposed to help one problem can create or intensify others. Response to PD medications can also be inconsistent because so many other factors influence their impact. This can mean that the same drug given at the same time each day can have different effects on different days. You cannot always count on predictable responses. Although it can be frustrating and disappointing when PD medications do not work consistently and the search for the perfect combination of medications becomes futile, current PD medications and other special treatments can and do produce life-altering improvements.

Getting Help is Relieving

Living with Parkinson's disease gets easier when patients and families understand what is going on. By describing any confusing, frustrating, or even frightening symptoms to your physician or mental health provider, you and your family will be better able to make sense of the symptoms, put them in perspective, and become more confident in dealing with them. Anger and frustration can give way to understanding and cooperation, and can help individuals and families adapt to changing needs.

Part III

Managing Parkinson's Disease Effectively

Learning to manage Parkinson's disease effectively can require a significant amount of your time and energy. Keeping up with medical appointments, discovering the newest treatment options, or finding the right clinical trial for you may sometimes feel like a full-time job. This section is intended to save you time by providing basic information about a wide range of practitioners and treatment alternatives. Managing PD so that you are able to remain as strong and active as possible does take time, but it can be time well spent that can have a very positive effect on your future.

The Benefits of an Interdisciplinary Team

By Tamara Rork, PT, MSPT and Terry Ellis, PT, PhD, NCS

Given the variation of symptoms among people with PD and the complexities of the disease, it is ideal to have a number of healthcare professionals on your team who have expertise in managing the various aspects of PD. This “interdisciplinary team” can collaborate with you and with one another in order to determine the best combination of information, resources, and treatment strategies for you.

Your core team will include a neurologist and primary care physician. Depending on your symptoms and situation, your team might also include a physical therapist, occupational therapist, speech and language pathologist, nurse, social worker, and/or registered dietician. Such an interdisciplinary team will help you live successfully with your PD and slow its effects as much as possible.

The most important members of your healthcare team are you and your family. Remember to keep all members of your team informed about how you are feeling, and consider their advice and recommendations. Clear and honest communication is crucial. It is also important for you to follow through with any prescribed medication regimens or therapy routines (such as in-home physical therapy exercises). With your input and participation, your healthcare team will be better able to help you manage your PD effectively.

Neurologist

A neurologist is a physician who specializes in the diagnosis and treatment of nervous system disorders. He or she is able to examine you and establish a plan to manage your PD symptoms. The neurologist plays a key role in the management of your medications and may refer you to other specialists such as physical or speech therapists. Because your neurologist plays such an important role in your treatment, be sure he or she is someone you trust and with whom you have a good rapport.

Movement Disorders Specialist Some neurologists specialize in movement disorders such as Parkinson's disease. These physicians have had additional training in the subspecialty of movement disorders, and they see a large number of people with PD in their practice. You may choose to enlist a movement

disorders specialist to be either the primary physician treating your PD or the doctor who provides a second medical opinion if you are under the care of another neurologist.

Physical Therapist

PD can cause mobility problems such as an unsteady gait or a tendency to fall. A physical therapist (PT) can help you with your gait and balance and other Parkinson's-related mobility problems. A PT is a licensed healthcare professional who is trained to evaluate and improve movement and function of the body. A physical therapist can work with you to create an individualized functional training program, which can help you improve your abilities with specific everyday tasks such as walking, running, standing up from chairs, and moving in bed. Some physical therapists are certified in neurological disorders by the American Physical Therapy Association and hold the title of Neurologic Certified Specialist. You can identify these PT specialists by the initials “NCS” after their name, which indicate that they have this certification.

It is now widely acknowledged that exercise plays a key role in helping to manage many of the primary and secondary symptoms of Parkinson's disease. The role of exercise in slowing down the progression of the disease is also currently being studied. Exercise typically includes strength training, stretching, and aerobic activities. Physical therapists can help you establish an individualized exercise program.

Occupational Therapist

An occupational therapist (OT) as defined by the American Occupational Therapy Association is a licensed healthcare professional trained to help people develop “skills for the job of living.” An OT can also evaluate your home or work environment and make suggestions for adaptations that can help you perform tasks more comfortably or effectively. This may include helping to problem-solve any safety or mobility issues.

Speech and Language Pathologist

Some people with PD experience issues with speech or swallowing. Speech and language pathologists (SLP) are licensed healthcare professionals

trained to evaluate and treat these problems. An SLP can design a program of vocal and facial stretching and strengthening exercises to help increase the loudness of your voice or clarity of your speech. SLPs can also teach compensatory strategies to help you manage communication or swallowing issues.

Some SLPs are trained in a technique called Lee Silverman Voice Treatment (LSVT), a speech and voice therapy that was developed specifically for people with Parkinson's disease.

Nurse

We all know that nurses provide care to patients when they are sick. However, nurses also provide education about health and wellness. Nurses who regularly see patients with PD often help with problems regarding medications or changes in symptoms. A nurse can also help determine if and when you should speak with your neurologist about concerns.

Nurses have many different titles, certifications, and roles as healthcare professionals:

Nurse Practitioners (NP) This is a registered nurse who has completed advanced education and often serves as a patient's primary healthcare provider in an outpatient setting. Depending on the state in which the NP practices, he or she may or may not be under the supervision of a physician.

Clinical Nurse Specialists (CNS) This is a registered nurse who has had additional training and education with a particular patient population.

While these two types of advanced nursing designations have some overlap between their roles, a CNS generally is more involved in education, consultation, administration, and research while an NP is more involved in direct patient care.

Social Worker

Coping with PD can feel overwhelming at times. Because of this, a social worker is a valuable person to have on your team. He or she can:

- Help you identify and utilize available federal, state, and community resources to address your concerns.
- Provide counseling to help you and your family members cope with new challenges presented by PD.

- Provide support, help you solve problems, and explore your options related to such issues as employment, parenting, finances, disability programs, or other areas of uncertainty or stress.
- Lead patient/family PD support groups.
- Educate other healthcare providers about community resources and psychosocial issues of concern for people with PD and their family members.

Registered Dietician

For all of us, a healthy diet can help us achieve or maintain normal body weight and a healthy digestive system. If you have PD, you may have additional concerns such as managing constipation and coordinating medication with meal schedules. Because some foods interfere with the absorption of medications, you may ask a Registered Dietician (RD) to help you identify these foods and make suggestions about timing your meals around medication times.

A Registered Dietician is a food and nutrition expert who has completed academic and clinical training and passed a nationally administered board exam. When making an appointment, be sure to ask if the dietician has had experience working with people with Parkinson's disease. During your appointment, the RD will talk with you about your health concerns related to diet, weight management, medications, food allergies, and other related dietary topics. He or she should provide you with written recommendations that you can then discuss with your neurologist.

Keep in mind that the title "nutritionist" is sometimes used interchangeably with "dietician." However, a nutritionist is not the same as a Registered Dietician. Anyone can call himself or herself a nutritionist even if he or she has no special education or certification in the field.

Beyond the Traditional Healthcare Team

Aside from healthcare professionals, there are other important potential team members that can help you better manage PD. There may be opportunities in your local area to participate in tai chi, yoga, and group or individual exercise at a gym or community center.

Activities such as tai chi and yoga are often recommended and enjoyed by people with PD because of their focus on fluid movement, balance, stretching and strengthening. They are also known to promote relaxation which is an important component in helping to manage day to day stress. The instructors who lead these activities will have varied backgrounds and training and are generally not licensed healthcare professionals, so it is important to initially see a physical therapist for exercise recommendations and guidelines.

Finding the Right Professional

Even the most expert and capable medical professionals cannot help you very well unless they allow sufficient time to see you and talk to you. A healthcare professional should be available for appointments within a reasonable period of time, be a good listener, and address your questions and concerns. If a provider is overscheduled, doesn't seem to listen to you, or doesn't provide a treatment plan that (over time) relieves some of your symptoms, you may want to consider finding another provider.

Your insurance coverage may also guide your choice of healthcare providers to some extent. Healthcare services and the requirements to access them vary from state to state and from company to company. Most insurance companies will cover both outpatient and home therapy services (including OT, PT, speech, and nursing services) with a physician's referral. Ultimately, however, it is your responsibility to find out whether providers—even those you have been referred to by your primary care doctor or neurologist—are covered by your insurance.

Other people who are living with Parkinson's disease can also be an excellent resource. If you attend a local support group, ask the other members if they have found professionals they would recommend. Likewise, if you have had a good experience with a group of professionals or a particular facility, it is important to share this with others.

Making the Most of Your Appointments

It's not uncommon for people to return home after an appointment with their neurologist or other healthcare professional and then to remember the questions they forgot to ask or the troubling symptoms they forgot to mention.

Here are some ways to ensure that you are prepared to make the most of your healthcare visits:

- **Write down questions.** Keep a running list of questions and concerns as you experience them and take this list with you to your next appointment. Don't rely solely on your memory.
- **Keep a log.** If your symptoms vary from day to day or from hour to hour, keep a log of your medication times and how they relate to your troubling symptoms for a couple of days prior to your appointment.
- **Write down all medications.** Bring a list of all your current medications including how much of each you are taking and when. Include all vitamins, supplements, and over-the-counter medications as well as prescription drugs. Give this list to ALL healthcare professionals who are treating you for ALL conditions. Update the list if your medications change in any way (being sure to include the date of revision in the list title), and provide an updated list to ALL of your doctors.
- **Take a support person.** Bring a family member or friend with you to the appointment as a support person. You may want to ask that person to take notes during the appointment so that you can direct your attention to the healthcare professional without worrying about having to remember everything you are hearing. The notes will remind you of any recommendations made by the doctor. Tape recording your conversation with your doctor is another option for recalling what was said during your appointment.
- **Don't be afraid to voice concerns.** This is especially the case regarding issues you might feel embarrassed about, such as questions related to sexual, bowel, or bladder health. Your overall health and well-being are paramount, and any concerns or questions you have are always relevant. If you are uncomfortable discussing these with your relative or friend in the room, it is appropriate for you to ask for privacy during this discussion.
- **Be clear on follow-up.** Ask what you should do or who you should call if something should go wrong with your treatment or if you have questions before the next appointment.

Getting a Second Opinion

Parkinson's disease in young people is often difficult to diagnose, particularly in the early stages. Getting a second opinion can confirm the diagnosis or, in some cases, lead to a different diagnosis or treatment. Second opinions are particularly a good idea if your doctor is not sure of the diagnosis or if you have questions or feel uncertain about the recommended treatment.

Many people feel anxious about getting a second opinion and worry that this will in some way upset their current doctor. However, good doctors usually understand the value of second opinions, even welcome them. If you want to pursue a second opinion:

- Inform your doctor of your intentions. If he or she objects to this plan you might question whether this is the doctor you want to continue to treat you.
- Be sure to check your medical insurance to see if it covers second opinions and if you must stay within your health network for coverage.
- Get copies of all relevant medical records and tests from doctors who have seen you. It may take time, so begin the collection process well before your appointment for your second opinion.
- If possible, choose a specialist who is not associated with the practice of your current physician or with the hospital or facility where he or she practices. This may give you a wider perspective on your condition.
- Always request a report of all test results or other diagnostic procedures done, and get the second opinion report in writing. See if the report agrees with what you understood your original doctor to say about your condition.

Surround yourself with people you trust and with whom you have good rapport. This pertains to everyone from your neurologist to the receptionist at the neurologist's office. You deserve high-quality, individualized care from everyone on your healthcare team.

The Role of Complementary and Alternative Medicine

By Leslie Mendoza Temple, MD and Cynthia A. Holmes, PhD

According to Dr. Andrew Weil, Director of the Integrative Medicine program at the University of Arizona, "The integrative approach is based on a physician/patient partnership within which conventional and alternative modalities are used to stimulate the body's natural healing potential. It neither rejects conventional medicine nor uncritically accepts alternative practices." Physicians who use the integrative approach work from a model of health and often focus on prevention. In contrast, the conventional disease model typically attempts to treat the disease once symptoms become evident. Practitioners who use the integrative approach also consider nutritional and lifestyle influences on health and illness and offer natural treatments in addition to drugs and surgery. Integrative medicine selects from or combines the best of conventional medicine and complementary and alternative medicine.

Treatment Modalities Defined

The terms "conventional," "complementary," and "alternative" can be difficult to define. In fact, these labels are relative and in some cases vary depending upon context. While there is some debate about the exact meaning of each term, they are defined as follows for the purposes of this discussion:

- **Conventional treatment** is what physicians deem to be the "standard of care" for a particular condition, either because the treatment has been studied scientifically and found to be safe and effective, or because there is consensus that the treatment works.
- **Complementary medicine** refers to interventions used *together with* conventional medicine. An example of a complementary therapy is the use of aromatherapy. The scent of essential oils from flowers, herbs, and trees when inhaled are thought to promote health and well-being and lessen a patient's discomfort following surgery.
- **Alternative medicine** is used *in place of* conventional medicine. An example of an alternative therapy is the use of a special diet to treat cancer instead of the surgery, radiation, or chemotherapy that has been recommended by a conventional doctor.

To help you understand how each term might apply to the treatment of Parkinson's disease, consider this example: Carbidopa/levodopa is a *conventional* drug treatment for Parkinson's that has been extensively studied and is routinely used by physicians. Acupuncture would be considered a *complementary* therapy if used in addition to the carbidopa/levodopa. Acupuncture would be considered an *alternative* therapy if used *instead* of carbidopa/levodopa or another first-line medication.

On a practical level, conventional medical treatment is more likely to be covered by insurance than a complementary or alternative therapy. However, more insurance companies are recognizing the value of acupuncture and massage therapy and providing limited coverage for these services. Contact your insurance carrier to determine your benefits.

The Benefits of Complementary and Alternative Medicine

Patients often turn to complementary and alternative medicine (CAM) if they are searching for more information about proper diet, exercise, and stress management. Others may turn to CAM to help them address some of the secondary symptoms of PD such as constipation or fatigue. These secondary symptoms can be just as troubling, or even more troubling, than the motor symptoms. Although the vast majority of people with Parkinson's benefit from antiparkinson medication, some may experience only partial relief or are bothered by side effects. Many individuals, particularly those diagnosed young, are interested in minimizing the amount of medication they take in order to delay possible long-term side effects like dyskinesia (involuntary movements). For these and other reasons, a growing number of individuals, faced with years of living with Parkinson's disease, seek out information regarding alternative or complementary therapies or visit practitioners in these specialty areas.

Types of Therapy

The following list includes examples of the multiple dimensions of therapies available within the discipline of CAM.

Biologically Based Therapies

- **Orthomolecular and megavitamin therapy** involve the adjustment of concentrations of molecules normally present in the body (e.g., vitamins, minerals, amino acids, hormones, and metabolic intermediates) for the

prevention and treatment of disease. Coenzyme Q 10 and omega-3 fatty acid-rich fish oils are examples of supplements in this category used by patients with PD.

- **Phytomedicine** is often called herbal or botanical medicine and refers to the therapeutic ingestion of plants. Herbal medicine dates back at least 5000 years and has been used by all races, religions, and cultures throughout the world.

Energy Medicine

- **Reiki** is a Japanese-derived healing modality in which a healing effect is induced by "life force" energy wherever the patient needs it most. The Reiki practitioner lightly applies hands on a clothed patient and channels healing energy as a general or localized treatment.

Manipulative and Body-Based Practices

- **Aromatherapy** uses the aromatic oils of plants to improve and maintain well-being. More than three hundred different oils are produced from flowers, leaves, stems, and roots. The action of aromatherapy depends on the link between smell and memories. Massage and penetration of the oils into the body may also have a direct effect.
- **Electric stimulation** involves the application of mild electric shocks to the skin. Chiropractors, massage therapists, and other practitioners of body work use this therapy to help relieve pain.
- **Massage therapy** is a common therapeutic treatment where manual rubbing, stroking, tapping, and kneading the body (either a particular area or the whole body) is performed for the purpose of treating physical and emotional disorders, increasing blood flow, reducing pain, promoting relaxation, releasing muscle tension, and enhancing general health and well-being.

Mind-Body Medicine

- **Biofeedback** involves the use of instrumentation to monitor, amplify, and report physiologic data for therapeutic purposes. The main objective of biofeedback is to change or regulate a physical process for better health, such as lowering one's heart rate with controlled breathing and guided visualization.

- **Relaxation techniques** can be helpful in reducing stress levels and include techniques such as progressive muscle relaxation and diaphragmatic breathing. More advanced techniques include hypnosis, guided imagery, and meditation.

Whole Medical Systems

- **Ayurveda** is Sanskrit for “life knowledge,” and it is one of the oldest known systems of healing. Ayurveda approaches health as the balance of body, mind, emotion, and spirit. Treatments include yoga, meditation, purification regimens, dietary changes, and herbal remedies.
- **Oriental Medicine** is an ancient system of diagnosis and treatment that corrects imbalances in Qi, or vital energy, with acupuncture, herbs, massage, nutrition, and movement. Acupuncture uses fine needles gently inserted at specific points along energy pathways of the body to encourage healing. Acupressure and low level laser acupuncture are non-invasive methods also aimed to balance one's Qi.
- **Naturopathy** is an alternative health system which emphasizes the body's ability to heal itself. Therapies include the use of natural foods and supplements, massage, hydrotherapy, homeopathy, and exercise that supports self-healing. Practitioners of naturopathy generally prefer to use treatment approaches they consider the most natural and least invasive instead of using drugs or surgery.

Finding the Right CAM Professional

A general rule of thumb is to avoid practitioners who claim to “cure” Parkinson's disease or require large, up-front payment for services. Also, beware of practitioners who advocate abruptly stopping or weaning prescription medications without a thorough, accurate explanation. Even with this information, consult your neurologist or primary care physician for an opinion, or seek the advice of an integrative medicine physician.

Evaluating the Safety and Usefulness of CAM Therapies

Reliable evidence for a number of complementary and alternative approaches will be forthcoming as more and more of these approaches are evaluated in carefully designed studies. At this time, there may be some complementary

treatment approaches you are willing to try without definitive proof, such as massage or tai chi. Other techniques or procedures, especially more invasive or experimental ones, should be supported by a strong base of evidence before they are utilized.

One of the best sources of information on CAM therapies is the National Center for Complementary and Alternative Medicine (NCCAM). Congress mandated the establishment of the Office of Alternative Medicine in 1998 to facilitate research that would help determine the safety and efficacy of alternative medicine modalities. NCCAM is one of the 27 institutes and centers that make up the National Institutes of Health (NIH). The Center funds research, provides grants to train researchers, and shares its findings about CAM therapies with medical professionals and the public through its information clearinghouse, fact sheets, Distinguished Lecture Series, continuing medical education programs, and publication databases.

Alternative therapies that have the potential to benefit people with Parkinson's must also be evaluated for their potential to do harm. *Natural* does not necessarily mean *safe*. Keep in mind that a truly effective CAM therapy usually takes a significant investment of time and effort to notice a benefit. Sensible CAM therapies combined with conventional medicine therapies should maximize the potential benefits of both treatments and should be discussed with your neurologist or primary care physician. This is especially true if you choose to use supplements or herbs in a complementary or alternative manner. Always inform your physician of any supplements or herbs you are thinking of using or are already taking since some herbs can interfere with conventional drug treatments.

The most successful patients with Parkinson's disease are typically those who are the most well-informed and have a balanced and realistic view of what conventional medications and alternatives can currently provide, as well as an understanding of their limitations and side effects. Patients should proceed with open-minded skepticism regarding CAM therapies. Complementary and alternative therapies are typically not used in isolation, and traditional medicines are usually necessary at some point. With proper medical guidance, the true integration of conventional therapies with CAM may help reduce or delay the effects of Parkinson's, as well as provide a greater sense of one's personal control over the disease.

Clinical Trials: Could They Be Part of Your Disease Management Strategy?

By Paula McFeely Wiener, MSW, LCSW

Clinical trials are often misunderstood by the general public; however, they are essential in our quest to find new treatments and a cure for Parkinson's disease. Have you considered volunteering to participate in clinical research as a part of your disease management strategy?

To help you understand clinical trials and dispel some of the myths associated with them, let's explore what a clinical trial is, the risks and benefits of participation, and how you can find and become involved in one.

What Is a Clinical Trial?

A clinical trial is a scientifically designed study that helps to answer specific questions about PD or the effectiveness of a treatment. For example, some studies may look at the risk factors for developing PD by asking detailed questions about where you grew up and what kind of work you do. Other studies may be designed to examine the disease progression or analyze the effectiveness of non-drug therapies such as exercise on PD symptoms. There are also studies that examine new drug treatments, new drug delivery systems, and new surgical treatments. Some studies focus on better management of PD symptoms, while others may examine the neuroprotective value of a given treatment. If you are interested in contributing to the understanding, treatment, and eventual cure of PD, there is almost certainly a way for you to participate in clinical research and be comfortable with your choice. Since there are some studies that ask for volunteers who are not yet taking any PD medications, you may want to consider participating if you are newly diagnosed.

What Are the Benefits and Risks?

Like almost all things in life, there are benefits and risks to be considered when making a decision to participate in a clinical trial. Benefits include:

- The opportunity to potentially advance treatments and therapies for yourself and others now and in the future. It's important to remember that the treatments available today are there only because someone like you was willing to volunteer to be part of an earlier clinical trial.

- You have a chance to receive new and potentially useful therapies, usually free of charge, under the supervision of leading Parkinson's experts.
- You can increase your knowledge and understanding of PD.

There are also some possible risks. If you enroll in a treatment study:

- You may be assigned to the placebo group (those who do not receive the treatment under study) and, therefore, will not receive any potential immediate benefit from the experimental drug or procedure being studied.
- If you do receive the experimental treatment, you may experience undesirable side effects.
- The study you join may not succeed. If the sponsors of the study are not getting the results they predicted, they can choose to end the study immediately. If this happens, you will not be able to continue the treatment even though you may have felt it was working for you.
- The study may require a long time commitment or travel expenses that will not be reimbursed.

Finally, if you are only concerned with how it may improve your life right now, you are probably not a good candidate. People who agree to join studies are trying to make the most of today, but ultimately do so because of their strong belief in a better tomorrow.

How Do I Find Clinical Trials?

Finding information on studies that are currently enrolling people can take a little work on your part. If you have Internet access, a good place to start is www.PDtrials.org. This Web site is part of a coalition initiative of the major Parkinson's organizations to increase awareness and understanding about clinical trials. The Web site offers a listing of more than 50 clinical trials that are currently seeking participants and allows you to sign up to receive regular monthly updates on new trials. If you don't have online access, you can call the *PDtrials* initiative at (800) 801-9484 to receive a print bulletin of the same information that is provided online. The *PDtrials* initiative has also created an educational pamphlet entitled "Getting Involved in Parkinson's Clinical Research."

If you find a study you are interested in and you meet the qualifications for participation, the trial investigator and coordinator will provide you with extensive information about the study and what will be required of you. You will have the opportunity to ask questions. When you feel confident that you understand the purpose of the study and the procedures, you will be asked to sign the informed consent form. All participation is on a voluntary basis. You may drop out of a study at any time, and all information obtained about you from the study is confidential.

Is a Clinical Trial Right for Me?

The decision to join a clinical trial is a very personal one and should be made after discussing it with your neurologist, family, and other significant people in your life. As a person with young onset PD, you have a full life ahead of you. Staying informed on current studies can help you make more knowledgeable choices about treatment strategies. With comprehensive information, you can feel empowered to work with your physician as a partner in developing your plan of care. It is through clinical trials that new medications and treatments for PD become available. Without a sufficient number of participants, studies can be delayed. Currently it takes an average of 14 years, from the time of discovery, for a new drug therapy to be approved by the FDA. Delaying the study process means an even longer wait for new and more effective treatments.

Is participating in a clinical trial right for you? Only you can answer that question. With the wide variety of educational resources available, it should be easier to make a well-informed choice. Finally, ask yourself the question: If I choose not to participate in research, who will take my place?

Traversing Technology: How to Navigate the Internet

By Sheryl Jedlinski

The more you know about Parkinson's disease, the better able you will be to participate in decision-making about your treatment options. According to former U.S. Surgeon General and Parkinson's patient Dr. C. Everett Koop, "The best prescription is knowledge."

Nowhere is medical knowledge more readily available than on the Internet. Every day brings new health-related sites offering free access to a seemingly infinite amount of information. If you don't want to search the Web yourself, you can subscribe to free services, such as Google alerts (www.google.com/alerts) which will send you the very latest PD-related news throughout the day, from sources across the Web.

Not all sites are created equal, however. Anyone with a computer and Internet access can publish information in cyberspace. How can you distinguish reliable from incomplete or inaccurate content when you have little or no medical or scientific knowledge? Rely on common sense and a healthy dose of skepticism.

PD Message Boards and Chat Rooms

Used wisely and cautiously, the Web is a powerful resource for finding new ways to live well with Parkinson's. PD message boards and chat rooms are great for making virtual friends who will lend an ear 24/7 — sharing their experiences and strategies for coping with PD, and providing support when needed. You needn't feel bad if you opt not to post your own message right away. New members - "Newbies" - often "lurk" for weeks or months, simply reading other people's posts. A word of caution: do not assume that your disease progression will be the same as someone else's. PD is a "designer" disease and no two people diagnosed with it follow the exact same course.

Web Surfing Guidelines

These "safe surfing" guidelines can help you get the most from the Internet:

- Visit sites of trusted sources such as major PD organizations, medical centers recognized for excellence in Parkinson's research, patient advocacy groups, and government health agencies.

- Recognize that surfing even trusted Web sites is no substitute for obtaining your doctor's medical diagnosis and advice based on a physical exam.
- Make search engine queries as specific as possible to limit the number and increase the relevance of suggested sites. Be aware that paid advertisers rise to the top of the list.
- Verify when the information was last updated and confirm it with at least two other respected, independent sites before you assume it is true.
- Determine the site's purpose (e.g., education, sales, etc.) and who funds it.
- Look for contact information. Who are the authors/editors? Look for links labeled "Bios" or "About Us" to check their credentials and determine the level of expertise on the topic at hand.
- Do not share personal information on message boards or on chat lines with people whom you do not know very well.

Yes, knowledge is power; just remember to always carefully check out its source!

Part IV

Changing Roles and Relationships

Who are you? Are you a man or a woman? Are you single or married, a spouse or a partner? Are you a parent? We all identify ourselves in a variety of ways. Sometimes the groups with which we identify the most are based upon our gender, physical appearance or functioning, or the role we play in our family or social environment. When you are young and still establishing your sense of who you are and where you fit in, a diagnosis of YOPD can make you question your sense of belonging, self-worth, and purpose. If your perception of yourself or other's perceptions of you change, how will you adjust? While we can never fully anticipate our reactions in advance, considering some of the potential physical and emotional changes PD can create in your life and in your relationships, and having a plan for how you might address those changes, can be very helpful.

Gender Differences

By Lisa Shulman, MD

“Men are from Mars, women are from Venus.” This little phrase, popularized by Dr. John Gray’s book of the same name, did much to capture a phenomenon that had previously been quite difficult to put into words. It’s something we all learn quite early in life; boys and girls, men and women, are different—not just in our physical characteristics but often our psychological make-up as well. In fact, gender differences can also have implications for how medical conditions are treated, how we perceive situations, and how we relate to others.

Gender Prevalence

Parkinson’s disease is more common in men than in women. However, women have a longer life expectancy than men, which may result in a longer lifespan with PD symptoms. Consequently, therapeutic goals and long-term care issues may vary between women and men. This greater longevity in women results in a rising percentage of females affected with PD, despite the lower incidence in this group.

Gender Disparities in Symptoms and Treatment

Recognition of the existence of gender differences in medical conditions is relatively recent. Descriptive studies and clinical trials that focus on gender issues have mainly emerged during the last 10 to 15 years. Our understanding of gender disparities in Parkinson’s disease has provided some interesting preliminary findings, though much more research is necessary to draw firm conclusions.

Gender comparisons of PD symptoms among participants in clinical trials show similar rates of tremor, rigidity, bradykinesia (slowness of movement), and handwriting difficulty in women and men. In one study, women were more likely to report pain as a major component of their symptoms—describing discomfort of the neck and lower back—and were also more likely to describe depression as “continually distressing” than their male counterparts. Men reported more problems with dexterity, walking, and motivation. Urinary incontinence is a relatively common non-motor symptom of PD. In a recent study, about 40% of people with PD reported some problem with urinary control. Urinary dysfunction was more common in women (41%) than men (30%), and was also associated with greater age and PD severity in both women and men.

Gender differences are generally not acknowledged in published guidelines of PD management. However, evidence of gender disparities in medication response and side effects suggest the need for more attention to gender differences in medical management. Although levodopa and other antiparkinson medications remain effective throughout the duration of the disease, long-term use results in fluctuations of response and dyskinesias (involuntary movements) in most patients, particularly younger ones. Standardized dosing of PD medications leads women to receiving higher dosages of antiparkinson medications than men relative to their weight. This may explain why several studies show that women are more likely to have drug-related dyskinesias and also why levodopa administration was found to result in greater improvement in motor function in women than in men. Although drug-related dyskinesias are a major problem in PD management, to date no studies of levodopa dose adjustment by weight have been conducted.

Special Considerations for Women with PD

Female Lifecycle Changes

The female lifecycle is characterized by hormonal fluctuations coinciding with menstruation, pregnancy, and menopause. Medical and surgical treatments that result in hormonal changes include the administration of oral contraceptives or hormone therapy, as well as hysterectomy (removal of the uterus), and oophorectomy (removal of the ovaries). The effect of fluctuations of hormonal levels on brain function and PD has begun to be studied, and there is some evidence that less exposure to estrogen may be associated with an increased risk of PD.

Young women with PD report a relationship between their menstrual cycles and fluctuations in their PD symptoms. Surveys have shown that 25% of menstruating women with PD report premenstrual worsening of their PD symptoms with alterations of response to PD medications. This suggests that there might be a benefit in adjusting medication regimens during the menstrual cycle in younger women with PD who experience menstrual-related fluctuations of their PD symptoms.

The Role of Estrogen

Although we are still in the infancy of our understanding of hormonal effects on the brain, an impressive amount of basic scientific research supports

estrogen's effects on the dopamine pathways. Dopamine is the neurotransmitter that is in short supply in people with PD due to progressive injury to the dopamine-producing cells in the brain (neurons). Estrogen has been shown to influence dopamine synthesis and release. This hormone also affects the number of connections (synapses) between neurons. Through a process often called "brain plasticity" or "remodeling," the number of synapses in the brain is actually continually changing, and the presence of estrogen enhances the number of these connections.

Estrogen has also been speculated to have "neuroprotective" properties. This means that estrogen might have the ability to promote the survival of neurons and thereby prevent neuronal injury such as occurs in PD. It is unclear why PD is more common in men than women, but one possible explanation is that the presence of estrogen in women has a protective effect.

Clinical research trials of estrogen's effects in PD are limited, but recent studies suggest that estrogen has a beneficial effect on PD symptoms. Estrogen administration was associated with improved symptom severity and less "off" time. Also, the necessary levodopa dosage for relief of symptoms was reduced in the presence of estrogen.

Better understanding of estrogen's effects in PD could influence the way we care for women with PD. For example, physicians could better anticipate the effects of changes in estrogen with the monthly menstrual cycle, the onset of menopause, or the introduction or discontinuation of estrogen replacement therapy (ERT). Women could be counseled on the kinds of changes of symptoms that may occur at these times, and physicians could anticipate the need for adjustment of Parkinson's medications. Postmenopausal women are faced with the decision whether or not to use ERT. For women with PD, information about estrogen's effects in PD would facilitate decision-making.

There are many questions about estrogen's potential risks and benefits that remain to be answered, and those answers will ultimately help women and their physicians make better informed healthcare decisions.

Pregnancy

There are limited reports of pregnancy in women with PD, so information in this area is somewhat limited. We do know that having PD does not affect fertility in either men or women, and it does not affect the woman's ability to carry the pregnancy to full term.

Some case reports suggest that pregnancy may result in progression of the symptoms of PD. One report documented a significant increase of Parkinson's symptoms during pregnancy in a woman with early PD who had not begun any medications. Nevertheless, the initiation of symptomatic therapy following the birth resulted in marked improvement. It is unclear whether this progression of PD was due to the effects of pregnancy or the natural course of PD over a nine month period. Women with PD who plan a pregnancy should be counseled that their PD symptoms may worsen during pregnancy, and that the long-term impact on progression of the natural course of the disease is unclear.

The additional effects of hormonal changes and pregnancy-associated stresses may also exacerbate PD symptoms. The available literature on medications during pregnancy suggests avoiding the administration of amantadine (Symmetrel®) during pregnancy. It appears that the use of carbidopa/levodopa is safe during pregnancy, and should be used in the lowest reasonable dosage. With little data available on other antiparkinson medications, it is safest to avoid medication when possible or to rely on levodopa alone during pregnancy.

If pregnancy is an option that is being contemplated, there are important questions that should be considered. If disability progresses, does the person with PD have a well partner and/or family members who are able to provide support in parenting responsibilities? Will the costs of raising a child while dealing with a chronic medical condition create a financial hardship? Will the stress associated with pregnancy and parenting be manageable? All of these issues require careful consideration before a decision is made.

Sex and Sexuality

By Thomas Keeler, MD

At one time or another, people with Parkinson's disease may have issues related to sexual function. Quality of life studies report sexual dysfunction in young people with PD at rates in the 30% range. This compares to healthy populations of young individuals reporting 3%-15% rates of sexual dysfunction. Because sexuality plays an important role in the lives of most people, the onset of PD may bring special challenges. However, with proper diagnosis and treatment, it may be possible to resolve or improve any sexual problems that may develop.

Sexual Dysfunction and Its Treatment

The most common sexual problem reported by men is erectile dysfunction (the inability to have or sustain an erection). One of the most significant advances in the treatment of male erectile dysfunction has been the introduction of a class of medications called phosphodiesterase (PDE) inhibitors. PDE is an enzyme found in many areas of the body. PDE-5 has been determined to be highly concentrated in penile tissues as well as clitoral and vaginal tissues. By blocking this enzyme, an increase in blood flow will occur, thus improving the quality of an erection.

Currently, there are three PDE-5 inhibitors available: sildenafil (Viagra®), vardenafil (Levitra®), and tadalafil (Cialis®). All three medications are effective in the treatment of erectile dysfunction and, with a few variations in their side effects, are safe and well tolerated. Caution must be taken in patients with Parkinson's disease who have autonomic nervous system dysfunction such as low blood pressure because these medications can cause a further lowering of blood pressure. This could result in dizziness or fainting. Patients with low blood pressure conditions should have their initial dosing at the doctor's office so that blood pressure effects can be assessed. Patients diagnosed with coronary artery disease should also avoid this class of medications. To date, female sexual dysfunction has not been found to respond as dramatically to these medications, and these medications continue to be studied.

Not all men respond to PDE-5 inhibitors or they may not tolerate certain side effects. Other forms of therapy are available and effective. Oral medications such as yohimbine and trazodone have shown some success. Apomorphine, which stimulates central dopamine receptors, is under study for erectile dysfunction. Injectable therapies with alprostadil (Caverject®) or other injectable

medications can be quite effective. This form of therapy requires direct injection of medication into the penis. This is a minimally invasive, well tolerated therapy and can be taught to one's partner if the hand coordination of the person with PD is not steady. Topical medications are also being studied. MUSE® is alprostadil available in the form of a topical urethral pellet (inserted into the penis). Lastly, mechanical intervention with a vacuum device or a surgically placed penile prosthesis may be right for some patients.

Less is known about sexual problems in women. Decreased sexual drive is a common complaint, but it is unclear how or in what ways it may be related to the disease process, medication side effects, or hormonal changes due to advancing age. Women may benefit from estrogen replacement, either topically (in the form of a cream or vaginal suppository) or systemically, for vaginal dryness and improved vaginal elasticity. Various types of vaginal lubricants may also be helpful if intercourse is painful.

Some people with PD, men or women, can experience hypersexuality which can be a side effect of PD medications. It is important to discuss any concerns about this type of behavior with your physician so changes in medications or other treatment can be considered.

Some cofactors related to sexual dysfunction can include cigarettes, alcohol, and certain drugs or medications which may need to be modified or eliminated. Other important factors contributing to sexual dysfunction in Parkinson's disease patients are sedentary lifestyle and depression. Staying physically active with exercise helps maintain cardiovascular integrity and a sense of well-being. Depression, when aggressively treated and corrected, may help resolve many sexual problems in both men and women. Although depression is a common cause of sexual dysfunction, it is important to note that some antidepressants may also cause sexual problems.

Patients are often reluctant or embarrassed to discuss issues of sexual functioning with their physicians, and physicians often neglect to ask questions about this subject. However, if you will initiate conversation about sexual problems with your doctor, he or she may be able to help you and/or make a referral to a specialist for evaluation, usually a urologist for men or gynecologist for women.

In summary, evaluation and treatment of sexual dysfunction in patients with Parkinson's disease has been shown to effectively improve quality of life and reduce depression. Treatment for men is generally well tolerated and effective. Treatments for women remain elusive and continue to be under study.

Sex and Intimacy

Intimacy is important for everyone. We interact and communicate with our partners in all kinds of intimate ways, sexual and non-sexual. Often these patterns of behavior have become well established over time. Symptoms of Parkinson's disease such as tremors, problems with movement (either too little or too much), fatigue, or decreased libido (sex drive) can interfere with some of the activities that may have historically provided a deep sense of connectedness. With imagination, creativity, and flexibility, new and satisfying ways of relating intimately can be discovered together.

It is not true that the best sex is spontaneous sex —a little planning can go a long way in enhancing the experience for both partners. Try to plan sexual activity for a time when PD medications are working best. Foreplay can take many forms and will help set the stage for a positive experience. This might include candlelight, soft music, loving words, and an assurance of privacy. If slowness of movement interferes with sexual relations, new positions which require less movement on the part of the person with PD can be explored.

Sex is a two-way street; it involves two people, each of whose needs and feelings are mutually important. It is helpful for each person and couple to define their own goals regarding intimacy and sexual activity. Remember, sex isn't just about penetration and orgasm. If either partner no longer wants or cannot have full sexual intercourse, hugging, holding hands, kissing, and touching are important ways of being intimate and showing affection which can keep a loving relationship alive.

Depression can be both a cause and a result of sexual problems. Stress and anxiety can have a profound effect on libido, whether caused by the sexual problem itself or other things happening in a person's life. Trained sex therapists can be very instructive in addressing communication barriers and in helping identify mutually satisfying ways of interacting with each other.

Partners: In Sickness and In Health

By Linda O'Connor, LCSW, Sheryl Jedlinski and Julie Sacks, LCSW

Maintaining a marriage or a committed relationship with a significant other can be challenging in the best of times; it takes work as anyone will tell you. But add into the mix a diagnosis of Parkinson's disease, and the "work" of the relationship takes on new meaning.

When one partner is diagnosed with PD, it deeply affects the other as well. When you began your life as a couple, your dreams and expectations for that life did not include a chronic illness. Now you must consider how PD might change your relationship with each other and your already busy lives. You might even be wondering whether your relationship can survive the challenges of living with a chronic illness like PD. The answer to these and other related questions depends, in part, on the strength of your relationship prior to the diagnosis of PD. How well do you and your partner talk to each other about important issues? Are you typically able to resolve differences and support each other when life stresses become overwhelming? If so, this is a good foundation from which to work. If you need help in these areas, don't despair. You can learn how to better communicate and support each other with concerted effort and practice.

You and your partner are likely to experience a range of emotions as you navigate the unfamiliar terrain of PD. It is no surprise that the stress associated with the diagnosis and treatment of PD can take its toll on both of you. What is surprising is that many couples find that by joining forces and managing the situation together they are actually able to strengthen their relationship.

Supporting Each Other

One of the best ways to create or maintain a healthy relationship while managing PD is to identify *when* and *how* you need support. Keep in mind that the person with PD is not the only one who will need support; you both will. Here are several ways you can nurture the relationship *and* get your needs met:

Talk openly and honestly. Talk with your partner about how PD is impacting your life together and how each of you can make life easier for the other. Share your fears and concerns including the potential for disability, unemployment, reduced income, and greater dependence on others.

Focus on mutual giving. Although a person with PD may sometimes need extra help from his or her spouse or significant other, remember that you are *both* providers of care for each other, just in different ways. Each of you can try to determine what the other needs and how you might best meet those needs. Keep in mind, doing things for your partner is not the only way to care for him or her. Simple gestures, such as a hug, a kiss, or even a well-placed “thank you,” can convey appreciation. Sometimes the greatest need your partner may have is for you to just listen and offer encouragement, especially when he or she is overwhelmed or stressed.

Be flexible. Limitations in functioning due to PD symptoms may cause roles and responsibilities to shift within the relationship. Whether you are assuming a new role or household task or relinquishing an old one, you may find that one or both of you are feeling resistant to the change. Focus on approaching the situation with flexibility and it may make the shift easier. Tell your partner when you need help and when you don’t. Although it may take the partner with PD longer to complete certain tasks, that does not mean he or she wants to be “rescued” from doing them. Most people with Parkinson’s want to remain independent as long as they can.

Identify the positive. This does not mean burying your head in the sand. You and your partner will undoubtedly face certain challenges related to PD, but by being creative and willing to make adaptations to your activities and/or routine, you and your partner may be able to continue to pursue the things you have always enjoyed doing together. Spending some time apart doing things you enjoy, whether alone or with a friend, can often replenish you and bring you back to the relationship feeling rejuvenated.

Consider counseling. Sometimes extra help is needed to effectively cope with the changes PD brings. Couples counseling can help facilitate constructive communication between partners, strengthen your relationship, and maintain positive family functioning. Allow yourself to need and ask for help; knowing when to seek counseling is a sign of strength, not weakness.

Stay informed. There is much truth in the saying that knowledge is power. The more you both continue to learn about PD, the better prepared you will be to handle the issues that may arise. Consider asking your partner to accompany you on doctor visits so he or she can ask questions, raise concerns, and develop a better understanding of PD and appropriate expectations for the future. The APDA and other PD organizations offer many types of educational programs. Request that each organization place you on its mailing list so you and your family will be aware of all the resources available to you.

Though the diagnosis of PD changes life for both partners in a relationship, it does not have to define who you are as an individual or as a couple. With the perspective that you and your partner are a team, you can better encourage and support one another. Maintaining a generally hopeful attitude, while at the same time strengthening your ability to communicate openly and honestly with each other, will make life with PD easier, and may even deepen your commitment and partnership.

Beginning a New Relationship

What if you have been diagnosed young with PD and, at the time of diagnosis, haven’t yet found “the one?” Or what if the person you thought was “the one” turns out not to be, and after years of being with a partner who knew everything about you, you are faced with starting over?

While YOPD has many motor and non-motor symptoms that can make socializing, dating, and sex more complicated, these aspects of life are not off limits to you because of PD. A chronic illness like PD does not eliminate the desire for or the possibility of a romantic relationship. Your doctor may have provided you with many prescriptions, but “no dating” and “no sex” probably weren’t among them. In fact, quite the opposite is true. Most doctors are supportive of any activity that keeps you active (as long as it is safe) and diminishes isolation and depression.

If you are dating, you will inevitably be faced with decisions about which potential partners you feel you want to tell about your illness, and when and how you will do so. Similar to disclosing your diagnosis to your employer, these decisions are extremely personal ones and will depend upon many different factors including the severity of your current symptoms, how comfortable you are with the other person, and the personality of your partner. It is not unusual for people to dread this one conversation so much that they avoid any situation that might lead to a romantic involvement. It can be helpful to remind yourself that not everyone needs to know and not everyone needs to know right away. On the other hand, if being upfront with others makes you feel most comfortable, and allows you to become more fully involved, saying something sooner rather than later may be the right decision for you.

Many young people are surprised to discover that their illness is not a “deal-breaker” for a prospective partner. Whether you are single or divorced, if you find yourself wanting the kind of intimacy often reserved for couples, remain open to the possibility and see what happens.

Parenting Children and Teens

By Nicholas Long, PhD

Parenting, even under the best of circumstances, is a challenging and often stressful endeavor. When one has young onset Parkinson's disease, being an effective parent can be an even greater challenge. You must decide when to tell your children about your condition, what to tell them, and how to best help them cope with changes occurring in the present and those to come in the future. While there is no single or "right" way to address these concerns, the purpose of this article is to provide general guidance in these areas.

Educate Yourself About PD

Having a comprehensive understanding of PD is the first step in not only helping yourself live well with PD but also in helping your children understand and adapt to the changes to come. Actively pursue reliable information about PD. The more you understand about the disease and how it progresses, the better prepared you will be to make the best decisions about your own healthcare, and to accurately answer your children's questions.

Explain PD to Your Children

As a general rule, you should tell children sooner rather than later. Children are perceptive and will likely know that something concerns you. Choose a quiet time when your children are rested and are able to engage in a conversation. If you have children of different ages, you might speak with your older children first. Perhaps the older children will want to help you tell your younger children. Try to have these conversations as close together as possible so that all members of the family are aware of the situation and have a chance to support each other.

When explaining PD to your child, strive for age-appropriate honesty. With younger children, provide information using simple language that your child can understand, such as the name of the disease and symptoms they may initially observe. Over time you can add to their understanding of PD. With older children and adolescents your initial explanations can be more detailed. However, regardless of your children's ages, explaining PD to your children should be viewed as a process that occurs over time rather than a one-time event. Remember also *how* you speak to your children is as important as *what* you say. Using a calm reassuring voice, even if you become sad, will help your children see how you are trying to cope. It will help them do the same.

Discuss with your children the symptoms of PD they are likely to see in you. With young children you should probably keep your description of symptoms focused on what they might be noticing right now, and wait to discuss any symptoms that might occur in the future. With older children and adolescents you might want to discuss potential symptoms in advance to help them prepare for upcoming changes.

Invite Questions

Let your children know that you are available to answer any questions they may have. Try to anticipate common questions your children might ask, and think about how you might respond. Depending on their age, expect them to ask questions such as:

- What is PD?
- What causes PD?
- Is PD contagious?
- Can it be cured?
- What is the treatment for PD?
- Are you going to die?
- What is going to happen to you?
- Can it be inherited?

Younger children often believe that their behavior is powerful and that they may be responsible in some way for your being sick. They may believe that they could have caused your PD by being "bad" or by not being "good enough." They may wonder (out loud or to themselves) if they behave better will you get better? Reassure them, as often as is needed, that their behavior has in no way caused or contributed to your PD.

Provide enough information to adequately answer their questions, but stop short of giving too much information so they are not overwhelmed. Remember that children, especially young ones, tend to have short attention spans, so do not talk longer than they can listen. Having more frequent, brief discussions may be more helpful and productive than the occasional, more structured, and emotionally intense family meeting. Make your illness part of your family's ongoing dialogue, but try not to have it be your primary family focus.

Help Your Children Deal with Their Feelings About PD

It is hard to predict how a specific child will react to the knowledge that his or her parent has PD. Make every effort to help your children deal with the range of emotional reactions they might have. You can do this by providing support, listening to your children, and discussing their feelings. Some children may resist discussing their concerns or feelings in order to protect their parents from becoming upset. It is critical that children know they can talk to you about any concerns or feelings without fear of being judged negatively or causing you to become overly upset. You should also keep in mind that your child's thoughts and feelings about the illness may change over time. This is why it is important to keep the lines of communication open. Ask your children on a regular basis if they have any questions or issues they would like to talk about. To encourage conversation, try asking open-ended questions (questions that cannot be answered with a one-word response such as “yes” or “no”).

Older children and teens might need additional outlets to express and work through their emotions. Options may include: journaling, poetry, exercise, counseling, or a teen support group. The goal is to find the outlets that work best for your child.

Over time, watch for any emotional changes in your children that might indicate they are stressed from worry. Check to see if they are confused or have misinformation about PD. Sometimes children hear misleading information from other people and have unfounded worries about something that isn't true.

There are also a number of resources available to help children understand PD. The American Parkinson Disease Association publishes a booklet for young children entitled, *My Mommy has PD...But It's Okay! A Guide for Young Children about Parkinson's Disease*. You can also check with your local library, bookstore, or APDA for other helpful resources. It is important to remember that books should be used as a supplement to one-on-one discussions with your child and never as a replacement for talking to your child about PD.

Prepare Your Children for the Reactions of Others

Children often do not know how or what to tell others about their parent's condition. You can help your children by suggesting some simple and concise explanations of the disease and how it is treated. It may help for the parent and child to role-play examples of questions others might ask. Do not avoid doing things

with your child because you are concerned about the reactions of others. Your child needs you to be an active, involved parent, regardless of the presence of PD.

Older children and teenagers may feel self-conscious or embarrassed about having a parent who is “different.” Getting them involved with other children who are also living with a parent who has PD can be a source of encouragement and support. You can find this type of support in a teen PD support group, if one is available in your area. An alternative would be any group that provides support to teenagers who have a parent with a chronic illness.

Teenagers are often more masterful at retrieving information from the Internet than their parents. While you should encourage them to learn as much as they can about PD, it is also important that you help them understand that they must seek out reliable sources online (see *Traversing Technology* section). Provide your children with Web sites you know are sound sources of information about PD, and help them utilize the information they obtain by talking it over with them. It is also important to emphasize that PD affects each person differently.

Be Mindful of What Your Children Can Overhear

Children are naturally curious and will often make an effort to listen in on conversations that go on between their parents. This is especially true if they are worried about something. Avoid discussions regarding your concerns or issues related to PD when your children have the potential to overhear what is being said.

Have Fun with Your Children

One of the best ways to strengthen your relationship with your children is to have fun together. Find interactive activities that you and your children enjoy doing together. Choose activities that will be manageable for you but also bring enjoyment for everyone involved.

Preserve Family Routines and Set Limits

Make an effort to maintain your normal schedule, such as wake-up times, meal-times, bedtimes, and other regular activities, as much as possible. Children typically do best when their daily routines are predictable and consistent. Of course, this is not always possible, but making an effort to maintain regular routines and schedules for all family members will be reassuring to children.

Many parents feel guilty that their children have to endure the consequences of living in a household with PD. As a result, some parents with PD are reluctant to set firm limits and appropriately discipline their children. However, children do best, even amid health concerns, when there are clear boundaries and they know what they can expect from their parents.

Work with Your Children's School

While you attend to the relationship with your child on the home front, it is also important to work closely with your children's teachers. Consistent contact with teachers will give you additional clues about how your child may be adjusting to any PD-related changes in you or in the family dynamics. Is schoolwork being completed correctly and on time? Are there any behavioral problems in class or with peers?

Regular contact with teachers will also allow you insight into how you can best help your child explain to peers what living with PD is like. To help your child, you might do a presentation on PD for his or her class or work with teachers to allow your child to do a research project on PD to learn more about the disease.

In addition, make an effort to keep your children involved in extra-curricular activities and social events. These activities offer another avenue for your child or teen to find support from others such as friends, coaches, and teachers.

Part V

Living Today and Planning Ahead

A diagnosis of young Parkinson's disease is often followed by a litany of questions about the future including: What does this mean for me and my family? Will I be able to continue working? If so, for how long? You may find yourself preoccupied with matters of financial security you always thought you would attend to later. Suddenly, "later" must be now, and planning for the future may take on a sense of urgency that can leave you feeling overwhelmed.

Keep in mind that each person with Parkinson's disease presents a unique combination of symptoms, work-related issues, and family and financial circumstances. Seeking input and support from your family, physician, and appropriate financial and legal professionals can help you make the best choices for your particular situation. It is reassuring to know that with current advances in the medical treatment of Parkinson's disease, and laws that require employers to make adaptations for employees with physical challenges, you will most likely have many productive work years ahead.

This section will define many legal terms, offer employment and financial options, and describe government benefits and programs for which you may be eligible and can apply.

Employment

By **Kenneth Skord, MS, CRC** and **Sarah Marcotte, MS**

We are fortunate to be living at a time when forward-thinking businesses are demonstrating increased interest in diversity, which includes people with disabilities. Besides being “the right thing to do,” employers find that recruiting or retaining employees with disabilities is a solid business strategy for increasing an organization’s applicant and promotion pool, decreasing turnover, and enhancing a company’s appeal among employees and the public. Additionally, computer hardware and software, as well as assistive devices and technology, are enabling increased productivity among workers with all types of limitations.

While some with young onset Parkinson’s disease will find that they need to reduce their workload or cease working altogether, many are able to make adaptations to their work environment or work schedule, making it possible for them to remain employed longer.

Workplace Considerations

After a diagnosis of Parkinson’s disease, it becomes important to evaluate the physically and emotionally challenging aspects of your symptoms and how they may relate to your job performance. If you begin experiencing difficulty at work due to your symptoms, first and foremost, discuss your issues with your doctor. Adjustment of your medications or other modifications to your treatment regimen may be helpful.

You may also find it helpful to approach your job from a different perspective. Finding alternative ways of doing things like creating new schedules, adjusting your workload, or making changes in the organizational design of your work space can decrease stress and make continued employment possible and more comfortable.

Disclosing Diagnosis or Disability to Your Current Employer

Deciding if, when, and how to disclose information about your diagnosis or disability is an extremely personal choice and will depend on many factors. One of the most central considerations is likely to be the degree to which your job performance is or may become affected over time.

Only you can judge the likelihood of a positive outcome from sharing your circumstances at work.

You may want to consider voluntarily disclosing disability-related information if:

- you feel that doing so will further your chances of being retained.
- your symptoms are affecting your performance and you are ready to ask for some type of accommodation.
- your symptoms have been apparent to your co-workers. They may be relieved to know the source of your physical changes or changes in your job performance.
- trying to keep your diagnosis a secret is increasing your stress and compromising your performance.

If you choose to disclose, you do not need to be specific about your health issues or disabilities. You should, however, communicate how your performance is affected so that you and your employer are able to work together to identify a suitable adjustment or modification (called an “accommodation”) that will allow you to continue completing your work duties successfully. Because you live day-to-day with your symptoms, you are likely to be able to propose a simpler change or adjustment based on your abilities than your employer could imagine. So, think creatively about the kind of accommodations that would enable you to continue to perform your current responsibilities. If you feel some type of accommodation will help maintain or improve your work performance you can consider approaching your employer before your work performance suffers. Employers are not required to forgive previous poor performance if the need for an accommodation due to disability is not known to them.

When talking with your employer about your Parkinson’s and necessary workplace changes, relate your suggestions to your company’s overall goals and strategies. Illustrate, verbally, how the changes you suggest can benefit not only you, personally, but the corporate “team” as a whole as you work together to meet company objectives. Finally, remember that no employer wants to lose a skilled employee.

Disclosing to a Potential Employer

While employment and civil rights laws prohibit an employer from asking an individual to disclose a disability when he or she applies for a job, you may decide that disclosing is in your best interest now or at some point in the future. Generally speaking, an employer is free to hire an applicant of its choosing as long as applicants are not eliminated from consideration based on disability, gender, race, age, or religious preference—categories referred to as protected classes. If two people apply for a job requiring speed and accuracy, an employer has the right to hire the candidate with the higher speed and accuracy because he or she is more qualified.

The successful applicant views the job interview as a major opportunity to make the case that he or she is most qualified for the job by communicating abilities and accomplishments, as well as giving good examples of relevant work experience, education, personal achievements, and personal strengths. Voluntary disclosure during an interview can:

- build trust and rapport with the employer, especially when a disability is visible.
- fill in gaps in a work history.
- explain a career change.
- provide a rationale for an accommodation.
- help an employer gain an understanding of who you are as a person and how you approach work and life challenges.

Weighing Your Options

If you reach a point where your disabilities pose a safety hazard on the job or your job becomes too demanding, frustrating, or unrewarding, it may be time to consider retiring or looking for other options. Before leaving your company, it's a good idea to check on other job openings within the organization that may fit your interests, experience, and ability level. Also investigate your medical and retirement benefits before finalizing your decision. If you are being threatened with termination because of your condition, call an attorney for professional legal advice, preferably one who specializes in employment or disability law. If you feel you can't afford an attorney, there may be low-cost or free legal services offered by legal organizations in your area. Local universities or community

centers may be able to assist you in finding these resources. Many young people who have decided to leave their jobs have used their talents to start their own businesses. The Internet has allowed people with disabilities to continue to “do business” without many of the pressures of a structured workplace. Particularly for people with PD who are having difficulty falling asleep or staying asleep, an online business can allow you to do business at any hour of the day or night.

Accommodation, Disability and the Law

To help you better understand the provisions made by the government for those with disabilities, here are some of the current laws and most frequently asked questions as they pertain to employment and accommodations.

What is a disability?

The Americans with Disabilities Act (ADA) is a law that makes it illegal to discriminate against people with disabilities in the areas of employment, public accommodations, public services, and telecommunications. Under the ADA an individual who has a disability is protected by the law if he or she has an “impairment” that “substantially limits” one or more “major life activities.” A key ADA principle is that individuals with disabilities who want to work and are qualified have equal opportunity to work.

What are the employment provisions of the ADA?

The ADA prohibits discrimination against all qualified people with disabilities in all areas of employment including job applications, hiring, training, dismissal, and compensation. Employers with 15 or more employees are covered under the ADA.

How do I know if I am a “qualified” person with a disability?

You are a qualified employee or job applicant if you meet the employer's objective requirements for the job (usually found in a job description) and, with or without reasonable accommodation, can perform the essential functions of the job.

What is a “reasonable accommodation?”

A reasonable accommodation is any change or adjustment to a job, the work environment, or the way things are usually done that allows the person with a disability to apply for a job, perform job functions, or enjoy equal access to workplace benefits available to applicants and employees without disabilities.

Examples of reasonable accommodations are:

- changing a work schedule.
- making existing facilities accessible to and usable by people with disabilities.
- providing additional unpaid leave.
- acquiring assistive technology equipment or devices.

Does my employer have to grant my request for reasonable accommodation?

When an accommodation would cause an employer significant difficulty or expense, it is considered an “undue hardship,” and employers are not required to make accommodations for such requests. Factors such as business size, financial resources, and the nature of the business operation are taken into account when determining undue hardship. Employer tax credits and State-Federal Vocational Rehabilitation funds may be available to help pay for facility accessibility and assistive technology.

What should I do if I think my ADA rights have been violated?

If you think you’ve been discriminated against, here are some helpful resources:

- The U.S. Equal Employment Opportunity Commission (EEOC) Web site (www.eeoc.gov) offers technical assistance on the employment aspects of the ADA including information on how to file complaints. The EEOC also staffs an information line at (800) 669-4000.
- The U. S. Department of Justice (www.ada.gov) has information about the ADA and options available if you feel you have been discriminated against. They also operate an ADA Information Line at (800) 514-0301 for answering your questions.

What is the Family and Medical Leave Act (FMLA?)

The U.S. Department of Labor states that the Family and Medical Leave Act mandates that businesses with 50 or more employees must give eligible employees up to a total of 12 work weeks of unpaid leave during any 12-month period for any of the following reasons:

- birth and care of a newborn child.
- placement of an adoptive or foster child.
- care of an immediate family member with a serious health condition.
- medical leave when an employee is unable to work due to a serious health condition.

The Department of Labor has a Web site (www.dol.gov/elaws/esa/fmla/faq.asp) that gives helpful answers to many frequently asked questions.

If you become unable to work, there are many state and federal programs that address the needs of individuals with disabilities in the areas of employment, income support, and healthcare coverage. Be sure to maintain a detailed file with copies of all your medical records. This will be helpful when you are required to provide evidence of disability when applying for any of the disability benefit programs (see *Financial Planning* section for details of these programs).

Financial Planning

By Mary Anne Ehlert, CFP®

Financial planning means different things to different people. To most of us, the concept of financial planning means investing. However, there is much more to financial planning than simply investing for the future. This section will provide you with an overview of financial and legal terms as well as government-sponsored programs that will help you and your family make sound decisions regarding your financial future.

To help organize your planning strategy, first you need to do some basic financial planning followed by some special planning for your particular needs. There are six steps in the process of thorough financial planning with a condition like PD in mind. Taking a candid look at your financial situation and organizing all of the relevant documents is often the best place to begin.

Getting Organized (Step 1)

Go through all of those papers you might have lying around and organize them into categories. These may include, but are not limited to:

- Bank statements
 - Account statements
 - Life insurance and disability policies and statements
 - Health insurance information
 - 401K and retirement statements
 - Mortgage papers
- Refinancing papers
 - Social Security statements and correspondence
 - Medicaid/Medicare documents
 - Medical documents
 - Estate documents
 - Funeral arrangements or wishes

After you’ve finished sorting them by topics, store each topic in its own file folder. That way, as you receive new correspondence, you can easily file or retrieve what you need.

Then, create a spreadsheet or list showing the above categories. It’s not necessary to list all of the documentation in each category on the spreadsheet, just list the categories.

On this spreadsheet you also should include:

- User name and passwords to any Web sites that you use for banking and investments
- Attorney(s) name and phone number
- Accountant(s) name and phone number
- Financial Advisor name and phone number

Keep the folders and spreadsheet/list in one central place, such as a box, filing cabinet, or safety deposit box. The best type of container is a fireproof one. Tell someone you trust, such as a family member, your power of attorney, executor of your estate, or a relative or friend where this information is kept. If you’re using a safety deposit box, make sure someone knows where the key to the box is kept and give them signing privileges to access the safety deposit box.

Understanding Your Current Financial Situation (Step 2)

The next step is to take a realistic and honest look at what you spend every month and compare it to your monthly income. Most people do not know where their money goes. To assess this you will have to do more than flip through your checkbook. You will need to do some digging through all of your financial records (credit card statements, cash receipts, automatic withdrawals, etc.) to come up with accurate figures. Some expenses are easily overlooked. For example, think of all the gifts you buy, money spent on eating out, special programs for your kids, school fundraisers, dance classes, music lessons, etc. Record both the recurring and special expenses. Be honest and don’t underestimate.

After you have a good idea of what you’re spending you need to begin to identify your assets and liabilities. Take a blank sheet of paper and draw a line down the middle. On the top of the left side, write “What I Own.” On the top of the right side, write “What I Owe.” The left side will include your bank accounts, your retirement accounts, any savings, your home value, and any cash in your life insurance policies. The right side will include your mortgage balance, your credit cards, any loans on your life insurance, and any other outstanding loans or debts. Total the amounts in each column.

On the bottom of the page, write the death benefits of your life insurance policies as well as any disability insurance coverage you now have at work or outside of work.

Building on Your Existing Plan (Step 3)

After you understand your current investments and insurance, it is time to look closely at opportunities that may be available to you individually or through your workplace. Making wise decisions today can help you and your family in the future. Start investigating your current benefits at work. The following categories will help you begin this assessment.

Disability insurance coverage Employer group or individual disability insurance benefits replace a part of your income due to disability. If you have disability insurance through your employer or an individual plan prior to the onset of PD, the benefits will probably be supplemented by Social Security Disability. The amount depends on the plan that covers you. If you have employer group disability coverage, see if you are allowed to increase the coverage and when. If this is available to you during open enrollment without underwriting (medical questions), accept as much coverage as you can while still working. If you have an individual disability plan, check the policy to see if you have the right to increase your coverage without underwriting. If so, increase the coverage at every opportunity.

Long term care insurance coverage If long term care insurance is offered at work with little or no underwriting, sign up for as much as you can. The purchase of individual long term care insurance will probably not be an option available to you, but you might want to check that out as well.

Life insurance coverage If you have a term life insurance policy with a disability rider it means that your life insurance premiums will be paid for you by the insurance company once you are no longer working due to PD. If you don't have a disability rider, see if you can still add one to your term policy. You will probably not be able to, but it never hurts to ask.

If you have term life insurance and can afford to convert it to a permanent whole life insurance, you might consider this. Be sure to have a disability rider on this plan so the premiums would continue to be paid for you when you can no longer work. Not only will the death benefit remain in place with a permanent whole life policy, but the cash value would continue to grow. This adds to the financial security for your family.

Health insurance coverage If your company offers several plans of health insurance, be sure to be on the plan that provides the best coverage for your situation. Typically, you are able to change plans once a year if the company offers several options.

Understand the type of health insurance continuation offered by your employer. *The Consolidated Omnibus Budget Reconciliation Act (COBRA)* is a federal law which allows an individual and/or dependents to continue group health and dental coverage once a qualifying event (loss of employment) occurs. Small companies are not required to offer COBRA, but will be required to offer whatever your state requires for small companies.

The COBRA law allows a terminating employee to stay on his or her employer's health insurance for up to 18 months (36 months for dependents losing coverage) and an additional 11 months as a disability extension. It is imperative that you apply for disability early enough in your initial 18 months so that Social Security will have time to process and approve your claim. There are strict guidelines for these applications so it is important to become familiar with all of the rules and follow them carefully.

Liabilities Pay down your credit card debt. This is an expense that causes problems later, so it is best eliminated as soon as possible. If your credit cards offer disability coverage which is reasonably priced, you might consider buying it if, and only if, your debts were to be waived upon proof of disability.

Saving: Emergency funds and retirement savings Continue to save wisely, while also enjoying your vacations and free time with your family. Build your emergency funds to equal six months of fixed expenses. Continue to fund your retirement savings, at least up to the amount that your employer matches.

Understanding the Availability of Special Needs Options (Step 4)

As an individual with future special needs, it is important that you understand what government benefits and legal options might be available to you. We often hear people say they are not eligible for benefits, or that everyone is turned down the first time they apply. Both of these statements are not true. What follows is a brief explanation of government benefits for which you may become eligible and will want to investigate.

Social Security Disability Insurance (SSDI) is a federal cash benefit that may be available if a person becomes disabled. It pays benefits to the individual and certain members of the individual's family if you are "insured," meaning that you worked long enough and paid Social Security taxes. Every year, each insured individual should receive a statement from Social Security, explaining his/her status of eligibility. Your benefits are based upon the "credits" 78

earned through work. You can request a current benefits statement from Social Security to understand the numbers of current credits you have earned and the amount of disability coverage you would be entitled to under the Social Security Disability program. Make sure your Social Security record includes all of your work history credit. If you do apply for Social Security Disability benefits, keep the following guidelines in mind:

- **Apply immediately after becoming disabled.** It can take Social Security offices 60–90 days to process your disability claim while they gather the pertinent medical information and evaluate your case.
- **Respond promptly to requests for additional information.** Since benefits can be retroactive to your date of application, it is imperative that you stay on top of responses or requests for additional information.
- **Provide a medical history that is as pertinent and clear as possible.** Maintain a list of your doctors' names and phone numbers. Keep a journal of your hospital stays, where you were treated, and the treatment dates. A summary of your work history is also important.
- **Keep a record of everything you submit.** If the Social Security office misplaces any of your paperwork, having copies on hand will allow you to easily resubmit it. Send all information via certified mail or take it in person, obtaining a receipt for delivery. When talking to the Social Security office, note the name of the representative, along with the date, time, and substance of all communication.
- **Be your own advocate.** Follow up on the status of your application. If you need help with the application or are denied this benefit, you might consider getting professional help. There are services that can handle the entire process for you. Keep in mind, benefits are retroactive to the date of your completed application. Once your application has been approved, you probably will not receive benefits until after the sixth full month of your disability.

Supplemental Security Income (SSI) is a federal income supplement program funded by general tax revenues (not Social Security taxes). Its purpose is to help the aged, blind, and disabled who have little or no income. It currently provides a monthly payment to be used for basic needs such as food, clothing, and shelter. It is generally for people who have little or no work history. The assets an individual can own in order to qualify for this benefit are limited. The rules and benefits for this program can vary by state, so it is best to contact your

local Social Security office. There are also professionals who can help you understand your options in regard to this program.

Medicare is a federal health insurance program for people 65 years of age or older, certain younger people with disabilities, and people with end-stage renal disease (permanent kidney failure with dialysis or a transplant). Medicare does not cover everything, and it does not pay the total cost for most services or supplies that are covered. This plan usually goes into effect two years after becoming eligible for SSDI.

Medicaid provides medical assistance for certain individuals and families with low incomes and resources. Medicaid eligibility is limited to individuals who fall into specific categories. Although the federal government establishes general guidelines for the program, the Medicaid program requirements are actually established by each state. In addition to paying for some medical services and prescriptions, Medicaid may also pay for residential facilities and other programs. This program has asset limitations similar to the SSI limitations, but a married couple is allowed additional assets in order to qualify.

Know Your Legal Options (Step 5)

There are important planning steps you should take to ensure that your wishes for financial and health matters are followed. Should there come a time when you are unable to make those decisions on your own, you can choose someone to speak on your behalf as it pertains to these decisions. When thinking about all your legal options, it can be very helpful to speak with an attorney who has extensive experience and knowledge in the area of Special Needs Planning. Following are some of the options you might consider:

Power of Attorney for Property If at some point in the future you need assistance handling your financial affairs, the Power of Attorney form authorizes someone to act on your behalf. This includes access to your bank account, managing your investments, paying your bills, etc. A durable Power of Attorney gives specific and limited authority to someone you choose and becomes effective immediately or upon your disability. It is important to choose someone you feel confident will act appropriately on your behalf. If you don't designate someone to have this authority with a Power of Attorney and you become incapacitated, your family may need to go to court to become your guardian or conservator. This might take the choice of who manages your affairs out of your own hands and could also cost your estate money.

Power of Attorney for Healthcare At the point when you need the assistance as described above, you may also need assistance in making medical decisions. The Power of Attorney for Healthcare allows you to appoint your choice of agent to make future medical decisions for you. This is a critical document to have prepared while you are well and of sound mind to make such decisions.

Many people believe that a spouse or other family member is legally entitled to make decisions on your behalf in regard to surgery/no-surgery, being kept alive by artificial means, etc. There may be a Health Surrogate rule in your state giving family members some rights, but not all states have such a law. It is important for you to choose who you will want to make decisions on your behalf if and when you are no longer able to do so.

It is also advisable to prepare a Living Will. Should it become necessary for your Power of Attorney for Healthcare to make decisions on your behalf, this document will provide him or her with direction regarding your wishes. You will want to talk to an attorney about all of these documents to make sure you have the appropriate choices made for you in the future.

Discretionary Supplemental Trusts There are several types of discretionary trusts that can be set up to hold various types of assets so that those assets will not disqualify you from receiving certain government benefits. A qualified attorney can help you determine if such a trust is appropriate or advisable for you.

Family Communication (Step 6)

It is important that financial and healthcare wishes be discussed at length with family members before your condition worsens so that everyone is clear about your wishes. This might also be an opportunity to write down the values you would like to share with others. Pass this information along in some written form.

By thinking through your wishes, organizing your financial matters, writing down thoughts of importance you want your family to know, and discussing your desires with your family, you are securing your future. You are also eliminating the guesswork for your family members and possibly eliminating future disagreements between them.

Planning for an uncertain future can be confusing and just plain daunting. But if you do your homework one day at a time and one step at a time, you will be better prepared for your future.

Part VI Hope for the Future

“There is no medicine like hope, no incentive so great, and no tonic so powerful as expectation of something better tomorrow.”

—Orison Marden

Our “better tomorrow” will be determined by the research so many scientists are doing today, and by the ways in which we individually, and as a community, choose to invest our resources, time, and energy.

Advocacy: Helping Yourself, Others and the Community

By Linda Herman and Susan Reese, RN, LCSW

Woody Allen said, “People can be divided into three groups: those who make things happen, those who watch things happen and those who wonder what happened. Showing up is 80% of life.”

You had no choice about the entrance of Parkinson’s disease into your life, but you DO have a choice in how you will live your life and what your future will be. You may be thinking, “What can one person do to make a difference or affect the future?” The answer is: plenty!

Become an Advocate for Parkinson’s Disease

Advocates make things happen. Advocating for Parkinson’s disease takes as little or as much commitment as you decide to put toward the cause. Advocacy can take many forms. Here are some ways you can make a difference:

Walk out your door and let others see you with your symptoms. In this way you will be educating others about what PD is—and is not.

Participate in a Parkinson’s walk-a-thon or other Parkinson’s fundraising program in your area. These activities provide much needed research dollars for finding new therapies and an eventual cure, and also raise awareness about Parkinson’s disease in our communities. The annual Parkinson’s Unity Walk in New York’s Central Park is the largest national grassroots event raising Parkinson’s awareness and funds to find a cure. One hundred percent of all donations raised goes directly to Parkinson’s research. Visit www.unitywalk.org to learn more about the Unity Walk and how to participate.

Attend PD support group meetings. This is one of the best ways to learn about PD, get support from others who are experiencing issues similar to yours, find resources, or share your own knowledge about PD with others. Over time, as you get to know the members of the group, it becomes more comfortable to be with people at various stages of the disease. Some will inspire you. You can find support groups specifically for young people with PD in some geographic areas, or a general PD support group may hold separate meetings or programs for younger members. If there are no young onset support groups in your area,

consider starting one. APDA’s National Young Onset Center can help you locate or start a young onset support group.

Enroll in a clinical research study to help expand our knowledge about PD. The more researchers learn about PD, the sooner they will be able to develop new treatments, stop the progression of the disease, and find the cure. Go to www.pdtrials.org to find a trial that is right for you.

Let your state and federal elected officials know who you are. One of the most effective ways to ensure a better future is to get state and federal support for Parkinson’s disease. You can call, email, and/or visit your elected officials and tell them what they must do to expedite a cure. It is their job to listen to you, but they will only listen if you speak up. The Parkinson’s Action Network (PAN) has established a strong national grassroots advocacy program which provides a unified voice in Washington D.C. on numerous public policy issues affecting the Parkinson’s community. To find out more about PAN’s advocacy training or national advocacy forums, or to sign up for *Action Alerts*, visit www.parkinsonsaction.org.

Volunteering Can Be Therapeutic

When faced with a chronic illness, it is sometimes difficult to feel that you have something to offer or have a sense of purpose. You may begin to feel disconnected from family as you juggle work, family responsibilities, and the many activities of your life while trying to live the best possible life with PD. Helping others can take the focus off your own personal problems and provide insight into what skills you have to contribute to the overall needs of society. There are countless opportunities for volunteering, both within the PD community and outside of it. Volunteering as a family for a community service project can be a fun and satisfying way to strengthen family bonds and also set a good example for children about helping others.

Reasons to get involved in volunteering:

- **It feels good.** The satisfaction and pride you feel when helping others are important reasons to volunteer. When you commit your time and effort to an organization or cause you care about, the fulfillment can lift spirits and feel empowering. As a parent, you are also a role model for making the world a better place.

- **It strengthens your community.** Organizations and agencies that make use of volunteers are providing important services at low or no cost to those who need them. When a community is doing well as a whole, the individuals are better off too.
- **It can strengthen your family.** Volunteering is a great way for families to have fun and feel closer to each other.

Where to Find Places to Volunteer

Volunteer opportunities can be found by calling any national Parkinson's disease association or other not-for-profit organization, your local hospital, synagogue or church, senior center or park district. The Internet also offers many sites with information about volunteer opportunities.

The act of volunteering can take many forms. Even the smallest child, with supervision, can help pick up garbage at the park, playground, or beach. Work together as a family at a community food bank or soup kitchen. Organize a family or community fundraiser project for Parkinson's disease research or services. Offer your family's help at the local animal shelter. Help plant flowers or trees. The list of possibilities is endless.

Whatever you choose to do, volunteering and community service can benefit you, your family, and the community.

Research: What Lies Ahead

By Un Jung Kang, MD

Treatments for PD have vastly improved in recent years thanks to advances in science. New and better medical and surgical treatments are continually being developed, which attest to how basic research leads to successful therapy in alleviating the symptoms of PD. The accelerated pace of research in the last decade has addressed limitations with current therapy and has provided new insights on fundamental approaches to halting the progression of the disease and going beyond treatment of symptoms only.

Many innovative approaches to improving current symptomatic therapy have been developed. Novel ways of providing the continuous delivery of drugs using transdermal patches and infusion devices are being developed to address fluctuating levels of dopamine. In addition, better methods of dealing with other neurotransmitters that interact with the dopamine system are being researched and show promise for symptom improvement.

Gene therapy and stem cell therapy have been and continue to be a focus of investigation. Gene therapy made its way into clinical application about two decades ago, and its therapeutic prospect has great potential. Advances continue to be made regarding the use of a virus to transport a therapeutic gene into a small target of the brain. A wide therapeutic application of this principle will require the discovery of vehicles that can be safely introduced into the brain. These vehicles must have sufficient capacity to carry the genes and to regulate their activities, as over-activity or under-activity would be ineffective as a therapeutic modality. Stem cell research has focused on generating dopamine neurons that can survive well after transplantation into patients' brains, can settle into the environment without producing adverse effects, and can produce sufficient amounts of dopamine. In order to be successful in the future, stem cell applications will need to address the limitations that were noted in the earlier human fetal transplantation studies. To date, the efficacy of human fetal cell transplantation studies remains controversial.

Other areas of focus for PD therapy include symptoms beyond the traditional motor deficits of PD. Non-motor symptoms such as cognitive dysfunction and autonomic nervous system problems (such as low blood pressure) have been recognized more and more as we understand the disease better and treat motor symptoms with reasonable success.

As we gain a better understanding of the causes of these non-motor symptoms, we will see better treatment approaches. The ultimate goal of therapy for PD is to cure the disease. Replacing the dopamine or other related neurotransmitter abnormalities is not enough for this to happen; the reason for the degeneration of dopamine producing neurons and other neurons must be found.

Early detection research studies are investigating possible conditions and precursors to the onset of the disease in an effort to identify those individuals at risk for PD prior to the onset of symptoms. Neuroprotective therapies are being studied in hopes of initiating therapy prior to symptom onset in identified subjects.

The genetic contribution to PD was unrecognized until 1997, when genetic mutations were found in some families with PD. Since then, an explosion of knowledge has led to discoveries of more than a dozen different genetic variants related to PD. A better understanding of genetic forms of PD is revealing more clues about how PD occurs and is contributing to the design of better models for research. There has been a convergence of knowledge from multiple sectors of research study which is a sign of positive progress.

We are on the precipice of new and dramatic discoveries, some of which are already in the pipeline. These discoveries hold the promise of restoring normal motor function, or at least slowing the progression of the disease, as well as identifying risk factors and pre-symptomatic conditions for developing the disease, and neuroprotective therapies for preventing its onset. All of these discoveries are cause for optimism about an eventual cure.

About APDA

The American Parkinson Disease Association, Inc., (APDA) was founded in 1961 to “Ease the Burden and Find a Cure” for Parkinson’s disease. This dual mission of providing information, education, and support directly to people with PD and their families, as well as maintaining its place as a major contributor to scientific research related to the cause of and potential cure for PD, makes APDA unique. In fact, APDA has many distinguishing characteristics including its recognition as the:

- Largest grassroots PD organization in the United States with a nationwide network of more than:
 - 50 chapters that raise awareness and funds
 - 60 Information and Referral (I&R) Centers
 - 1,000 PD support groups nationwide
- First and only PD organization to operate a full-time National Young Onset Center dedicated to educating and supporting young people with PD, their family members, friends, and healthcare providers.

APDA’s National Young Onset Center is committed to helping young people and their families manage the disease and “live well and stay strong” by focusing on programs and support services that promote education, networking, and wellness. The National Young Onset Center is able to connect you with a broad range of national, regional, and local resources. Some of these resources address Parkinson’s in a more general way and others are more customized and designed to provide you with support that is as unique to you as your particular problem or circumstance.

In addition to this handbook, the National Young Onset Center publishes the *Young Parkinson’s Newsletter: Living Well & Staying Strong*. APDA publishes many other booklets and educational supplements on a variety of subjects related to PD and all are available free of charge.

To register for the *Young Parkinson’s Newsletter*, or to learn more about young onset Parkinson’s disease or the Young Onset Center’s programs and services, please contact us by phone or email, or visit our Web site.

APDA National Young Onset Center

Glenbrook Hospital
2100 Pfingsten Road
Glenview, IL 60026
(877) 223-3801

www.youngparkinsons.org
apda@youngparkinsons.org

APDA National Office

135 Parkinson Avenue
Staten Island, NY 10305
(800) 223-2732

APDA West Coast Office

10850 Wilshire Boulevard, Suite 230
Los Angeles, CA 90024
(800) 908-2732

Following is a list of additional resources related to the subjects covered in this handbook. Please be aware that new resources on a wide range of PD topics are continually being identified and investigated. Contact APDA's National Young Onset Center at any time for the most updated resource/reference information.

NOTE: Many Web site addresses can be difficult to type due to odd abbreviations, use of the underscore or backslash symbols, and overall length. Therefore, when a resource has a Web site address that is lengthy and/or complex to type, a "tinyurl" has been provided as well. A "tinyurl" is essentially an abbreviated Web site address that will link you directly to the intended Web site. For more information about "tinyurls," please visit <http://tinyurl.com>.

General Resources

APDA National Young Onset Center

(877) 223-3801

www.youngparkinsons.org

The only national center dedicated to educating and supporting young people with PD and those who care about them. Increases awareness of YOPD in the general population and within the PD community, publishes books and supplements on a variety of PD-related topics, provides national and local resources and referrals, and coordinates YOPD events and programs across the country.

American Parkinson Disease Association, Inc. (APDA)

(800) 223-2732

www.apdaparkinson.org

National headquarters of the American Parkinson Disease Association, located in Staten Island, NY.

DVDs/Books

Managing Parkinson's: Straight Talk and Honest Hope, 2nd Edition, 2008.

APDA Washington State Chapter, Seattle, Washington

(206) 277-5516

www.waparkinsons.org/edu_research/sthh_dvd_request.php

<http://tinyurl.com/6n4grw>

This DVD is an excellent introduction for anyone who has been recently diagnosed with Parkinson's disease, as well as those involved in the care of a patient with PD. Includes a special segment on living with young onset PD.

The Parkinson's Disease Treatment Book: Partnering with Your Doctor to Get the Most from Your Medications, by J. Eric Ahlskog. New York: Oxford University Press, 2005.

When Parkinson's Strikes Early: Voices, Choices, Resources and Treatments, by Barbara Blake-Krebs and Linda Herman. Alameda: Hunter House Publishers, 2001.

Medical Management

RxList

www.rxlist.com

Features an index of FDA-approved drugs. Provides a detailed description of each drug as well as known drug interactions and side effects.

U.S. Food and Drug Administration Center for Drug Evaluation and Research (CDER)

General information line: (888) INFO-FDA; (888) 463-6332

Drug information line: (301) 796-3400

www.fda.gov/cder/consumerinfo/my_medicine_record.htm

<http://tinyurl.com/552fhw>

CDER's best-known job is to evaluate new drugs before they can be sold. "My Medication Record" page on Web site offers a form for keeping track of your prescription medicines, over-the-counter medicines, and dietary supplements.

Surgical Intervention

Activa® DBS

Medtronic, Inc.

(877) 438-3574

www.activadbbs.com

Activa® Deep Brain Stimulation Therapy is a surgical treatment that can reduce some of the symptoms associated with PD.

National Institute of Neurological Disorders and Stroke (NINDS)

(800) 352-9424

www.ninds.nih.gov/disorders/deep_brain_stimulation/deep_brain_stimulation.htm

<http://tinyurl.com/cgnfy>

This NINDS "Deep Brain Stimulation for Parkinson's Disease Information Page" offers information about treatment, prognosis, and current research related to DBS.

PBS

"Wired Science" Series, Episode 5

www.pbs.org/kcet/wiredscience/video/255-deep_brain_stimulation.html

<http://tinyurl.com/ypdddz>

This "Wired Science" episode discusses DBS and provides links to several other DBS-related videos.

Genetics

National Institutes of Health (NIH)

(301) 496-4000

www.nih.gov

NIH is a part of the U.S. Department of Health and Human Services and is the primary Federal agency for conducting and supporting medical research. Comprised of 27 Institutes and Centers, NIH works towards discovering the causes, treatments, and even cures for common and rare diseases, as well as how to prevent disease.

Genetics Home Reference

(888) FIND-NLM; (888) 346-3656

www.ghr.nlm.nih.gov/condition=parkinsonsdisease

<http://tinyurl.com/55cvj4>

A service of the U.S. National Library of Medicine, this Web site provides a comprehensive overview of the key genetic issues as they relate to Parkinson's and genetics.

Gene Reviews

www.genetests.org/query?dz=parkinson-overview
<http://tinyurl.com/67hqyj>

An excellent overview of PD with extensive information about its genetic components.

The National Human Genome Research Institute (NHGRI)

(301) 402-0911
www.genome.gov

Currently, the NHGRI's mission encompasses a broad range of studies aimed at understanding the structure and function of human genetics and its role in health and disease. This Web site provides information about genetics and its potential link to Parkinson's disease.

Sleep**American Academy of Sleep Medicine (AASM)**

(708) 492-0930
www.aasmnet.org/PatientsPublic.aspx

Accredits centers and labs that treat people who have sleep problems; AASM accreditation is the "gold standard" for the field. This organization also certifies behavioral sleep medicine specialists. The Web site offers links to helpful resources for sleep problems and disorders.

National Institute of Neurological Disorders and Stroke (NINDS)**Brain Basics: Understanding Sleep**

(800) 352-9424
www.ninds.nih.gov/disorders/brain_basics/understanding_sleep.htm
<http://tinyurl.com/5hnyux>

Offers a general overview on the subject of sleep, including common sleep disorders, tips for a good night's sleep, as well as a section on sleep and disease.

National Sleep Foundation

(202) 347-3471
www.sleepfoundation.org

Offers extensive information and resources on sleep-related issues.

Restless Legs Syndrome Foundation

(877) INFO-RLS; (877) 463-6757
 (507) 287-6465
www.rls.org

Offers comprehensive information about Restless Legs Syndrome including an online community and list of support groups.

Books

Sleep Thieves, by Stanley Cohen. New York: Free Press, 1997.

The Promise of Sleep, by William C. Dement and Christopher Vaughan. New York: Dell Publishing, 2000.

No More Sleepless Nights, by Peter Hauri and Shirley Linde. New York: Wiley Publishing, 1996.

Depression**National Institute of Mental Health (NIMH)**

(866) 615-6464
www.nimh.nih.gov/health/publications/depression/complete-publication.shtml
<http://tinyurl.com/2fnqm9>

Offers booklets and fact sheets on depression, including an extensive and informative primer on depression. Electronic copies are available for online viewing and for download. Hard copies may also be ordered.

Books***Antidepressant Medicines: A Guide for Adults with Depression***

Agency for Healthcare Research and Quality (AHRQ)
 (301) 427-1364
www.effectivehealthcare.ahrq.gov/repFiles/AntidepressantsConsumerGuide.pdf
<http://tinyurl.com/5al2u8>

This publication provides basic information on the use of common medications used to treat adults with depression.

Memory**Medline Plus**

(866) 615-6464
www.nlm.nih.gov/medlineplus/memory.html
<http://tinyurl.com/5zqwz9>

A service of the U. S. National Library of Medicine and the National Institutes of Health (NIH), offers extensive information and online resources on many health topics including memory.

Managing PD Effectively**Books*****BE ACTIVE! An Exercise Program for People with Parkinson's Disease***

American Parkinson Disease Association, Inc. (APDA), 2008.
 To order a free copy of this publication, contact:
 APDA National Office (800) 223-2732; www.apdaparkinson.org
 APDA National Young Onset Center (877) 223-3801; www.youngparkinsons.org

300 Tips for Making Life with Parkinson's Disease Easier, by Shelley Peterman Schwarz. New York: Demos Medical Publishing, 2002.

Healthcare Team**Movement Disorders Specialist:**

APDA Information and Referral (I&R) Centers can help you find movement disorders specialists in your area. A list of Centers as well as their locations and phone numbers can be found at the conclusion of this section.

Your health insurance provider or primary care physician may be able to provide names of movement disorders specialists in your area.

Physical Therapist:

American Physical Therapy Association (APTA)

(800) 999-2782

(703) 684-2782

[www.apta.org/AM/Template.cfm?Section=Find_a_PT3&Template=/](http://www.apta.org/AM/Template.cfm?Section=Find_a_PT3&Template=/APTAAPPS/FindAPT/findaptsearch.cfm)

[APTAAPPS/FindAPT/findaptsearch.cfm](http://www.apta.org/AM/Template.cfm?Section=Find_a_PT3&Template=/APTAAPPS/FindAPT/findaptsearch.cfm)

<http://tinyurl.com/5okjgu>

Enter your zip code and “Find a PT” in your area. Offers the option of narrowing your search by area of expertise.

Occupational Therapist:

The American Occupational Therapy Association (AOTA)

(301) 652-2682

www.aota.org

AOTA educates the public and advances the profession by providing resources, setting standards, and serving as an advocate to improve healthcare.

Speech Therapist:

American Speech-Language-Hearing Association (ASHA)

(800) 638-8255

www.asha.org/findpro/

Professional, scientific, and credentialing association for audiologists, speech-language pathologists, and speech, language, and hearing scientists. Offers an online directory of audiology and speech-language pathology programs.

Lee Silverman Voice Treatment (LSVT)

www.lsvt.org

A treatment technique for people with PD and other neurological disorders that focuses on a specific therapeutic target, increased vocal loudness, which acts as a “trigger” to increase effort and coordination across the speech production system.

Social Worker (counseling or psychotherapy):

HelpPRO®

(800) 652-0155

(781) 862-5215

www.helpstartshere.org/common/Search/Default.asp

<http://tinyurl.com/5kl5g9>

A collaboration between the National Association of Social Workers (NASW) and HelpNet, Inc. A database of licensed social workers including information about professional credentials, areas of expertise, payment options and more.

Your local community mental health center may offer counseling and/or psychotherapy services on a sliding fee scale.

Complementary and Alternative Medicine (CAM)

To find CAM Practitioners:

The state board for each specialty may have referral information. Be aware that licensing requirements vary by state.

National professional associations (including those following) may be able to help you locate practitioners in your area.

American Academy of Medical Acupuncture

(323) 937-5514; www.medicalacupuncture.org

American Board of Holistic Medicine

(509) 886-3046; www.holisticboard.org

American Massage Therapy Association

(877) 905-2700 or (847) 864-0123; www.amtamassage.org

American Society of Clinical Hypnosis

(630) 980-4740; www.asch.net

Council on Naturopathic Medical Education

(413) 528-8877; www.cnme.org

National Certification Board for Therapeutic Massage and Bodywork

(630) 627-8000; www.ncbtmb.org

National Certification Commission for Acupuncture and Oriental Medicine

(904) 598-1005; www.nccaom.org

National Institute of Ayurvedic Medicine

(212) 685-8600; www.niam.com

The American Association of Naturopathic Physicians

(866) 538-2267 or (202) 237-8150; www.naturopathic.org

Consumer Lab

(888) 502-5100

(914) 722-9149

www.consumerlab.com

Provides information about the potency and purity of many health supplements.

Dr. Andrew Weil

www.drweil.com

Harvard trained MD and well-known researcher in CAM for healthy living and aging. Offers consumer resources for education, information, products, services, and research reviews based on the principles of integrative medicine.

National Center for Complementary & Alternative Medicine (NCCAM)

(888) 644-6226

www.nccam.nih.gov

Part of the NIH, the federal government's lead agency for scientific research on complementary and alternative medicine.

Natural Standard

(617) 444-8629

www.naturalstandard.com

Evidence-based information about complementary and alternative therapies.

University of Arizona Program in Integrative Medicine

(520) 626-6417

www.integrativemedicine.arizona.edu

Focuses on creating, educating, and actively supporting a community of professionals who embody the philosophy and practice of Integrative Medicine. Find national and international graduates of the Fellowship program by using the “Find an IM Practitioner” search.

Clinical Trials

ClinicalTrials.gov

www.clinicaltrials.gov

A registry of federally and privately supported clinical research studies. Offers a detailed description of the clinical trials process, allows for search of trials by category (condition, drug intervention, sponsor, or location), and provides a helpful glossary of clinical trials terms.

Parkinson Pipeline Project

www.pdpipeline.org

Organized by a grassroots group of advocates, provides the patient perspective in the treatment development process. Advocates for the rights of clinical trial participants and offers a database that follows new treatments from pre-clinical development through to FDA approval.

PD Internet Community

BrainTalk Communities

brain.hastypastry.net/forums/

An online discussion forum for people with various neurological health conditions to come together and “chat” about issues of daily living. Includes several PD-specific communities.

PD Plan for Life

www.pdplan4life.com

Co-created by two women with young onset PD, this Web site provides information on a variety of subjects including exercise, clinical trials, and advocacy. The “journal” format allows Web site visitors to consider different aspects of living with PD by reading the creators’ very personalized accounts of daily life.

P-I-E-N-O Parkinsn (Parkinson Information Exchange Network Online)

www.parkinsons-information-exchange-network-online.com

<http://tinyurl.com/68gay3>

Also known as “Parkinsn list,” this Toronto-based discussion archive and listserv allows individuals to “subscribe” free of charge, then post and respond to questions about a wide range of PD-related news and topics.

We Move (Worldwide Education and Awareness for Movement Disorders)

www.wemove.org

Provides information and discussion forums for all movement disorders, including PD. Visitors who register can access online classes at We Move’s “Virtual University.”

YOPA (Young Onset Parkinson’s Association)

www.yopa.org

A Web site that provides young people with Parkinson’s an opportunity to express their views and opinions and connect with others who may have similar thoughts or concerns. Includes Message Board and Chat Room as well as a “Pharmacist’s Forum.”

Sex and Sexuality

Books

In Sickness and In Health: Sex, Love, and Chronic Illness, by Lucille Carlton. Miami: National Parkinson Foundation, 1994.

Enabling Romance: A Guide to Love, Sex and Relationships for People with Disabilities (and the People who Care About Them), by K. Kroll and E. L. Klein. Horsham, PA: No Limits Publications, 2001.

Pregnancy

Books

Parkinson’s: A Personal Story of Acceptance, by Sandi Gordon. Boston: Branden Books, 1992.

Relationships/Caregiving

Family Caregiver Alliance

(800) 445-8106

www.caregiver.org

Offers a wide range of information and services based on caregiver needs including resources at the local, state, and national levels.

Well Spouse Association

www.wellspouse.org

Provides support to wives, husbands, and partners of the chronically ill and/or disabled. Offers monthly support group meetings for caregivers.

Books

Mainstay: For the Well Spouses of the Chronically Ill, by Maggie Strong. New York: Penguin Books, 1988.

Parenting

Center for Effective Parenting

(501) 364-4605

www.parenting-ed.org

Offers general information on parenting issues and a list of “Parent Links” to helpful parenting and family resources.

Books

My Mommy Has PD...But it’s Okay!

Publication of the American Parkinson Disease Association, Inc. (APDA), 2007

To order a free copy of this publication, contact:

APDA National Office: (800) 223-2732; www.apdaparkinson.org

APDA National Young Onset Center: (877) 223-3801; www.youngparkinsons.org

Employment

AbilityHub

(802) 775-1993

www.abilityhub.com

Provides assistance with finding information on adaptive equipment and alternative methods available for accessing computers.

Ability Links

(630) 909-7440

www.abilitylinks.org

A nationwide job board for employers and qualified persons with disabilities where job seekers can post resumes, search for jobs, and find a variety of other employment-related resources.

Job Accommodation Network (JAN)

(800) 526-7234

www.jan.wvu.edu

Free service of the U. S. Department of Labor, Office of Disability Employment Policy. Assists people with disabilities and employers in the area of accommodations. Offers helpful information and resources related to maintaining employment, job search, and legal assistance.

Patient Advocate Foundation

(800) 532-5274

www.patientadvocate.org

Provides assistance to patients with specific issues regarding insurance, job retention, and/or debt crisis matters relative to their diagnosis. Publications and articles on insurance, disability, discrimination, and financial resources by state are also available.

Volunteer Match

(415) 241-6868

www.volunteermatch.org

Find a volunteer opportunity that fits your interests, skills, and schedule with Volunteer Match's online search engine.

Finances**Centers for Medicare and Medicaid Services**

(800) MEDICARE; (800) 633-4227

www.cms.hhs.gov

Part of the U. S. Department of Health and Human Services, provides an extensive list of links to information and articles that describe the various aspects of Medicare and Medicaid including those related to eligibility and enrollment.

DisabilityInfo.govwww.disabilityinfo.gov

Comprehensive information about federal disability programs, services, laws, and benefits as well as state and local disability resources.

DisabilitySecrets.comwww.disabilitysecrets.com

A comprehensive description of the SSDI/SSI claims and appeal process.

National Academy of Elder Law Attorneys (NAELA)

(520) 881-4005

www.naela.org

Professional association of attorneys in both the private and public sectors who have expertise in elder law and issues of disability. Often able to assist younger as well as older clients. Offers a "Locate an Elder Law Attorney" search function.

Protected Tomorrows

(847) 522-8086

www.protectedtomorrows.com

Provides access to information as well as one-on-one advice on the entire special needs planning process. See the "Family Event Calendar" to find a seminar near you and to learn more about such issues as: Potential Funding Sources, Legal Options, Family Communication, and Special Needs Trusts.

Special Needs Alliance

(877) 572-8472

www.specialneedsalliance.com

A national network of attorneys dedicated to public benefits and disability law. Web site includes a "Locate a Special Needs Alliance Attorney" search function.

U. S. Department of Health and Human Serviceswww.medicare.gov

Answers questions about Medicare and Medicaid enrollment, billing, and plan choices. Use the "Search Tools" to compare healthcare plans and to find physicians and facilities in your area.

U. S. Office of Social Security Administration

(800) 772-1213

www.ssa.gov

Official Web site of the U. S. Social Security Administration. Provides information on SSDI, SSI and Medicare.

Benefit Eligibility Screening Tool (BEST)

(800) 772-1213

www.connections.gov/benefits.gov/ssa_en.portal<http://tinyurl.com/6axuxu>

Can help you determine if you may be eligible for different types of benefits Social Security administers.

Armed Forces Veterans**APDA Information and Referral Center**

(888) 838-6256 - 1 - 1715#

Located at the Veterans Administration Medical Center in Reno, Nevada. Serves the general community as well as the veteran population.

U.S. Department of Veteran Affairs

(800) 827-1000

www.va.gov

Provides an overview of government programs and services available to veterans including healthcare, disability, and education benefits. The Web site offers an online claims service.

Advocacy and Awareness

Congress.org

(800) 659-8708

<http://www.congress.org>

Find your federal, state, and local officials, their stance on issues, how they voted, bills up for discussion or vote, and other issues of interest.

Network for Good

(866) 650-4636

www.networkforgood.org

Search thousands of volunteer opportunities that match your interests through the online search engine.

Parkinson's Action Network (PAN)

(800) 850-4726

(202) 638-4101

www.parkinsonsaction.org

Serves as the unified voice of Parkinson's at the state and national level on legislation and public policy issues impacting the PD community. Learn how you can become a grassroots coordinator in your state and sign up for email *Action Alerts* so you can contact your legislative representatives when important Parkinson's issues arise in Congress.

Parkinson's Unity Walk

(866) 789-9255

www.unitywalk.org

Held annually in New York City, the largest grassroots Parkinson's fundraiser for research in the PD community.

U.S. House of Representatives

(202) 224-3121

www.house.gov/writerep

Offers online assistance in sending a message directly to your Representative by identifying your Congressperson and providing contact information.

Research

National Institute of Neurological Disorders and Stroke (NINDS)

Parkinson's Research Web

(800) 352-9424

www.ninds.nih.gov/funding/research/parkinsonsweb/index.htm

<http://tinyurl.com/3nyp2m>

Provides information on funding and research for Parkinson's disease studies.

Parkinson Study Group (PSG)

www.parkinson-study-group.org

A non-profit, cooperative group of Parkinson's disease experts from medical centers in the United States and Canada who are dedicated to improving treatment for people affected by Parkinson's disease.

APDA Information and Referral (I&R) Centers

Alabama, Birmingham

University of Alabama
at Birmingham
205-934-9100

Arizona, Phoenix

Banner Good Samaritan
Medical Center
602-239-3542

Arizona, Tucson

University of Arizona
866-897-1261
520-626-5055
Arkansas, Hot Springs
St. Joseph's Regional
Health Center
800-345-6621
501-622-3990

California, Fountain Valley

Orange Coast Memorial
Medical Center
877-610-2732
714-378-5022

California, Laguna Hills

Saddleback Memorial
Medical Center
877-610-2732
714-378-5022

California, Long Beach

Long Beach Memorial
Medical Center
877-610-2732
714-378-5022

California, Los Angeles

Cedars-Sinai Health System
877-223-3277
310-423-7933

California, Los Angeles (UCLA)

Reed Neurological
Research Center
310-206-9799

California, Northridge

Center for Aging Research
866-499-2732
818-885-8623

California, Pasadena

Huntington Hospital
626-397-2684

California, San Diego

Information & Referral Center
858-273-6763

California, Stanford

Stanford University
Medical Center
866-250-2414
650-724-6090

Connecticut, New Haven

Hospital of Saint Raphael
203-789-3936

Florida, Jacksonville

Mayo Clinic, Jacksonville
904-953-7030

Florida, Deerfield Beach

North Broward Medical Center
800-825-2732
954-786-2305

Florida, St. Petersburg

Edward White Hospital
727-328-6246

Georgia, Atlanta

Emory University
School of Medicine
404-728-6552

Idaho, Boise

St. Alphonsus Medical Center
208-367-6570

Illinois, Glenview

Glenbrook Hospital
800-223-9776
847-657-5787

Iowa, Des Moines

Iowa Health – Des Moines
877-872-6386
515-241-6379

Kentucky, Lexington

University of Kentucky
866-544-2732
859-257-2732

Louisiana, New Orleans

Ochsner Clinic Foundation
504-842-4272

Louisiana, Shreveport

Louisiana State University
318-675-6142

Maine, Falmouth

Maine Medical Center
800-832-4116
207-781-1735

Maryland, Baltimore

University of Maryland
800-862-5457

Massachusetts, Boston

Boston University
School of Medicine
800-651-8466
617-638-7737

Minnesota, Minneapolis

Abbott Northwestern Hospital
Minneapolis Neuroscience
Institute
888-302-7762
612-863-5850

Mississippi, Gulfport

Gulfport Memorial Hospital
228-575-1330
601-618-2772

Missouri, St. Louis

Washington University
Medical Center
314-362-3299

Montana, Great Falls

Benefits Health Care
800-233-9040
406-455-2964

Nebraska, Omaha

Creighton University
866-626-7347
402-449-4535

Nevada, Las Vegas

University of Nevada
School of Medicine
702-464-3132

Nevada, Reno

V.A. Medical Center
775-328-1715

New Hampshire, Lebanon

Dartmouth-Hitchcock
Medical Center
603-650-5280

New Jersey, New Brunswick

Robert Wood Johnson
University Hospital
732-745-7520

New Mexico, Albuquerque

University of New Mexico
877-515-4560

New York, Albany

The Albany Medical College
518-262-6402

New York, Far Rockaway

Peninsula Hospital
718-734-2876

New York, Manhattan

New York University
212-983-1379

New York, Old Westbury

New York College of
Osteopathic Medicine
516-626-6114

New York, Smithtown

St. Catherine's of Siena
Hospital
631-862-3550

New York, Staten Island

Staten Island
University Hospital
718-226-6129

Ohio, Kettering

Kettering Medical Center
513-948-9355

Oklahoma, Tulsa

Hillcrest Medical Center
System
918-747-3747

Pennsylvania, Erie

Health South Rehabilitation
Hospital
814-456-4210

Pennsylvania, Philadelphia

Crozer-Chester
Medical Center
610-447-2911

Pennsylvania, Pittsburgh

Allegheny General Hospital
412-441-4100

Rhode Island, Warwick

Kent Hospital
401-736-1046

Tennessee, Memphis

Methodist Hospital
901-516-0677

Tennessee, Nashville

Centennial Medical Center
800-493-2842
615-342-4635

Texas, Bryan

St. Joseph Regional
Rehabilitation Center
979-821-7523

Texas, Dallas

Baylor University
Medical Center
214-820-3800

Texas, Lubbock

Convenant Hospital
800-687-5498
806-785-2732

Texas, San Antonio

The University of Texas HSC
210-567-6688

Texas, Tyler

East Texas Medical Center
866-491-2732
903-596-3648

Utah, Salt Lake City

University of Utah
801-585-2354

Vermont, Burlington

University of Vermont
888-763-3366
802-847-3366

Virginia, Charlottesville

University of Virginia
Medical Center
434-982-4482

Washington, Seattle

University of Washington
206-543-5369

Wisconsin, Madison

University of Wisconsin
608-263-7991

Wisconsin, Neenah

The Neuroscience Group
of Northeast Wisconsin
888-797-2732
920-721-1522

Dedicated Centers

Armed Forces Veterans

Reno, Nevada
775-328-1715

National Young Onset Center

Glenbrook Hospital
Glenview, Illinois
877-223-3801



American Parkinson Disease Association, Inc.

APDA National Office

Parkinson Plaza
135 Parkinson Avenue
Staten Island, NY 10305
(800) 223-2732
www.apdaparkinson.org
apda@parkinson.org

APDA National Young Onset Center

Glenbrook Hospital
2100 Pfingsten Road
Glenview, IL 60026
(877) 223-3801
www.youngparkinsons.org
apda@youngparkinsons.org

APDA West Coast Office

10850 Wilshire Boulevard, Suite 230
Los Angeles, CA 90024
(800) 908-2732
www.apdawest.org
apdawc@earthlink.net

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