



Parkinson's Disease: Mind, Mood & Memory

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Foreword

Written by: Matthew Stern, MD

Parkinson disease (PD) is known for its classic physical symptoms of tremor, muscle rigidity and slowness of movement. Indeed, research has focused predominately on the development of treatments to alleviate these motor symptoms and many patients now enjoy long-term relief of their parkinsonian symptoms. However, we have come to learn that it is not only the tremors and slowness of PD that affect a patient's sense of well-being. It is also the neurobehavioral problems such as depression, anxiety, psychosis and dementia that prevent patient, family and caregiver from coping effectively with their disease. Recent surveys of PD patients have stressed the importance of anxiety and depression. While most patients acknowledge the frequency of tremors and other motor symptoms, they often report that it is depression, fatigue and/or loss of alertness and cognition that is most disabling to them. Other studies have documented worsening of caregiver burden associated with patients who are depressed or confused. Moreover, it is the hallucinations and confusion that serve as the prime reasons for moving patients to a nursing facility.

This handbook provides an overview of the mental health aspects of PD and how they can be effectively managed. Starting with depression and moving onto anxiety and lesser known problems such as loss of emotional control and loss of impulse control. Clinicians, patients and caregivers will be heartened by the attention given to these troubling symptoms and the useful management strategies conveyed. Further, changes in memory and confusional states are addressed with an excellent discussion of dementia with Lewy Bodies, a common form of dementia usually seen with parkinsonism. Psychosis, an often misunderstood phenomenon, is also thoroughly discussed and explained. Finally, sleep problems are universal in PD. Insomnia, excessive daytime sleepiness and generalized fatigue are now recognized as primary symptoms requiring attention in PD and are addressed in Chapter 6.

It is crucial that physicians, patients and their families understand the approaches to these problems to lessen the overall burden of PD. Minimizing disability is the primary goal of PD therapy and it is the neurobehavioral aspects of PD that frequently define a patient's true sense of well-being. In addition, a caregiver's burden is further stressed when caring for an individual with depression, confusion or excessive fatigue. Caregiving issues and tips are thoroughly discussed in Chapter 7.

The authors of this handbook have conveyed this material in a simple and careful manner. However, it may take the reader time to fully digest the information as this novel and complicated area of Parkinson disease is introduced. We encourage you to share and discuss this handbook with your healthcare providers so that awareness can spread and proper treatment can be ensured for all individuals struggling with PD and mental health issues.

Those of us involved in research to find better treatments for PD are constantly adjusting the design of clinical trials and the methods we use to evaluate PD disability. We now realize that while tremor, stiffness and slowness are the clinical hallmarks of PD, it is “**mind, mood and memory**” that really matter.

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****PLEASE NOTE:** Words printed in *italicized red* are included in the **comprehensive glossary** on p. 84 (Appendix A). The glossary can assist you in understanding terminology commonly used by the medical community.

Chapter 1

Parkinson Disease & Mental Health

The symptoms of *Parkinson disease* (PD) were first described in 1817 by an English physician named James Parkinson. In his composition titled *An Essay on the Shaking Palsy*, Dr. Parkinson clearly outlined the *motor symptoms* of PD. This included resting tremor, stooped posture, *shuffling* gait, balance problems and generalized slowness. Although, these symptoms were the focus of his report, Dr. Parkinson went on to mention other less obvious characteristics of this complex disorder. Of special interest, he noted disturbances in *mood*, which he referred to as “*melancholy*”.

PD is generally considered a disease that affects only the body. However, as noted by Dr. Parkinson, it commonly affects the mind and spirit as well. This handbook will better explore the *mental health* aspects of PD, which until recently, have been under-recognized and poorly treated. It will also discuss related issues, such as sleep disorders and a similar disease called *dementia with Lewy bodies*.

Parkinson Disease Overview

PD is a slowly progressive *neurological* disorder, or disorder of the brain. It affects roughly 1.5 million Americans, which is more than Multiple Sclerosis and Muscular Dystrophy combined. PD is diagnosed in one out of every 100 people over the age of 60. It is generally seen as a disease that occurs later in life, yet approximately 15% of individuals are diagnosed under the age of 50. The cause of PD remains unknown however, most doctors believe it is due to a combination of genetic and environmental risk factors.

There are currently no medical tests or studies that can detect PD. Diagnosis relies solely on the patient's report and the clinician's examination. Most clinicians look for at least two of the *cardinal* symptoms to be present before considering the diagnosis of *idiopathic Parkinson disease* (IPD). In addition to the cardinal symptoms of PD, a large number of secondary symptoms exist. Diagnosing IPD can be challenging due to other known forms of *parkinsonism*. Parkinsonism refers to conditions that produce parkinson-like symptoms but are not true Parkinson disease.

Treatment of PD typically consists of a combination of medications, exercise and proper diet. Medications not only include anti-PD agents, such as carbidopa/levodopa (Sinemet ®), but also medications that help alleviate secondary symptoms. *Deep brain stimulation* has also become an excellent option for a selective group of individuals. Although a cure does not yet exist for PD, great strides are continuously made in developing new and effective treatments.

Symptoms of Parkinson Disease

➤ **Cardinal Symptoms of PD:**

- ***Bradykinesia***
(Generalized slowness)
- **Muscle rigidity**
(Stiffness)
- **Postural instability**
(Poor balance)
- **Resting tremor**
(Shaking of the hand(s), arm(s), leg(s), lips or jaw while at rest)

➤ **Secondary Symptoms of PD:**

- *Anxiety*
- Constipation
- *Depression*
- Dandruff or oily skin
- Difficulty walking with start hesitation, *freezing* and/or *shuffling*
- Diminished blinking
- Blunted facial expressions (“masked face”)
- Diminished sense of smell
- Excessive sweating
- Low blood pressure or dizziness when standing up
- Low volume of speech and/or muffled speech
- Memory changes
- Pain
- Reduced arm swing while walking
- Sexual dysfunction
- Sleep changes such as excessive fatigue, *vivid dreaming* and/or acting out your dreams
- Small handwriting
- Swallowing problems and drooling
- Tingling or numbness
- Urinary changes

Mental Health Overview

Mental health can be defined as an interconnected balance of the mind, body and spirit. It allows an individual to properly cope with the many challenges and stresses of life. There are several key factors that allow our brains to maintain healthy *emotions* and/or behavior. These factors include:

- Physical health and *biological* factors
- *Genetic* traits
- Personal/spiritual beliefs
- Environmental resources
- Cultural influences
- Personal relationships and support systems

A disruption in just one of these areas can bring on *mental illness*. Unfortunately, the term “mental illness” is commonly misunderstood. It is often connected with patients who suffer from severe, chronic psychiatric disorders, such as *schizophrenia*. However, mental illness is merely a term used to describe a change in one’s mental or emotional well-being.

Linking PD and Mental Health

For many years, PD was simply considered a neurological disease. However, following the advancement of research and clinical observations, it has more recently been classified as a *neuropsychiatric disorder*. The term “neuropsychiatric” describes the mixture of both *neurological* and *psychological* symptoms. This newer classification properly acknowledges the mental health aspects of PD in addition to the well-recognized motor symptoms.

Although mental illness in PD has been receiving greater recognition in the healthcare arena, many patients and families continue to struggle with the complexities of these symptoms. This is primarily due to inadequate education and limited patient and family resources. Therefore, it is our hope that this handbook will assist you in recognizing and accepting the mental health challenges often experienced with this complex disease.

The information shared in this handbook reflects general information based on clinical expertise and research. It is important to consider individual diversity, including personal, spiritual and cultural beliefs, when reviewing this material. It should not be used as a substitute for direct medical care or advice. All questions or problems should be directed to your healthcare clinician.

Chapter 2

Emotional Changes in Parkinson Disease

Written by: Dan Weintraub, MD

Parkinson Disease (PD) is considered a “*neuropsychiatric*” illness, meaning that *mental health* changes are just as important as *motor symptoms*. The original description of PD by James Parkinson almost two hundred years ago mentioned *mood* changes caused by the illness.

Most commonly, mood changes involve *depression* and/or *anxiety*. It has been thought that up to 50% of PD patients experience a mood disturbance at some point during their illness. Though depression and anxiety are commonly reported in patients with other chronic diseases, some research suggests that they are even more common in PD.

Mood disturbances in PD lead to worsening of *function* and quality of life. Despite their high occurrence and negative effect, mood changes in PD are less well studied and understood than motor symptoms.

Depression

It is estimated that up to 50% of patients with PD may experience some form of depression during the course of their illness. The majority of these individuals experience *minor depression* (less severe depression). However, *major depression* (more severe depression) can occur in roughly 5-10% of cases.



Key Point: During the course of their illness, as many as 1 out of 2 people with PD will develop some form of depression.

What Causes Depression?

There are likely many causes of depression in PD. Both *psychological* and *biological* factors play a role. One explanation is that depressed patients with early or mild PD experience a psychological reaction to having a chronic illness, while those in the later stages have a biological depression related to the loss of certain brain cells that occurs with PD.

1. **Psychological factors:** It is understandable that living with PD could lead to sadness, helplessness, and hopelessness about the future. These feelings may be due to the chronic course of the illness and the way it affects patients' lives. Another factor that may lead to depression is isolation that can occur when patients avoid being in public so other people won't notice their PD symptoms.
2. **Biological Factors:** Possible biological causes of depression in PD can include:
 - History of mental health issues: Research suggests that patients with PD are more likely to have experienced depression or anxiety earlier in life, which means depression may not simply be a psychological reaction to having the illness. Research also suggests that people with depression or anxiety in midlife are more likely to develop PD later in life.
 - Changes in the brain: Regions of the brain affected by PD are the same as those affected by depression. Changes in the *basal ganglia* are responsible for causing the motor symptoms of PD and increase the risk for developing depression. In addition, changes to the *frontal lobes* of the brain are often seen in both PD and mood disturbances. Finally, three brain chemicals (*dopamine, serotonin, and norepinephrine*) change in both PD and depression.



Key Point: Depression should be considered a symptom of PD caused by chemical imbalances in the brain. As with tremor or any other symptom, medications are available to correct these imbalances and improve the symptoms of depression.

What are the Symptoms of Depression?

Depression can present differently in PD, and each patient is unique. Below is a list of depressive symptoms commonly reported by patients:

- feelings of guilt
- thoughts of death or suicide
- decreased interest or pleasure
- poor attention and concentration
- sleep problems
- feeling slowed down or restless inside
- self-blame or worthlessness

What You Should Know About Depression:

- Patients sometimes report *chronic depression* dating back to the beginning of their PD symptoms or even earlier. Some patients state that the early stages of a chronic illness led to their depression, and their mood continues to be affected by thoughts of how the disease has changed their life. Other patients with chronic depression state that although the depression started around the time of the motor symptoms, it seemed to come out of the blue, and was not connected with any negative thoughts that they had.
- Depression in PD can also begin after patients have had the illness for some time. Sometimes these depressive episodes have an obvious cause, such as the loss of a loved one, early retirement, or having to move from one's home. Depression that occurs suddenly and involves clear changes in mood, thinking, and behavior is easier to diagnose and responds better to treatment.
- Other psychiatric symptoms are common in PD patients with depression. For instance, most depressed patients also experience anxiety. It has been reported that some patients with significant *motor fluctuations* become depressed and anxious during these periods. However, other patients cannot identify a pattern of mood changes that is related to their medication schedule.
- Another disorder that commonly occurs with depression is *psychosis*, usually *visual hallucinations* and sometimes suspicious thinking. It is not clear why these two disorders should commonly occur together. In non-PD patients, severe depression can cause psychosis. However, in PD it is possible that having psychotic symptoms may lead patients to become depressed.
- The link between depression and *cognitive* impairment in PD is not clear. Some studies have found that patients with greater cognitive or memory impairment are more likely to have depression. Confusing the issue is that patients with cognitive changes may not be aware of mood changes that other people notice.
- Another common cognitive change in PD is trouble planning and completing activities, which is related to changes in the frontal lobes (or regions) of the brain. In elderly patients without PD, depressed patients are more likely to have these cognitive changes than non-depressed patients, and patients with these changes have a worse response to antidepressant treatment. It is not clear if the same is true for depression in PD.

How do you Diagnose Depression?

Depression in PD is diagnosed by asking about certain *signs* and *symptoms*, the same as those commonly reported by depressed patients in general. Depression is commonly divided into major and minor depression, major depression being more severe.

To have major depression, a patient must have one of the following most of the time over the previous two weeks:

- depressed mood
- loss of interest or pleasure

In addition, some of the following symptoms must be present:

- changes in sleep or appetite
- decreased concentration or attention
- increased fatigue
- feeling slowed down or restless
- feeling worthless and guilty
- suicide ideas or a wish for death.

Diagnosing depression in PD can be difficult, as some of the symptoms of depression can also occur in PD without depression. For instance, feeling tired and slowed down are common in both depression and PD, and it is hard to know if these symptoms reflect true depression. Also, to have depression, a depressed mood is supposed to be present most of the time on a daily basis, but some experts think that depression in PD often involves frequent, shorter changes in mood. Finally, many Parkinson patients express less *emotion* due to the effect of the disease on the muscles of the face, and this may make them look as if they do not enjoy things.

Another difficulty in diagnosing depression in PD is that some patients do not realize or admit that they are depressed. This may be because some PD patients have trouble noticing emotions, both in themselves and in other people. Patients with cognitive changes also may not be aware of being depressed. For these reasons, it is helpful to ask a caregiver or significant other if he or she has noticed any of the changes commonly reported in depression.

What are the Treatment Options for Depression?

Antidepressants are used commonly in PD. Approximately 20-25% of patients who receive care from a specialist are taking an antidepressant. Of the medications currently used to treat PD, there is no consistent evidence that

levodopa improves mood on an ongoing basis. However, some research suggests that *dopamine agonists* may have antidepressant properties in PD.

Treatment of Depression with Medications

Most depressed patients are treated with a *selective serotonin reuptake inhibitors (SSRI)*, either fluoxetine (Prozac ®), sertraline (Zoloft ®), paroxetine (Paxil ®), citalopram (Celexa ®), or escitalopram (Lexapro ®). These medications work equally well, though they differ slightly in their side effects and interactions with other medications. There are also several non-SSRI antidepressants, including venlafaxine (Effexor ®), mirtazapine (Remeron ®), bupropion (Wellbutrin ®), and an older class of medication called tricyclic antidepressants.

Antidepressants can be very helpful for certain patients, sometimes leading to dramatic improvement. There are many published reports stating that these medications improve depression and are safe overall. However, the effect of these medications on the motor symptoms of PD is unknown. Also, it is not clear how long a patient should be kept on a medication or what dosage should be used to get full effect. In general, a full antidepressant trial should last between 6-12 weeks and reach the highest tolerated dosage within the usual range.

Research suggests that many PD patients do not receive adequate treatment for their depression. Many patients with ongoing depression receive only low to moderate dosages of antidepressants, and most have only a single antidepressant trial. For patients who improve with treatment, it is not clear how long they should remain on an antidepressant. Many PD patients are on antidepressants long-term, but it is not clear that this is needed. In general, a first episode of depression should be treated for about 6-12 months, but patients who have had many episodes of depression in their life should stay on an antidepressant long-term.



Key Point: Depression may be under-treated in many people with PD. If one trial of an antidepressant medication fails, other medications, combinations of medications, or alternative treatments should be tried until symptoms are adequately controlled.

Alternative Treatments of Depression

There are other types of treatment for depression in PD. Individual *psychotherapy* can focus on changes in thinking and behavior that occur in depression. It can also provide support, understanding and education. Patients may be seen alone, as a couple or family, or in a group. Psychotherapy is an important treatment option, as some PD patients may not tolerate, respond fully, or want to take an antidepressant. In addition, psychotherapy is often combined with antidepressant treatment. Finally, PD support groups, although not truly

psychotherapy, allow patients to open up and share their emotions in a supportive and caring environment.

Another form of treatment for severe or non-responsive depression is *electroconvulsive therapy*, also known as shock therapy. Though people often think negatively about shock therapy, it is the most effective treatment available for severe depression, and it also temporarily improves motor symptoms in PD. Its major drawbacks are the time involved in getting the treatment, the need to undergo general anesthesia many times, and possible memory problems and/or confusion as a complication of treatment.

Additionally, exercise has been found to be a simple therapeutic approach for improving mood and depression. Exercise can be in the form of walking, stretching, yoga, tai-chi, and all basic forms of physical activity. There are also many non-conventional types of therapy that are used to treat depression. These include light therapy, relaxation techniques, message therapy, acupuncture, aromatherapy, meditation and music therapy.

What to Expect with Treatment for Depression

The goal of treatment is for depressive symptoms to go away or greatly lessen. There is evidence that suggests depression in PD leads to greater *disability*, therefore it is possible that improvement in depression may lead to improvement in daily functioning. It is even possible that thinking may improve, if some cognitive problems were caused by depression. Based on clinical experience, successful treatment of depression also leads to decreased *caregiver burden*.

Depression may have a negative long-term impact as well. Following both depressed and non-depressed patients over several years, depressed patients were shown to have greater worsening in their Parkinson symptoms, perhaps related to the greater disability that depression produces. Although these studies were not able to examine whether treating the depression might limit its negative impact, it is possible that treated depression has a better long-term outcome than untreated depression.

Anxiety

Anxiety is less well studied, yet may be as common as depression in PD. Up to 40% of patients experience some form of anxiety, most commonly *generalized anxiety*, *anxiety attacks*, *obsessive-compulsive disorder*, and *social avoidance*. Anxiety and depressive disorders often occur together in PD.



Key Point: There are many different ways that a person with PD can experience anxiety. As many as 2 out of every 5 patients with PD will experience one of these forms during the course of their illness.

What Causes Anxiety?

From a psychological standpoint, there are common worries that go along with anxiety in PD. One is a fear of being unable to function, particularly during a sudden “off” period. This sometimes leads to a need to be with someone at all times and a fear of being left alone. Another is a concern about being embarrassed, often related to having people notice symptoms of PD in public.

Many of the brain pathways and chemicals linked with depression in PD are also likely related to anxiety. In addition, PD patients also have abnormalities in GABA, a brain chemical closely linked with anxiety and targeted by one class of anti-anxiety medications.

In some cases, anxiety is directly related to changes in motor symptoms. Specifically, patients who experience “off” periods can develop severe anxiety during these states, sometimes to the point of full-blown anxiety attacks. No clear link has been shown to exist between anxiety and any other clinical features of PD.

What are the Symptoms of Anxiety?

Generalized anxiety is a feeling of nervousness and thoughts of worry most of the time. The worrying is in excess of what patients would normally expect and often feels out of control. Physical symptoms are also common, including butterflies in the stomach, trouble breathing or swallowing, racing of the heart, sweating, and increased tremors.

Anxiety attacks usually present suddenly, with a sense of severe physical and emotional distress. Patients may feel as if they cannot breathe or are having a heart attack, and a common worry is that a medical emergency is happening. These episodes usually last less than an hour, particularly when associated with “off” periods, though they can last for longer periods of time.

Social avoidance involves avoiding social situations secondary to a fear of embarrassment at having Parkinson symptoms, such as tremor, dyskinesias, or trouble walking, noticed in public. Exposure to these situations can lead to severe anxiety, which goes away when removed from the situation.

Obsessive-compulsive disorder involves thoughts and/or behaviors that repeat themselves and are not connected with real-life problems, generally do not make sense, and are troubling to the patient. It has been suggested that obsessive-

compulsive symptoms are associated with more severe PD or left-sided symptoms, though this is not certain.

How do you Diagnose Anxiety?

Overall, it is easier to diagnose anxiety than depression in PD, as the symptoms of anxiety and PD do not overlap as much. For example, anxiety attacks and obsessive-compulsive symptoms usually involve a clear change in a patient's previous behavior and are not easily confused with motor symptoms.

Worrying about one's physical condition and the future is a natural part of having a chronic disabling illness, so a diagnosis of generalized anxiety should be made either if there is a significant, unexplained increase in anxiety or a sense that the patient has symptoms in excess of what would normally be expected given the situation. Phobia can also be difficult to diagnose, as a patient may have a legitimate concern that a tremor or a change in walking ability may be noticed in public. In this case, a diagnosis is made if the person realizes that the concern is excessive or unreasonable, the situation is actively avoided, and it causes interference in the person's life.

What are the Treatment Options for Anxiety?

Treatment for anxiety disorders has changed in recent years. Newer antidepressants, such as the SSRIs, are typically the first medications used. All of these medications have been shown to be helpful for one or more anxiety disorders. Anti-anxiety effects are not sudden with antidepressants, sometimes taking weeks for full effect. For patients with anxiety attacks, very low dosages should be used at first, as there is evidence that these medications can actually increase attacks when first started at higher dosages. An added benefit of using these medications is that they can help with the depression that often goes along with anxiety.



Key Point: If SSRIs are used to treat anxiety, they should be started at a dose lower than the normal starting dose to avoid worsening the anxiety. Also, it should be realized that it may take several weeks to notice the full effect of these medications.

An older class of anti-anxiety agents is the **benzodiazepines**, also called “nerve pills”, which affect the brain chemical GABA. Most of these medications have been around for many years, including diazepam (Valium ®), lorazepam (Ativan ®), clonazepam (Klonopin ®), and alprazolam (Xanax ®). They can be very effective for anxiety, sometimes working better than antidepressants. In addition, they take effect very quickly, often providing some relief after a single

dose, though they have to be taken regularly for a lasting effect. Finally, these medications can help with other symptoms that may be present in PD, including certain types of tremor, muscle cramping, and sleep changes.

There are several possible drawbacks to using benzodiazepines in PD. These medications can affect memory and lead to confusion, worsen balance, and cause tiredness. All of these effects are more common in older patients. In addition, most need to be taken regularly and more than once a day for maximum effect, and missed doses can lead to a sudden increase in anxiety. Finally, these medications should not be stopped suddenly once they have been taken regularly, as patients can have uncomfortable and serious withdrawal symptoms. Therefore, these medications should be stopped over a period of time.



Key Point: Benzodiazepine medications should be used with caution in older patients with PD or in those with *dementia*. If used regularly, they should never be stopped suddenly to avoid serious withdrawal symptoms.

Though psychotherapy is commonly used instead of or in addition to medication for anxiety disorders in general, there has been no study of their use in PD. It is important to work with the neurologist to adjust medications to decrease the amount of time spent in “off” states for those patients whose anxiety is related to these periods.

As noted with depression, exercise and non-conventional therapies can also be helpful in alleviating anxiety and *panic attacks*. Many individuals typically find walking, yoga, relaxation techniques and meditation to be beneficial. Other simple techniques can include reducing environmental distractions, listening to music or just taking a few deep breaths.

Other Emotional Changes

In addition to depression and anxiety, some people who have PD are also susceptible to other emotional changes, including loss of impulse control, increased emotions, and decreased emotions.

Loss of Impulse Control

Loss of impulse control, or *disinhibition*, has been reported in PD, especially after exposure to certain medications such as levodopa and dopamine agonists. It has also been reported in some patients after *deep brain stimulation*. These changes may be related to addictive behavior or the compulsive behaviors seen in obsessive-compulsive disorder, as they involve activities that repeat themselves, are upsetting to patients, and are out of control.

The behaviors most commonly reported involve gambling and sexual preoccupation. Usually, such behaviors were not present prior to starting the medication or having brain surgery. They can lead to major problems, including bankruptcy and divorce. Though not well studied, it does appear that problems related to medication exposure improve or go away when the medication is stopped. In addition, post-surgical changes may improve simply with time.



Key Point: Compulsive behaviors, including gambling, should be reported immediately to your physician. They may be related to medications, particularly if the patient is taking a dopamine agonist, and may get better if these medications are withdrawn.

Medications can be used to treat loss of impulse control. Once again, newer antidepressants are commonly prescribed, though their benefit for this problem is unclear. Another commonly used class is the *mood stabilizers* (such as valproic acid (Depakote ®) and carbamazepine (Tegretol®)), which are anti-seizure medications commonly used in psychiatry for problems with impulse control. Finally, the newer antipsychotic medications (such as quetiapine (Seroquel ®), ziprasidone (Geodon ®), aripiprazole (Abilify ®), olanzapine (Zyprexa ®), and risperidone (Risperdal ®)) can be tried. However, antipsychotics must be used cautiously due to their ability to worsen parkinsonian symptoms.

Increased Emotions

Patients with PD sometimes report an increase in emotions since the onset of the illness. The example given most commonly is becoming more emotional, particularly tearful, when watching movies. Although not always a problem, it is a clear change from how the patient used to be. Despite these episodes of tearfulness, patients do not commonly report other symptoms of depression, do not feel sad during these episodes, and say that the episodes come out of the blue and pass quickly.

It is thought that increased emotions may be related to damage to the nerve pathways in the brain that connect the frontal lobes with the area that controls facial expression. Treatment is not always needed, but antidepressants and mood stabilizers have been used with good effect.

Decreased Emotions

Other PD patients experience an overall decrease in emotions, social interaction, and speech. A decrease in motivation or interest often goes along with this, in which case it is called apathy. Apathy may be connected to the thinking and

mood changes that can occur in PD, and patients may be unaware that they have changed in some way. Apathetic patients often need a push to remain physically, mentally, and socially active.

It is often assumed that apathy and depression are the same disorder. However, it is important in such cases to look for other signs or symptoms of depression, such as depressed mood, self-blame, tiredness, and sleep and appetite changes.

There are no approved treatments for apathy. Patients often do better with a structured schedule that keeps them active. There is some evidence that the dopamine agonists increase motivation and interest. Stimulants (such as methylphenidate (Ritalin ®) or dextroamphetamine (Adderall ®)), or medications related to stimulants (such as modafinil (Provigil ®)), are commonly used in clinical practice to treat this problem.

Conclusion

Emotional changes are very common in PD, probably affecting more than half of patients over the course of their illness. A wide range of changes can occur, from common disorders such as depression and anxiety to more unusual symptoms such as loss of impulse control and increased emotions. Although it is still unclear how best to diagnose and treat many of these disorders, the range of available treatment options is greater than ever before. Therefore, it is important that PD patients and their loved ones report any emotional changes to their health care providers, so an assessment can be performed and appropriate treatment started.

About the Author



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Chapter 3

Cognitive Changes in Parkinson Disease

Written by: Paul J. Moberg, PhD

In his original description of the “shaking palsy,” Dr. Parkinson reported his observations on six patients and originally thought that *cognitive* changes, or changes in memory, thinking and learning, were not experienced in *Parkinson disease* (PD). However, we now know that PD is often complicated by a variety of cognitive symptoms that range from isolated memory and thinking problems to severe *dementia*. While the *motor symptoms* of PD are well-known (i.e., tremor, rigidity, slowness of movement, imbalance), the commonly seen deficits in memory, attention, problem-solving, and language are less understood. These “*non-motor symptoms*” can be very disabling and in many patients are the most troubling symptoms.

Studies have shown that over 50% of people with PD experience some form of cognitive impairment. In the early stages of illness, many people with PD will complain of difficulties with attention and task completion, also known as *working memory* skills. For example, the patient may complain of being easily distracted, losing their train of thought, or getting easily “knocked off track” when performing a task. In the middle stages of illness, difficulties with decision-making, problem-solving, memory, and word-finding may become more apparent. In the later stages of illness, a more serious cognitive disturbance can arise with confusion, *visual hallucinations*, *delusions*, and agitation. In general, mental and motor decline tend to occur in parallel as the disease progresses. Significant cognitive impairment in PD is often associated with:

- Caregiver distress
- Worse day-to-day *function*
- Diminished quality of life
- Poorer treatment outcomes
- Greater medical costs due to nursing home placements
- Increased mortality

What is the Difference between “Cognitive Dysfunction” and “Dementia”?

The difference between the terms “cognitive impairment” and “dementia” is the extent of decline in thinking and memory. Dementia refers to problems in memory and thinking that are advanced, interfering with daily activities and quality of life. Typically, someone with dementia will show significant deficits in memory and at least one other area of cognition, such as problem-solving or attention. In contrast, milder cognitive impairment may be irritating or concerning to the person, but it does not significantly alter how they lead their lives. This more subtle form of cognitive impairment occurs in the majority of PD patients.



Key Point: While approximately 50% of patients with PD will experience some form of cognitive impairment, not all individuals will be diagnosed with full-blown dementia.

Cognitive Dysfunction

The term “cognitive” refers to thinking or the processes involved in knowing or putting together information. It includes a variety of mental skills such as attention, problem-solving, memory, language, *visual-perceptual skills*, and other aspects of reasoning and general intellect. Many persons with PD complain of slowness in thinking and difficulty with word-finding. Research has found that these mild symptoms of cognitive impairment occur in a majority of PD patients. Such changes do not typically hinder day-to-day activities and responsibilities. Some patients report mild improvements in motivation and concentration after taking *dopaminergic*, or anti-PD, medications. These medications, however, do not typically improve other aspects of memory and thinking abilities.

What Cognitive Problems Occur in PD?

Changes in cognitive function can be the most troubling and disabling symptoms in PD, even when considering the motor symptoms. Most patients with PD will report some decline in their thinking abilities, starting early in the course of illness. For example, they may notice slowing in how quickly they can process information as well as reduced organizational skills. While these subtle changes in attention, language and memory are often not noticeable in day-to-day activities, many patients will complain of mental sluggishness and problems with tasks requiring higher levels of functioning, especially if the task is both physically and mentally challenging. This slowed rate of thinking is called *bradyphrenia*.

Mild cognitive changes are also commonly seen on *neuropsychological tests* early in the disease course. Cognitive testing often reveals deficits in several areas, including *executive function* or problem-solving abilities, *visual-perceptual abilities*, memory, and language. Basic intellectual abilities, orientation (i.e., knowing the correct time and place), general knowledge acquired over the person’s lifetime, and memories from the person’s past typically remain intact until very late in the illness.

Cognitive deficits tend to be worse for patients with predominant symptoms of *bradykinesia* and rigidity. Patients with tremor predominant symptoms often report less severe changes in thinking and memory. The following cognitive functions are often disturbed in PD:

- 1) Attention: Patients with PD will often have problems on complex tasks that require them to maintain or shift their attention. Problems with the mental calculation of numbers or concentration during a task are also commonly described.

- 2) Speed of mental processing: Just as movement can be slowed in PD, thinking abilities can also become sluggish. This slowing in thinking is often associated with *depression* in PD. These problems can be seen as a delay in responding to verbal or behavioral stimuli, taking longer to complete tasks, and difficulty retrieving information from memory.
- 3) Problem-solving or executive function: A common cognitive change in PD is trouble planning and completing activities. People with PD will often experience difficulties in generating, maintaining, shifting, and blending different ideas or concepts. Caregivers may report that the patient is not as “flexible” in their thinking, and that the person has become more concrete in their approach to tasks. Patients with these deficits often benefit from regular cues or reminders and greater structure of activities. Non-demented patients with PD can also experience problems with generating ideas or language in a smooth and consistent manner.
- 4) Memory deficits: The *basal ganglia* and *frontal lobes* of the brain are important in the organization and recall of information. Damage to these areas leads to problems processing and retrieving information. As previously mentioned, problems with working memory are often present early in PD. As the disease progresses, some patients will begin to experience problems with common tasks such as making coffee, balancing their checkbooks, etc. Patients with full-blown dementia will typically experience both short-term and long-term memory impairment. Memory cues can often improve performance for these patients. When asked to recall a piece of information, many PD patients will comment, “I can’t tell you now, but I can tell you later.” This difficulty in retrieving memories on demand is one of the *cardinal* symptoms of cognitive impairment in PD.
- 5) Language abnormalities: Many PD patients will complain of word-finding problems, or the “tip of the tongue” phenomenon, and will feel embarrassed during conversations because they cannot find the right word. Problems in naming or misnaming objects may also be seen in the middle to late stages of PD. Difficulty with language when under pressure or stress is also a common complaint. Patients with PD may also report difficulty comprehending complex sentences where the question or information is included with other details. In many patients, their language becomes simpler due to problems with production of language and *dysarthria*. When compared to PD patients without dementia, those with dementia talk in shorter sentences, have a different “melody” of speech, have less spontaneous speech, and are less able to comprehend verbal and written commands.
- 6) Visuospatial difficulties: Patients with dementia can experience problems processing information about their surroundings or environment, even early in the disease process. These subtle visual-perceptual problems may contribute to the *visual misperceptions* or

illusions that are often seen in PD. Patients are especially susceptible to this phenomenon in low-light situations (ie; nighttime) and if they experience other visual problems like macular degeneration. These types of symptoms may continue to progress throughout the course of the illness. At their most severe, patients may experience problems telling apart non-familiar faces or in recognizing *emotions* expressed on another person's face.



Key Point: Cognitive changes can cause difficulties with everyday tasks, such as paying bills, eating, dressing and even speaking. Of special importance, all individuals with cognitive impairment should undergo a driving evaluation to assess driving skills and safety.

What is Dementia?

The term *dementia* refers to advanced cognitive deficits that impair normal functioning. It does not mean “crazy.” It comes from two Latin terms that roughly translate into “away” and “mind”. Dementia is a term used by healthcare professionals to describe a grouping of cognitive symptoms that can be experienced in a variety of diseases and disorders. “Cognitive impairment” becomes dementia when the person’s thinking and memory problems start to interfere with basic daily activities. Research has shown that 30-50% of people with PD will develop dementia. While many PD patients will complain of changes in their thinking and cognitive abilities, not all individuals will develop full-blown dementia. The behavioral consequences of dementia can be very difficult for the patient and his or her family. Patients may become confused, disoriented, and unable to be left alone. They may show *signs* of agitation, delusions, *mood* fluctuations, and increased impulsivity.

It is important to know the difference between the terms “dementia” and “*delirium*”, as these two conditions are often confused. The term delirium is related to a set of cognitive symptoms that involve a disturbance of *consciousness* with impaired alertness and attention. The person with delirium will often appear drowsy, and may fluctuate between periods of sleepiness and restlessness. Like the person with dementia, the delirious patient also shows symptoms of confusion, disorientation, and forgetfulness. Delirium can be caused by medical illnesses such as pneumonia, urinary tract infections, malnutrition, dehydration, fever, or reactions to medications. An important distinguishing feature from dementia is that patients suffering from delirium often improve once the underlying condition has been treated. The dementia patient, in contrast, experiences these cognitive problems on a routine basis. Delirium also has a rapid onset, often over the course of hours or days, while the onset of dementia is usually very gradual. Patients with dementia, however, are at higher risk of developing delirium than the average elderly person. (Please refer to Chapter 4 for more information on delirium.)



Key Point: Many PD patients live in the community with mild levels of dementia. Typically, they can function well with assistance from a supportive spouse and/or caregiver.

What are the Risk Factors for Dementia?

Research has shown that there are a number of risk factors for dementia in PD, yet none directly cause dementia. Rather, the more of these factors that are present, the higher the likelihood of developing dementia. These risk factors include:

- Increasing age
- Older age at PD onset
- Longer disease duration
- Family history of dementia
- Greater severity of motor symptoms
- Depression
- Hypertension (high blood pressure)
- Poor medication tolerance (ie; confusion or *psychosis* following administration of some medications)

What Causes Cognitive Problems and Dementia?

The primary cause of memory and thinking problems in PD is *biological*, meaning that these problems are due to changes in the structure and chemistry of the brain. It is thought that the same process that causes death of *neurons* in the *substantia nigra* and produces the motor symptoms of PD is also responsible for related cognitive changes. The substantia nigra is part of a larger brain system called the basal ganglia, which controls motor function. The nerve pathways between the basal ganglia and the frontal lobes of the brain are also affected in PD. This damage may contribute to difficulties with problem-solving, initiation of behavior, and impulsivity that are commonly reported by patients and family members. Most PD patients who show the clinical signs of dementia will, on autopsy, show changes in the brain that are consistent with *dementia with Lewy bodies* (please refer to Chapter 5 for more information on this disorder).

In addition to the primary biologic causes of cognitive impairment, *psychological* factors can also play a role. Depression and *anxiety* are common in PD and can cause or worsen cognitive deficits. For example, a person with PD may become anxious and embarrassed about their memory problems when conversing with others. This anxiety may directly worsen the already present cognitive deficits.

Similarly, sadness over the loss of function or ability can often interfere with efficient thinking and memory processes.



Key Point: Cognitive impairment usually involves both biologic and psychological factors. Changes in the structure of the brain as well as chemical imbalances can impair thinking and memory processes. Anxiety and depression can also worsen these cognitive deficits.

How are Cognitive Changes in PD different than Alzheimer's Disease?

The most common cognitive disorder in the elderly is Alzheimer's disease (AD), with over half of all dementia cases diagnosed with this condition. AD results in memory loss due to a progressive decline of cells largely on the outside portion of the brain. Overall, dementia produces a greater impact on social and occupational functioning in PD than that of AD due to the combination of motor and cognitive impairments. Dementia in PD is classified as a *subcortical dementia* because functions such as attention, the speed of thinking processes, memory retrieval, visuoperceptual abilities, and executive functions are the most seriously impaired areas of performance. Mood changes are also often seen. In contrast, AD is classified as a *cortical dementia* due to the high frequency of language and memory disturbances. Some researchers have distinguished between these two types of dementia by the nature of their behavioral problems. There is some overlap between symptoms and biological changes seen in AD and PD however, it is less likely for both disorders to occur at the same time. Most PD patients develop dementia as a direct result of the disease process versus a co-existing disease such as AD.

How do you Diagnose Cognitive Deficits or Dementia?

Cognitive disorders are commonly assessed and diagnosed by interviewing the person with PD, asking family members or caregivers about their observations, and by administering cognitive screening tests such as the *Mini-Mental State Examination (MMSE)*. The treating neurologist will typically ask questions that evaluate the patient's orientation, attention, memory, language and problem-solving skills. This type of assessment can detect more obvious impairments in thinking and memory, but may not be sensitive enough to detect more subtle or complex cognitive problems. The treating physician may refer the patient to a *clinical neuropsychologist* for a more detailed assessment. A clinical neuropsychologist is a licensed psychologist with expertise in how behavior and cognitive skills are related to brain structure and symptoms. A neuropsychological assessment can be an important diagnostic tool for differentiating PD from other dementing illnesses such as AD, stroke, or dementia with Lewy bodies. This is especially true in the earliest stages of the illness.

The typical neuropsychological examination will involve testing of the following cognitive areas:

- General intellectual abilities
- Higher level reasoning, sequencing and problem-solving skills
- Attention and concentration
- Learning and memory
- Language abilities
- Visual-spatial abilities (e.g., perception)
- Fine motor speed and coordination
- Sensory skills (ie, vision, touch, hearing, etc.)
- Mood and personality

In general, a neuropsychological evaluation involves an interview and testing. During the interview, the patient is asked about symptoms, medical history, medications and other factors important to PD. Testing involves taking paper-and-pencil or computerized tests and answering questions. Test results can be used to help with diagnosis, monitor disease progression, or plan management and treatment.

A difficulty in diagnosing cognitive impairment in PD is that some patients do not realize or admit that they have such problems. This may be related to embarrassment, fear of dementia, or worry that they will be placed in a nursing home or lose the ability to drive. In other cases, PD itself can cause problems with awareness or the ability to recognize cognitive problems. For these reasons, it is helpful to ask an informed caregiver if he or she has noticed any cognitive or functional changes.

Co-Existing Conditions Affecting Thinking and Memory

There are a number of other factors that can have a negative impact on a person's cognitive skills, such as disorders of mood, anxiety and sleep. In some cases, these factors can make memory and thinking deficits worse as well as directly affect quality of life.

- Depression – It has been reported that up to 50% of patients with PD may experience some form of depression, especially *minor depression*, during the course of their illness. Depression is more likely to occur in cases of severe cognitive impairment. The effects of depression on memory, attention and problem-solving skills have been well-studied in older people. For example, depressed mood directly impacts attention, memory, mental calculations as well

as problem-solving skills. Successful treatment of depression with medication and *psychotherapy* can also improve these cognitive symptoms.

- Anxiety – Anxiety may be as common as depression in PD. While less studied, up to 40% of patients experience some form of anxiety. Anxiety can interfere with memory storage, disrupt attention, and affect complex task performance. For example, most people remember “going blank” on a school exam when feeling anxious. Many patients with cognitive difficulties will experience *anticipatory anxiety* in situations where they have to use their cognitive skills. Similar to depression, successful treatment can lead to improvement of cognitive problems related to anxiety.
- Sleep disturbance – The impact of poor sleep on attention, alertness and memory are well-known. Studies of airplane pilots have shown that even mild reductions in sleep can directly impair a person’s attention, judgment and ability to *multi-task*. Problems with falling sleep and staying asleep are very common in PD, especially as the disease progresses. Four types of sleep problems have been reported in PD: 1) problems staying asleep and early morning awakening, 2) involuntary movements and pain that interrupt sleep, 3) increased nighttime urination and, 4) nighttime agitation, *vivid dreams* and visual misperceptions or hallucinations. In such cases, a *sleep study* is important to examine the person’s sleeping patterns and how their sleep is disrupted. Sleep problems are often addressed with medication and behavioral treatments, and as sleep improves, its impact on thinking and memory is reduced. (Please refer to Chapter 6 for more information on sleep disorders in PD.)
- Fatigue – Just as fatigue can cause problems with movement and walking in PD, it can also impair thinking and memory. For example, a patient with PD may have difficulty in performing a complex cognitive task, such as working on finances or taxes, over an extended period of time. It is often better to divide these tasks into short 10–15 minute sections that are more manageable and maximize the person’s attention and energy resources. Such a strategy will help minimize fatigue and keep the person on task. It is also important to be aware that as the day wears on, the person with PD may begin to fatigue, both physically and cognitively. Therefore, it is better to do more complex tasks earlier in the day when the person feels “fresh.” There are medications that are used to improve energy and alertness in PD (ie; methylphenidate (Ritalin®) and modafinil (Provigil®)), but many of these medications have yet to be studied extensively for this disorder. Some medications used to treat PD have also been shown to have stimulating effects on thinking and energy levels (ie; selegiline (Eldepryl®) and amantadine (Symmetrel®)).

The important thing to remember about the conditions listed above is that most of these disorders are treatable with medications and/or behavioral treatments. With successful treatment, related cognitive problems will often improve and quality of life can be restored.



Key Point: Cognitive changes will sometimes improve with the treatment of depression, anxiety, sleep disturbances, and fatigue.

What are the Treatment Options for Cognitive Problems?

Of the medications currently used to treat the motor symptoms of PD, there is no consistent evidence that levodopa improves cognition on an ongoing basis. Instead, there is some evidence that medications used to treat cognitive dysfunction in AD hold promise in PD. Many physicians use these medications once cognitive deficits become problematic. However, there is increasing interest in using these medicines early in the disease process to possibly delay the onset or slow the progression of cognitive impairment.

Treatment of Memory and Cognitive Problems with Medications

The primary class of medications used to treat thinking and memory problems are the **acetylcholinesterase inhibitors**, which are medications that increase levels of **acetylcholine** in the brain. These medications include tacrine HCl, (Cognex®), donepezil (Aricept®), rivastigmine (Exelon®), and galantamine (Reminyl®). While such medicines are commonly used in patients with AD, their effectiveness in PD is not yet fully understood. These medications are used to target the memory and attention problems seen in PD, and preliminary studies have shown positive results. Some studies have also found that acetylcholinesterase inhibitors can improve psychotic symptoms (please refer to Chapter 4 for more information on psychosis). These medications are relatively safe and have few side effects for PD patients. They do not typically produce marked improvements in cognition, but are thought to help slow the progression of cognitive deficits and help maintain the person's current level of functioning. It is important to bring cognitive changes to the attention of your healthcare provider, who can assess these issues and discuss treatment options.

In addition to medications for memory, there are medications that are used to improve attention, increase general levels of **arousal**, and reduce daytime sleepiness. Stimulant medications used to treat **attention deficit disorder (ADD)**, such as methylphenidate (Ritalin®), or medicines used to treat sleep disorders such as modafinil (Provigil®), can be used to decrease fatigue, sleepiness and mental dullness. Selegiline (Eldepryl®) is also used by some clinicians to combat daytime sleepiness and fatigue. In general, the goal of these medications is to boost a patient's energy level and stimulation. They do not, however, cure the biological cause of these cognitive problems.

In general, medications in combination with some type of behavioral treatment are usually the most effective treatment strategy (see below). For example, in addition to taking a medication to help with memory, the patient may also use behavioral strategies to improve memory performance, such as keeping a memory-book, using a calendar to remember appointments and important

activities, and trying to use “memory joggers” to help remember specific information.



Key Point: It is very important that you discuss all treatment options thoroughly with your physician before making any changes to your medications.

Alternative Treatments for Cognitive Problems

There are other types of treatment for cognitive deficits in PD that are used instead of or in combination with medications. For patients with milder cognitive deficits, different forms of psychotherapy may be useful in teaching the patient ways to “work around” their related problems. For example, *cognitive remediation therapy* is a treatment that emphasizes teaching the patient ways to compensate for their memory or thinking problems. In this treatment, the clinician uses information from neuropsychological testing to identify cognitive strengths that can be used to help overcome other areas of thinking that are not as strong. While widely used in the treatment of cognitive problems resulting from brain injury or stroke, there has been less use of this technique in patients with AD or PD. This treatment does not reverse or “cure” the cognitive disorder, but rather, the patient is taught strategies that can help with memory skills, such as organizing day-to-day tasks. Depending on the severity of cognitive impairment, many patients can use these skills independently. In instances where the patient is more impaired, caregivers or family members can help apply these strategies. This type of therapy is an important treatment option, as it gives the patient concrete strategies to help cope with their cognitive problems. It also provides a supportive environment to express concerns and frustrations over changes in mental functioning. Cognitive remediation therapy is usually conducted by a neuropsychologist or *speech-language pathologist* who is specially trained in these techniques. The major drawback of this treatment is that it works best with milder forms of cognitive deficits, as it requires insight into the patient’s own memory and thinking problems.

For patients with more significant dementia who may be unable to use self-generated strategies, behavioral management approaches are often beneficial. In this type of treatment, changes in the environment can be made to help minimize memory, visual-perceptual, or orientation difficulties. For example, simplifying the décor of the living area to reduce excessive stimuli may help with distractibility or confusion. Use of a nightlight or low-level lighting to reduce visual misperceptions and confusion at nighttime can also be beneficial. Behavioral strategies can also help deal with other problems such as impulsivity, wandering, poor initiation, and problems with communication. Many patients benefit from a regular routine in their day-to-day activities and feel more comfortable with a clear and structured schedule. These interventions are usually designed either by a psychologist experienced in *behavioral therapy* or by an *occupational therapist*.

Lastly, while not often discussed, there is support for the “use it or lose it” idea of maintaining good cognitive health. There is increasing research showing that maintaining an active mental and physical schedule can actually help delay or avoid some of the negative effects of aging. Staying busy with a variety of mental challenges can be beneficial both from a cognitive standpoint and in improving the person’s general quality of life. For example, reading and discussing articles in a newspaper or magazine, doing cross-word puzzles, going to plays or concerts, interacting with others, gardening, walking or other exercise, and “tinkering” at projects around the house are all activities that can keep the person with PD stimulated. Incorporating some of these activities into a PD patient’s daily schedule can greatly enhance their functional level as well as their self-esteem and enjoyment of life.



Key Point: A combination of medications and behavioral strategies is usually the best treatment for cognitive problems in PD.

What to Expect with Treatment for Cognitive Problems

The goal of treatment for cognitive impairment and dementia is to slow the progression of symptoms as well as teach the patient ways to compensate. These treatments will not, however, reverse the course of cognitive decline or cure these problems. Medication and behavioral treatments are considered successful if they help keep the PD patient functional and more independent in their activities of daily living for a longer period of time. As cognitive deficits can be very debilitating and frustrating, timely identification and treatment of these problems is very important. In the early stages of treatment, patients may be able to use behavioral strategies on their own (self-generated). However, as the disease and the person’s cognitive difficulties progress, a shift to behavioral strategies initiated by a caregiver or family member (externally-generated) may become necessary. Based on clinical experience, successful treatment of cognitive deficits often leads to decreased *caregiver burden* as well as a greater sense of self-worth for the patient.



Key Point: Caring for an individual with dementia can become extremely challenging and even frustrating. Caregivers must be conscious of their own mental and physical needs by seeking appropriate assistance and support. Social workers and other healthcare professionals can provide information on community resources and services.

Conclusion

Most patients with PD experience some level of disturbance in their thinking and memory skills. A wide variety of changes can occur, ranging from mild forgetfulness to gross confusion and dementia. These changes can significantly impact daily functioning as well as quality of life. Although we still have much to learn about how to diagnose and treat these cognitive problems, there are many more treatment options available as compared to just a few years ago. While many patients and family members are aware of changes in cognitive function, they commonly think there is little that can be done to help. Medication and behavioral treatments are often beneficial and all cognitive changes should be reported to your healthcare provider. It is important to remember that the treatment of thinking and memory problems can be as valuable as the treatment of motor symptoms in PD.

About the Author



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Chapter 4

Psychosis in Parkinson Disease

Written by: Rebecca Martine, APRN, CS, BC

“Psychosis” is a broad medical term used to describe a loss of contact with reality that often leads to behavioral and emotional changes. It is a common concern in the field of psychiatry but rarely associated with ***Parkinson disease*** (PD). In truth, psychosis is a serious problem in PD, affecting up to 40% of patients at some point in their illness. Although, it is typically experienced as a side effect of PD medications, a number of factors and causes can be involved.

Psychosis is one of the most disturbing and challenging complications for patients, families and clinicians. If not properly treated, psychosis can easily become more problematic than physical ***motor symptoms***. Furthermore, psychosis has been identified as the leading cause of nursing home placement for the PD community.

It is important for patients and families to be properly educated on this issue, as social stigmas have created alarming confusion and barriers to treatment. This chapter will better explain the two major symptoms of psychosis, ***hallucinations*** and ***delusions***, as well as treatment and management options. It will also review ***delirium***, a medial condition commonly confused with psychosis.

Chemical Changes in the Brain that Cause Psychosis

Many ***neurological*** and ***psychological*** disorders are caused by an imbalance of ***neurotransmitters***, or chemicals, in the brain. Both PD and psychosis are related to two neurotransmitters known as ***dopamine and acetylcholine***. Dopamine is primarily responsible for controlling movement, emotional responses and the ability to feel pleasure and pain. Like dopamine, acetylcholine helps control movement and ***emotions***, in addition to learning, memory and the regulation of many systems in the body.

There is a delicate balance between dopamine and acetylcholine that allows the body and brain to function effectively. Individuals with PD experience a loss of cells in the ***substantia nigra***, a region of the brain. Such cell loss causes a reduction in available dopamine and therefore, a disruption in the dopamine/acetylcholine balance. It is this imbalance and deficiency of dopamine that causes the motor symptoms of PD.

Psychosis, in contrast, is generally caused by abnormally high dopamine levels. Elevated dopamine levels in PD most commonly stem from prescribed medications that aim at alleviating motor symptoms. Again, a surge in the dopamine system triggers an imbalance with acetylcholine, which produces the symptoms of psychosis.

Psychosis is typically linked to major psychiatric illnesses, such as *schizophrenia*. However, it can also be seen with a variety of general medical disorders and conditions. Many PD patients become worried that psychotic symptoms suggest yet another disease. It is important to understand that psychosis is another symptom or complication of PD and does not mean that the individual suffers a new psychiatric illness.



Key Point: LOW dopamine levels cause PD symptoms.
HIGH dopamine levels cause psychosis.

What are the Causes of Psychosis?

Although fluctuating chemical levels play a direct role, the exact relationship between psychosis and PD is complex and not completely understood. Many different factors can cause psychosis in an individual with PD. All potential causes must be considered and examined before a clinician can determine the appropriate treatment. These potential causes can be broken down into 3 major categories, as described below.

1. ***Side effects of PD Medications:*** In the majority of PD cases, psychosis occurs as a side effect of drug therapy. Classic PD medications (ie; Sinemet and dopamine agonists) are designed to increase dopamine levels and thereby, improve motor symptoms. However, by boosting the dopamine supply, these medications can inadvertently produce psychosis. All PD medications can potentially cause psychosis. In addition, long-term use of such medications may increase the risk of developing this drug-induced complication.

Other medications used to treat PD can also cause psychosis by lowering levels of acetylcholine and shifting the balance with dopamine. These medications include anticholinergics (ie; Artane ® and Cogentin ®) and Amantadine.



Key Point: Most PD medications either increase dopamine or decrease acetylcholine levels in the brain. As a result, an imbalance in dopamine and acetylcholine levels can trigger psychosis.

2. ***Dementia:*** Psychosis can result from the basic chemical and physical changes that occur in the brain, regardless of other factors such as PD medications. This is most commonly seen in cases of PD with *dementia*. A diagnosis of *dementia with Lewy bodies* should be considered if both psychosis and dementia occur early in the disease process. (Please refer to chapters 3 and 5 for additional information on dementia and dementia with Lewy bodies.)



Key Point: Psychosis can sometimes occur early in the disease process, possibly before the motor symptoms. This is rare and usually suggests a different parkinsonian disorder than true PD. Be sure to bring this to your clinician's attention to ensure proper diagnosis.

3. *Delirium*: As we age, our bodies become more vulnerable to physical abnormalities and illnesses. PD typically occurs later in life and therefore, patients often experience other health problems in addition to this disease. In some situations, if these conditions are not properly treated, they can cause delirium. Delirium is best described as a reversible change in one's level of attention and concentration that results from a general medical condition or metabolic abnormality. It usually develops over a short period of time (hours to days) and resolves following treatment of the underlying condition. Delirium can be characterized by altered consciousness or awareness, disorganized thinking, unusual behavior and/or hallucinations. These widespread symptoms make it very difficult to differentiate delirium from other conditions, such as dementia or drug-induced psychosis. In order to diagnosis delirium, the patient must experience a change in their level of concentration or attention. Common causes of delirium include:

- Infection such as urinary tract infection
- Imbalance of sodium, potassium, calcium and/or other electrolytes balances
- Stroke
- Heart disease
- Liver disease
- Fever
- Vitamin B12 deficiency
- Head injury
- Sensory changes such as hearing loss and visual changes

In addition to medical conditions and changes, many commonly used drugs and chemical agents can also cause delirium, including:

- Anticholinergic medications including diphenhydramine hydrochloride (Benadryl ®), trihexyphenidyl (Artane ®), Benztropine (Cogentin ®), ranitidine (Zantac ®) and oxybutynin (Ditropan ®)
- Narcotics containing codeine or morphine
- Antibiotics
- Insulin
- Sedatives
- Steroids
- Nonsteroidal anti-inflammatory drugs (NSAIDS) including Aleve ®, Motrin ® and Advil ®
- Anti-seizure medications
- Alcohol
- Recreational drugs

Assessing Attention & Concentration

To assess one's level of attention or concentration following a sudden change in consciousness, awareness, behavior or personality, answer the following questions:

1. Is the person awake?

**If the person is asleep, are you able to arouse him/her?*

2. Is the person alert, confused or sluggish?

3. Is the person able to answer the questions below?

- What is your name?
- Do you know where you are?
- Do you know the date?

**If the person is able to answer one or more of the questions, was the answer(s) correct and provided in an appropriate amount of time?*

4. Is the person able to hold a conversation or does he/she easily lose attention or fall asleep?

5. Is the person able to respond to physical stimulus, such as a squeeze of his/her hand?

**If the person is not arousable or
UNEXPECTEDLY sluggish, confused and/or disoriented,
contact your clinician or go to the local emergency room!**

What are the Risk Factors for Psychosis?

Certain factors can increase one's risk of developing psychosis. They include:

- Use of PD medications (especially long-term use)
- Dementia or impaired memory
- **Depression**
- Individuals suffering from depression and PD are at a greater risk for developing psychosis. In addition, severe depression alone can cause psychosis.
- Sleep disorders such as **vivid dreaming**
- Individuals commonly report vivid dreaming prior to the onset of psychosis. Other associated sleep disturbances can include REM Sleep Behavior Disorder and general insomnia. (Please see Chapter 6 for additional information on sleep disturbances in PD.)
- Impaired vision
- Older age
- Advanced or late-stage PD



Key Point: Despite these known risk factors, every individual is unique and may or may not develop psychosis during the course of their illness.

What are the Symptoms of Psychosis?

Hallucinations

Hallucinations are best described as deceptions or tricks played by the brain that involve the body's senses. Hallucinations can be seen (**visual**), heard (**auditory**), felt (**tactile**), smelled (**olfactory**) or even tasted (**gustatory**). Although, they may appear to be very real to the individual, they cannot be seen, heard, felt, smelled or tasted by another person. Below are examples of the 5 types of hallucinations:

Types of Hallucination	Example(s)
• Visual	<i>Seeing</i> a furry creature run by your feet or <i>seeing</i> a deceased love one sitting in the room.
• Auditory	<i>Hearing</i> a voice that is coming from inside your head and not another person or object.
• Olfactory	<i>Smelling</i> an unpleasant odor that is not related to another source.
• Tactile	<i>Feeling</i> imaginary bugs crawling on your skin.
• Gustatory	<i>Tasting</i> a bitter or abnormal taste in your mouth that is not related to another source.

Although, all 5 types of hallucinations can potentially occur with PD, visual hallucinations are by far the most common. Auditory hallucinations are uncommon yet reported by a small percentage of patients. Olfactory, tactile and gustatory forms are extremely rare in PD. It is important to discuss all possible symptoms with your clinician, no matter how minor, rare or bizarre.

What You Should Know About Visual Hallucinations:

- Visual hallucinations can be either formed or unformed in appearance. Unformed images can appear as vague lights, lines, objects or shapes. Formed images can include very defined animals, objects (furry creatures) or people (deceased, historical, fictional or living).
- **Visual illusions**, also known as **visual misperceptions**, are also associated with psychosis in PD. Visual illusions are experienced when a person looks at a real object (such as a garden hose) and sees a different or altered object (such as a snake). Visual illusions are different from visual hallucinations as they mistake one object for another. Visual hallucinations, on the other hand, are entirely created by the mind without a specific trigger.
- PD patients often describe visual hallucinations as friendly and even pleasurable. Such hallucinations are referred to as **benign**, meaning that they are not bothersome or problematic. However, up to 30% of hallucinations can be frightening, disturbing and threatening. These forms of hallucinations require serious attention as they can lead to aggression, agitation and unsafe behavior.

- Initially, most patients understand that visual hallucinations are not real and are a complication of the disease. This is referred to as “*retaining insight*” and represents a less threatening problem. When patients “lose insight”, they believe that the images are real and are more likely to react and respond to the hallucinations. This can lead to severe behavioral disturbances with agitation, confusion and aggression.
- When visual hallucinations first occur, they tend to be short in duration (lasting only seconds to minutes) and disappear when the person focuses on the image or blinks his/her eyes.
- Recurrent images are common with visual hallucinations in PD. Patients often report seeing the same image repeatedly.
- Visual hallucinations can occur during the day however, are more often reported in the evening and at night. This is most likely related to poor lighting, changes in the sleep-wake cycle and/or medication dosing close to bedtime. It can also be related to *sundowning*, which is a period of confusion and behavioral changes at the end of the day that is often seen with dementia.
- Visual hallucinations are easy to confuse with general visual disturbances. Older individuals often experience visual disorders such as glaucoma, macular degeneration and cataracts. Such disorders can also produce odd or unusual changes in vision. However, these visual distortions are not hallucinations. All changes in vision should be reported to your clinician for proper diagnosis and treatment.
- Individuals who experience hallucinations may not always report their symptoms to their family and/or clinician. Reluctance to report these changes is often related to fears and social stigmas associated with psychiatric illness. It is important for caregivers and family members to pay close attention to personality and behavioral changes. Simply asking, “do you ever see things that may not be real?” can sometimes lead to surprising answers.

Delusions

Delusions are defined as fixed thoughts or ideas that are often illogical, irrational and dysfunctional. The individual will wholeheartedly believe these thoughts or ideas even though they are not based on reality. There are many types of delusions. The most common types reported in PD are described below.

Type of Delusion	Belief(s)	Behaviors
• Jealousy	The belief that your partner is unfaithful.	<i>Jealousy, false accusations, paranoia, aggression, social withdrawal</i>
• Persecutory	The belief that you are being attacked, harassed, cheated and/or conspired against.	<i>Paranoia, suspiciousness, agitation, aggression, defiance, social withdrawal</i>
• Somatic	The belief that your body functions in an abnormal manner or an unusual obsession with your body and/or health.	<i>Anxiety, agitation, reports of abnormal or unusual symptoms, extreme concern regarding symptoms, frequent visits with the clinician</i>

What You Should Know About Delusions:

- Delusions are less common in PD compared to visual hallucinations. They affect approximately 8% of patients. However, delusions tend to be more complicated and present a greater risk for behavioral disturbances and safety concerns.
- Delusions generally represent a more obvious deterioration or decline in one's condition.
- Delusions are typically more difficult to treat than visual hallucinations.
- Delusions are not only associated with medication side effects but dementia as well. As a result, delusional patients are often confused and extremely difficult to manage. In these cases, many caregivers require outside assistance from family members, neighbors and/or home healthcare agencies.
- Delusions can begin as generalized confusion at night. Overtime, this confusion can develop into clear delusions and behavioral disturbances during the day.
- All forms of delusions can be seen with PD although delusions of jealousy and persecution are most widely reported.

- Delusions of persecution (ie; *paranoia*) typically represent a greater challenge for treatment and general care by family members and loved ones. Patients are often suspicious, argumentative, defiant and sometimes aggressive. This can pose a serious safety risk not only to the patient but family members and caregivers as well. Paranoia can also lead to medication noncompliance, in which the patient refuses to take his/her pills because they are “poisoned” or “deadly”.



Key Point: Delusions cannot be controlled by the patient. Delusional thoughts are not deliberate or consciously created. Therefore, patients cannot simply stop or turn off these thoughts. It is important to understand that these beliefs and ideas are as real to the patient as “the sky is blue”. That is why delusions are often called “fixed”, meaning they are set, rigid and inflexible.

How to React and Respond to Psychosis

Practical Tips for Caregivers

- **Talk** to your loved one about their experiences with psychosis. They may be reluctant to introduce the subject on their own due to social stigmas related to *mental illness*. Openly discuss their thoughts, feeling and symptoms in a non-threatening environment. This can ease their anxiety and will allow you to have a better understanding of the situation.
- Try to **stay calm and patient**. Caring for an individual who is experiencing psychosis can be very challenging and frustrating. Remember that the patient cannot control these symptoms. If you become angry, aggravated or demanding, the patient's own aggression and agitation can worsen.
- **Be prepared** and know how to handle the situation if your loved one should become agitated or aggressive:
 1. Provide space without crowding.
 2. Talk calmly and evenly. Do not raise your voice.
 3. Provide reassurance. ("Everything is fine. You are safe.")
 4. Keep your hands in view and your movements to a minimum.
 5. Inquire about their feelings and their reason for being upset.
 6. Listen to their responses and comments.
- **Examine the environment** and make necessary adjustments. Below are several examples:
 - Visual hallucinations*: Lighting at night can help reduce shadows and the risk for visual illusions.
 - Delusions and confusion*: Keep dangerous objects in secure locations. Make sure furniture is arranged so that a confused patient cannot trip and/or fall.
 - Agitation or aggression*: Make sure that the environment is quiet and calm without disturbing noises or distractions.
- **Do not challenge** hallucinations or delusions by saying "*They are not real*". Alternatively, **do not reinforce** psychosis by endorsing the illogical behaviors or ideas. Try generic phrases instead, such as:

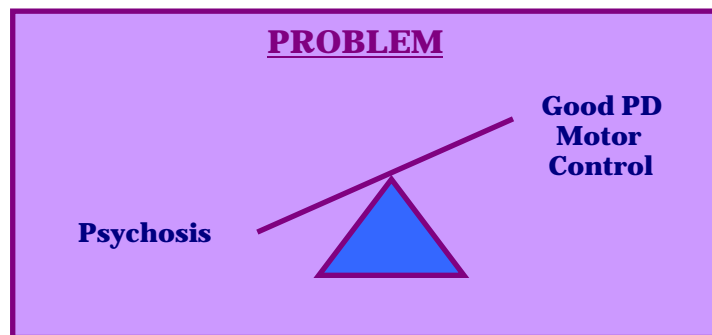
*"I understand that the children appear real to you but I cannot see them.
I wonder if they might be a hallucination."*
- **Educate others** who are frequently around your loved one about psychosis and *mental health* issues in PD. This will allow them to better understand the odd or unusual behaviors that they may observe. It can also relieve their fears and inhibitions while interacting with the patient. These individuals can be helpful in many situations, especially when you need immediate help.
- **Allow others to help**. Caring for someone with Parkinson disease can be challenging enough. Psychosis can make it significantly more difficult. You cannot properly care for your loved one if you do not care for yourself. Do not be afraid to ask for assistance from family or friends or seek assistance from social services or home health agencies.
- **Safety must be a priority**. Always ensure your own safety as well as the safety of your loved one. A patient who is experiencing psychosis can be confused, agitated, aggressive, suspicious and argumentative. If the situation becomes out-of-control and/or unsafe, leave the room and get help either from a family member, friend or neighbor. You can also call your local police department or 911. They can help gain control of the situation and will be understanding of the circumstances.
- **Explore available resources and options**. In rare cases, psychosis may progress despite treatment. This can make home-based care extremely difficult. It is appropriate to consider placement in a facility that can provide constant supervision to ensure that the patient is not a threat to himself or others. This can either be on a short-term or long-term basis. Social workers can be excellent resources when considering alternative care options.

What are the Treatments for Psychosis?

Treatment of psychosis in PD can be challenging. To ensure proper treatment, the underlying cause must first be identified. The clinician must determine if the psychotic symptoms are related to medication side effects, dementia or delirium. Again, this can be difficult as these three conditions can overlap and produce similar symptoms. Blood work and other forms of testing may be necessary. Once a probable cause is determined, treatment can begin.

Treatment of Psychosis Caused by PD Medications

As discussed earlier in this chapter, PD medications relieve motor symptoms by increasing dopamine in the brain. Consequently, elevated dopamine levels can trigger psychosis. For this reason, treatment often becomes a balancing act. On one side of the scale, high dopamine levels are needed for adequate control of PD motor symptoms. However, on the other, dopamine levels need to be reduced to alleviate psychosis. This can be a complicated process and often requires a 3-step approach.



STEP 1: Assessment and Plan

The first step in any treatment process is to assess the problem. It must first be determined if the psychotic symptoms are benign or problematic. Some clinicians will choose to postpone treatment if the symptoms are infrequent, non-threatening and if the patient “retains insight”. Other clinicians will start treatment based on the theory that psychosis will continue to get worse overtime. In addition, the clinician should consider the stage of PD, prior history of psychotic symptoms and social factors.

STEP 2: Adjust or Reduce PD Medications

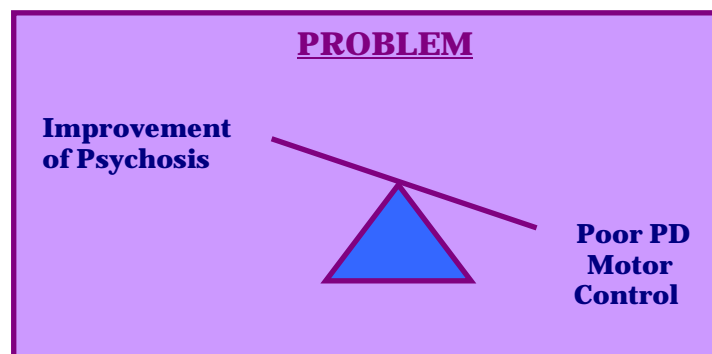
The next standard step of the treatment process is to adjust prescribed PD medications. The goal of this step is to improve psychosis without worsening PD motor symptoms. The clinician may decide to skip this step and proceed to step 3 if the patient is unable to tolerate potential worsening of PD symptoms. The following recommendations have been made for reducing or discontinuing PD medications for the management of psychosis.

1) Reduce or discontinue medications in the following order until psychosis resolves:

- Anticholinergic medications (Artane, Cogentin)
- Amantadine
- Selegiline
- Dopamine agonists (Mirapex ®, Requip ®, Permax ®, Parlodel ®)
- COMT inhibitors (Comtan ®)

2) If psychosis does not resolve, reduce Sinemet doses

There are a variety of techniques and measures that can be performed when adjusting PD medications. This approach generally improves psychotic symptoms. However, if motor symptoms become worse, PD medications may need to be restarted or increased, with Sinemet being the core of therapy, and Step 3 started.



Key Point: You should never make adjustments to your PD medications without first consulting your clinician. In addition, PD medications should not be stopped abruptly as this can cause life-threatening side effects.

STEP 3: Initiation of Antipsychotic Therapy

Antipsychotic agents are also designed to balance abnormal chemical levels in the brain. They work by reducing excess dopamine thereby, alleviating psychosis. Up until the 1990's, the use of antipsychotics in PD had been controversial. This was because older, also known as “typical”, antipsychotic medications were found to cause dramatic worsening of parkinsonian motor symptoms. Fortunately, newer medications have become available that are better tolerated by PD patients. This newer class of medications is referred to as “atypical” antipsychotics.

There are two “atypical” antipsychotic medications that are considered safe for PD patients. They cause limited worsening of parkinsonian symptoms while treating psychosis. These medications are clozapine (Clozaril ®) and quetiapine (Seroquel ®). Clozapine was once considered the best antipsychotic medication for PD patients. However, due to a rare yet serious side effect known as agranulocytosis, it is now primarily used if quetiapine is not tolerated or effective. Agranulocytosis is a reduction in white blood cells, which interferes with the body's ability to fight infection. Patients on clozapine are required to get weekly blood tests for the first six months and then every two weeks to monitor white blood cell levels. Quetiapine is similar to clozapine in its ability to reduce psychosis without causing significant worsening of motor symptoms. However, it does not cause agranulocytosis and is therefore, the first choice for many clinicians.




Risperidone (Risperdal ®) and olanzapine (Zyprexa ®) are two additional “atypical” antipsychotic agents. Unlike clozapine and quetiapine, these drugs may carry a greater risk for aggravating parkinsonian symptoms. Furthermore, there are two new antipsychotic agents on the market that are currently being studied to determine their effectiveness and safety for PD patients. These agents are geodon (Ziprasidone ®) and abilify (Aripiprazole ®).



Key Point: It can take several weeks before antipsychotic medications reach therapeutic levels in the bloodstream and improve psychotic symptoms. These medications must be given an appropriate amount of time to work and should not be discontinued without first consulting your clinician.

Antipsychotic Medications

Trade Name	Generic Name
Abilify	Aripiprazole
Clozaril	Clozapine
Geodon	Ziprasidone
Haldol	Haloperidol
Lidone	Molindone
Loxitane	Loxapine
Mellaril	Thioridazine
Moban	Molindone
Navane	Thiothixene
Orap	Pimozide
Permitil	Fluphenazine
Prolixin	Fluphenazine
Risperdal	Risperidone
Serentil	Mesoridazine
Seroquel	Quetiapine
Stelazine	Trifluoperazine
Taractan	Chlorprothixene
Thorazine	Chlorpromazine
Trilafon	Perphenazine
Vesprin trifluopromazine	Trifluopromazine
Zyprexa	Olanzapine

Key:	
	First choice antipsychotic medications for PD patients.
	Second choice antipsychotic medications for PD patients. Use with caution.
	These medications should <u>not</u> be prescribed for PD patients.

*It is important to be familiar with antipsychotic medications as many of them can cause worsening of motor symptoms and ***should not*** be prescribed for PD patients. Some of these medications, such as Haldol, are commonly prescribed in the hospital setting for patients who are agitated or anxious. If Haldol is prescribed, it should be given through an IV. This is the only form of Haldol that does not appear to worsen ***parkinsonism***. Notify all treating clinicians that older antipsychotics (those medications highlighted in red) should be avoided if possible.



Treatment of Psychosis Related to Dementia

Acetylcholinesterase inhibitors are medications used to treat memory impairment. They are commonly prescribed early in the management of dementia and include donepezil (Aricept ®), rivastigmine (Exelon ®) and galantamine (Reminyl ®). Through research and clinical observations, it has been found that these medications may also be beneficial in treating some forms of psychosis. If not already prescribed, acetylcholinesterase inhibitors should be considered.

In addition, antipsychotic therapy may also be necessary for treating dementia with psychosis. Again, quetiapine and clozapine are considered the best antipsychotic medications for PD patients. (Please refer to chapters 3 and 5 for additional information on the treatment of dementia.)

Treatment of Psychosis Related to Delirium

Delirium is generally caused by an acute medical condition. These symptoms should improve once the underlying condition is treated. However, during this process, additional measures are sometimes necessary to reduce unsafe and problematic behavior. These measures are commonly performed in a hospital or inpatient setting. Medications can be prescribed to calm an agitated or aggressive patient. Although these medications can be quite helpful, they can also produce serious side effects in elderly individuals. Two medications frequently used include lorazepam (Ativan ®) and haloperidol (Haldol ®). Again, haloperidol should be avoided in patients with PD when at all possible. In addition to medications, temporary physical restraints may be applied by some facilities. This is a controversial issue that should be closely monitored by the patient's family.



Key Point: Notify your PD clinician if the patient is hospitalized for any reason. This will allow the clinician to discuss PD-related issues and considerations with the hospital staff.

Conclusion

Psychosis is perhaps the most misunderstood and challenging complication associated with PD. Symptoms can involve changes in behavior, thinking and even personality. If not properly identified and treated, it can quickly become the most distressing component of this disease. Unfortunately, media and literature have painted a misleading picture of psychosis. This has led to public fears, poor recognition and barriers to treatment. It is important to understand that psychosis results purely from a change in brain chemicals. These symptoms require the same attention as tremor, stiffness and impaired gait. Management and treatment of psychosis can be complicated but is generally successful. All PD patients and families should be familiar with the risk of psychosis and should discuss possible symptoms with their clinician.

About the Author



Rebecca Martine, APRN, CS, BC is a board-certified Psychiatric/Mental Health Clinical Nurse Specialist who has focused her career on Parkinson disease and related movement disorders. She serves as both the Associate Director of Education and Clinical Nurse Coordinator at the Philadelphia VA Parkinson's Disease Research, Education and Clinical Center (PADRECC). Rebecca also serves as the Chairperson of the National VA Parkinson's Disease Consortium. She is actively involved in direct patient care, clinical research trials and national education and outreach. Her areas of interest include the neuropsychiatric aspects of Parkinson's disease as well as non-motor symptoms. Rebecca received her Bachelor's of Science in Nursing from the University of Delaware and her Master's of Nursing from the University of Pennsylvania.

Chapter 5

Dementia with Lewy Bodies

Written by: John Duda, MD

By now, it should be apparent that *Parkinson disease* (PD) not only affects the way we move, but also the way we think and feel. In fact, the majority of patients with PD will be affected by *mental health* changes during the course of their illness. But there are several ‘what ifs’ regarding mental changes in PD that we haven’t yet discussed. For example:

- ? What if a patient is affected by many mental health changes?
- ? What if these symptoms become the main problem for the patient?
- ? What if some of these symptoms develop before the patient develops the typical *motor symptoms* of PD?

In these situations, many patients will be diagnosed with another disease called *dementia with Lewy bodies* (DLB). So what is DLB? To answer this question, we first need to understand a little more about exactly what happens in the brain with PD.

How is the Brain is Affected by Parkinson Disease and Dementia with Lewy Bodies?

The human brain is made up of several different types of cells, the most important being the *neuron*. The neuron is able to send signals to other neurons through *neurotransmitters*, or brain chemicals. These connections support pathways and circuits in the brain that allow us to feel, move, think, remember, love, create, and so on. In short, it is these pathways and circuits of neurons that make us who we are. When neurons in these pathways and circuits become sick or die and are unable to communicate, our personality and behavior can change. For example, PD affects the *substantia nigra*, a collection of neurons at the base of the brain that communicates with other areas of the brain to control movement. This is why movement problems, including tremor, stiffness, slowness of movement, and difficulty walking are common symptoms in PD. Neurons in other parts of the brain may also be affected with PD and can impair the way we think.



Key Point: Doctors think that neurons become sick in the same way in PD and DLB. It is the location and connections between neurons that produce different symptoms in each disorder.

But what is really causing the neurons in the brain to become sick and die? The truth is that we really don't know. We do know that before those neurons die, many of them will develop abnormal 'clumps' of protein known as *Lewy bodies*. Lewy bodies are named after the doctor who first described them nearly 100 years ago, Friedrich Lewy. Recently, researchers have begun to understand the type of proteins that clump together in Lewy bodies, but are still unsure how Lewy bodies are formed, why they are formed, or even whether or not it is good for a neuron to have a Lewy body inside. Some researchers think that the Lewy body is one of the reasons that neurons eventually die. Others think that it might be a protective mechanism that the neuron uses to survive longer.

Lewy bodies develop in patients with PD as well as DLB. While the relationship between brain changes and clinical symptoms is not completely understood, a difference between these two disorders may be in the location of the neurons that are affected with Lewy bodies. In PD patients who have no *cognitive* problems, Lewy bodies are often found predominantly in the substantia nigra and surrounding areas of the brainstem (the part of the nervous system that connects the brain and the spinal cord). However, in patients with DLB, Lewy bodies are usually found in more widespread areas throughout the brain and degeneration of these other areas may be the cause of the cognitive symptoms of DLB.

Key Points about Lewy Bodies:

- 1) Lewy bodies are abnormal 'clumps' of protein that accumulate in neurons of patients with PD and DLB**
- 2) We don't know whether Lewy bodies help or hurt the neuron**
- 3) Lewy bodies only form in neurons in those areas of the brain that eventually degenerate in PD and DLB**

Why is it called Dementia with Lewy Bodies?

Diseases of the brain that occur later in life and involve the death (or degeneration) of neurons are referred to as neurodegenerative diseases. The most common neurodegenerative disease is Alzheimer's disease (AD). AD is called a *dementia* because it is a progressive decline in thinking that interferes with normal day-to-day activities. AD is not related to the formation of Lewy bodies. The second most common cause of dementia is now thought to be DLB. It is called that because

patients have a form of dementia and have Lewy bodies in neurons of many different areas of the brain. Patients with DLB have problems with thinking that are different from patients with AD. In addition, patients with PD may also develop dementia late in the course of their illness.



Key Point: DLB is the second most common cause of dementia. Dementia is defined as a progressive decline in thinking ability that is sufficient to interfere with normal day-to-day activities.

What are the Symptoms of Dementia with Lewy Bodies?

Unfortunately, as with PD, there is no single blood test or study that a doctor can order to make the diagnosis of DLB. Therefore, in order to diagnose DLB, a doctor will look for very specific *signs* and *symptoms* that are outlined in the following table. The doctor will then make a diagnosis of 'possible' or 'probable' DLB, because the only way to make a diagnosis of definite DLB is to confirm the presence of Lewy bodies with an autopsy.

Diagnosis of dementia with Lewy bodies

Central feature (*a patient has to have this*):

- Progressive cognitive decline severe enough to interfere with social and occupational **function**. Certain types of cognitive tasks, such as the ability to pay attention, copy a figure, and the ability to plan and complete tasks, are particularly impaired.

Core features (*if a patient has one of these he/she is said to have possible DLB; if two or more, it becomes probable DLB*):

- **Cognitive fluctuations** which are frequent changes in thinking ability, level of attention, or alertness
- **Visual hallucinations**
- Signs and symptoms of PD like stiffness, slowness of movement, difficulty walking, and less likely, tremor

Supportive features (*these features support a diagnosis of DLB but are not enough to make the diagnosis without the other features*):

- Repeated falls
- Fainting
- Temporary loss of consciousness
- Bad reactions to some drugs used to treat psychosis
- **Delusions** (firmly believing something that isn't true)
- **REM sleep behavior disorder** (see below)
- Difficulty with sense of smell
- **Depression**

As you can see, many of these signs and symptoms are similar to what has been described for PD in previous chapters of this handbook. A few distinct features of DLB are discussed below.

What does Cognitive Fluctuation Mean?

One symptom that has not been discussed very much and is very important in the diagnosis of DLB is cognitive fluctuations. This refers to frequent changes (also called fluctuations) in thinking ability (cognition), level of attention, or alertness of the patient. At times, a patient will seem to be back to his/her 'old self', with normal attention and cognition. However, at other times he/she will be excessively sleepy, confused, unable to hold a conversation, or even hard to wake up. These episodes may come on suddenly, as if the patient 'went blank'. They can occur right after waking up, and can last anywhere from minutes to weeks. When these episodes first happen, the patients will often be taken to the emergency room, where clinicians will assess for other problems, like a stroke or a seizure. Often it is the caregiver who understands the complexities of fluctuations the best. They will know that it is much easier to do things like bathing or meeting friends and family when the patient is doing well. There is usually no regular time when the fluctuations happen, and they are not the same as '*sundowning*' (when a person with dementia becomes more confused or agitated later in the day and at night).



Key Point: When a patient first starts having symptoms similar to cognitive fluctuations, they should be thoroughly evaluated by a clinician to rule out other *neurological* or medical conditions.

What is REM Sleep Behavior Disorder?

REM sleep behavior disorder (RBD) will be discussed briefly here and at greater length in the next chapter on sleep disorders (please refer to Chapter 6). RBD is a symptom that is more common in PD and DLB than once thought. In normal sleep, when we dream, part of our brain 'turns off' the muscles in our body so that we don't act out our dreams and hurt ourselves. The only muscles that are not 'turned off' are the eye muscles, and that is why if you watch a person who is sleeping and dreaming, sometimes you will see their eyes darting around quickly, otherwise known as rapid eye movements or REM. This phase of sleep is known as REM sleep. Unfortunately, some people with PD and DLB will not have their muscles 'turned off' and will actually 'act out' parts of their dreams. They will sometimes yell or scream, kick, punch, and even accidentally injure their bed partner or themselves while they are asleep. It is important to recognize this problem and report it to your clinician so that treatment can be started if needed.

What if a Patient with Parkinson Disease Develops the Symptoms of Dementia with Lewy Bodies?

It is common for PD patients to develop features of DLB during some point in their illness. This often causes confusion when trying to form an accurate diagnosis. To get around this problem, doctors have agreed that patients will only be diagnosed with DLB if they develop dementia and other specific features before, or within 1 year, of developing the common motor symptoms of PD. If more than one year passes between the onset of the motor symptoms of PD and the start of dementia, the patient is diagnosed with Parkinson disease with dementia (PDD). Patients with DLB and PDD can appear quite similar and in fact, are treated very similarly, so this distinction is not very important for the patient or family. Many doctors believe that the only difference between these two disorders is the timing and location of the brain changes.

Treatment Issues for Dementia with Lewy Bodies

When doctors consider how to treat someone with DLB, they have many of the same choices for each particular symptom that were discussed earlier in this handbook. There is no medication that is specifically approved to treat all aspects of DLB and therefore, the doctor must choose which symptoms to treat in a particular patient. It is very important that the patient and caregiver be involved in this decision-making process for 2 reasons:

1. The patient and the caregiver often have a better idea than the clinician about which symptoms are most troublesome
2. In many patients, treating one symptom has the potential to worsen other symptoms

For example, as was discussed in Chapter 4, when doctors use certain medications to treat symptoms of *psychosis* (like visual hallucinations and delusions), these medications can make the motor symptoms of PD worse. Likewise, some medications used to treat the motor symptoms of PD or DLB can make psychosis worse.

The first treatment option for many patients with DLB is the same treatment option as discussed in Chapter 3 on dementia, namely a class of medications called cholinesterase inhibitors. These medications were originally developed to treat AD, but also seem to work as well, if not better, in patients with DLB. While we are still waiting for the results of large research studies to prove that these drugs work well in DLB, virtually all of these medications have been shown to have some benefit for many patients. Although they were designed to treat dementia, they also seem to help with other symptoms of DLB, including problems with attention, hallucinations, and delusions.



Key Point: Currently available drugs to treat AD can also be very beneficial for patients with DLB.

The second major treatment concern for DLB is that some patients will not tolerate certain antipsychotic medications that are commonly used to treat psychosis (hallucinations and delusions). These patients can have very serious reactions to these medications with confusion, worsening of psychosis, and even death. Therefore, these medications should be used very carefully, if at all, in patients with DLB. As discussed in Chapter 4, if these medications are necessary, then very low doses of Clozaril (clozapine) or Seroquel (quetiapine) should be tried first as they have the least chance of causing serious side effects.



Key Point: Antipsychotic medications should be used very carefully in patients with DLB. If needed to treat hallucinations and/or delusions, then starting with very low doses of Clozaril (clozapine) or Seroquel (quetiapine) is recommended.

Conclusions

DLB is a very common cause of dementia and is similar to the dementia experienced by some people with PD. While there are no medications available to treat all aspects of DLB, most of the symptoms can be treated based on the needs of the individual patient. Progress is being made in understanding the relationship between DLB and PD with dementia that will undoubtedly lead to better treatments for both conditions.

About the Author



John Duda, M.D. is Co-Director of the Parkinson's Disease Research, Education & Clinical Center (PADRECC) at the Philadelphia Veterans Affairs Medical Center and Assistant Professor of Neurology at the University of Pennsylvania School of Medicine. Dr. Duda received his medical degree from Jefferson Medical College and completed a residency in neurology at Hahnemann/MCP University Hospital, where he served as Chief Resident. He also completed a 3-year Post-Doctoral Research Fellowship in the neuropathology of neurodegenerative diseases at the Center for Neurodegenerative Disease Research of the University of Pennsylvania. Dr. Duda is currently Principal Investigator for several federally-funded research projects, including a study defining the role of alpha-synuclein neuritic pathology in Parkinsonism and a multicenter trial of deep brain stimulation in Parkinson's Disease.

Chapter 6

Sleep and Parkinson Disease

Written by: Bradley Boeve, MD & Michael Silber, MD

Sleep disturbances are not specifically defined as *neuropsychiatric* complications of *Parkinson disease* (PD), yet *mental health* and sleep tend to go hand-in-hand. Sleep disturbances can cause mental health changes and mental health changes can cause sleep disturbances. For instance, *depression* is known to cause *insomnia* and *excessive daytime sleepiness*. And, sleep disorders alone can cause confusion, poor *mood* and even *psychosis*.

The human body needs sleep just as it needs oxygen-*simply to survive*. Sleep allows the body, especially the brain, to recharge and restore vital chemicals and *functioning*. It provides the necessary power to support all of the following areas:

- Alertness
- Energy
- Mood
- Body weight
- Perception
- Memory
- Thinking
- Reaction time
- Productivity
- Performance
- Communication skills
- Creativity
- Safety
- Good health
- Long life

Sleep is exceptionally important for individuals with PD. In addition to the daily needs of life and living, they must also cope with a chronic and often disabling disease. Without the proper amount of sleep, PD patients become vulnerable to worsening of *symptoms*, general ailments and mental health complications. Unfortunately, sleep disturbances are quite common in PD and can be challenging to manage. Patients and bed partners often report the following sleep problems:

- Inability to fall asleep
- Inability to stay asleep
- Inability to turn in bed and/or adjust bed sheets
- *Vivid dreaming* and/or *hallucinations* at night
- Acting out dreams and/or calling out during sleep

- Leg jerks during sleep
- Leg discomfort and/or pain before sleep
- *Non-restorative sleep*
- Excessive daytime sleepiness

In this chapter, we will provide a symptom-based approach that will help readers gain a better understanding of sleep changes often experienced with PD. We will also provide overviews of primary sleep conditions that are occasionally diagnosed in PD patients but are not necessarily related to PD itself. Sleep hygiene tips will also be provided at the end of this chapter so that better sleep can start tonight!

A Symptom-Based Approach to Sleep Disorders in Patients With Parkinson Disease

In the boxes to follow, we will review the four major categories of sleep complications that commonly occur with PD:

- Insomnia
- Excessive daytime sleepiness
- Excessive *motor* activity at night
- Nocturnal hallucinations/behavior problems.

Within each category, we will discuss the possible causes of that symptom as they relate to general sleep disorders, PD, medications, depression, and other factors.

Insomnia

If you answer “yes” to any of the following questions, you should read the material in this section to better understand the possible causes of insomnia.

- *Do you have trouble falling and staying asleep?*
- *Do you wake up repeatedly during the night and struggle to fall back to sleep?*
- ❖ **Sleep Disorders:** The following sleep disorders can cause insomnia in PD: *restless legs syndrome, periodic limb movements of sleep, psychophysiologic insomnia*, the sleep phase syndromes, *central sleep apnea syndrome*, and rarely *obstructive sleep apnea syndrome*. In the *advanced sleep phase syndrome*, patients struggle to stay asleep in the morning. Difficulty falling asleep at night is typical of *delayed sleep phase syndrome*.
- ❖ **Medications:** The following medications can cause insomnia: amantadine (Symmetrel ®), selegiline (Eldepryl ®), stimulant medications, and rarely carbidopa/levodopa (Sinemet ®) and *dopamine agonists*. More and more patients with PD are being treated with the cholinesterase inhibitors like donepezil (Aricept ®), rivastigmine (Exelon ®), and galantamine (Reminyl ®) for managing memory problems or hallucinations, and all of these can cause insomnia. Insomnia can occasionally result from use of the antidepressant medications fluoxetine (Prozac ®), bupropion (Wellbutrin ®), or venlafaxine (Effexor ®).
- ❖ **Depression:** Depression and anxiety are common causes of insomnia, especially in PD, and are usually associated with difficulty staying asleep from roughly 3 am onward (also known as “early morning awakening”).
- ❖ **Other:** Due to decreased mobility in bed, patients with PD can become uncomfortable and may be unable to change position in bed. A low dose of long-acting carbidopa/levodopa (Sinemet CR ®) before bedtime or in the middle of the night can improve mobility and comfort, thus reducing insomnia.

Nighttime Hallucinations/Behavior Problems

If you answer “yes” to any of the following questions, you should read the material in this section to better understand the possible causes of nocturnal *hallucinations* and behavior problems.

- Do you see objects, animals, or people in the home or outside the window that others don't see, especially at night?
- Does your bedpartner or family note that you become irritable or agitated in the late afternoon, evening, or night?
- ❖ ***Sleep Disorders.*** In PD, the vivid nightmares of *REM sleep behavior disorder* (RBD) may be misinterpreted as hallucinations. It is important to note that vivid dreaming occurs during sleep and hallucinations occur while awake. Violent limb activity of RBD may also be interpreted as agitation.
- ❖ ***Medications.*** Many medications can cause hallucinations or agitation, including carbidopa/levodopa (Sinemet ®), dopamine agonists, amantadine (Symmetrel ®), selegiline (Eldepryl ®), trihexyphenidyl (Artane ®), benztropine (Cogentin ®), tricyclic antidepressants such as amitriptyline (Elavil ®), *benzodiazepines* such as lorazepam (Ativan ®), and cholinesterase inhibitors such as donepezil (Aricept ®).
- ❖ ***Depression.*** These symptoms can occasionally be associated with severe depression known as “agitated depression” or “psychotic depression”. Antidepressant medications and, in severe cases, *electroconvulsive therapy* can greatly improve these symptoms in many patients.
- ❖ ***Other.*** There are several other issues one must consider in a patient with PD who develops nighttime hallucinations or behavior problems. Medical conditions such as a urinary tract infection, pneumonia or pain from a variety of causes should be evaluated. Hallucinations and behavior problems are also common in patients with PD who develop *dementia*. Caregivers of patients with PD and dementia often describe hallucinations or behavior problems developing or increasing during the late afternoon or evening hours. This is referred to as “*sundowning*”, which appropriately describes confused behavior once the sun goes down. Patients and their families should work with knowledgeable clinicians to determine the cause of hallucinations and agitation and determine the most appropriate treatment.

Excessive Daytime Sleepiness

If you answer “yes” to any of the following questions, you should read the material in this section to better understand the possible causes of excessive daytime sleepiness (EDS).

- *Do you feel unrefreshed when you wake up in the morning?*
- *Do you have trouble staying awake during the day in situations such as when you are reading, riding in a car, sitting in a quiet room, while watching TV?*
- *Do others who know you well consider you sleepy?*

- ❖ ***Sleep Disorders:*** The following sleep disorders can cause EDS in PD: obstructive sleep apnea, central sleep apnea syndrome, restless legs syndrome, periodic limb movements in sleep, narcolepsy-like conditions, and the sleep phase syndromes.

- ❖ ***Medications:*** While carbidopa/levodopa (Sinemet ®) clearly improves motor symptoms in patients with PD, EDS is a fairly common symptom with this medication. Patients must often reduce the dose of carbidopa/levodopa (Sinemet ®) to find a balance between the beneficial effects and EDS. A rare but worrisome side effect of the dopamine agonists, such as pramipexole (Mirapex ®) and ropinirole (Requip ®), is EDS which sometimes comes on abruptly. Many of the medications used at night for various problems can cause sleepiness in the morning, particularly when used at high doses. These include trazodone (Desyrel ®), clonazepam (Klonopin ®), mirtazapine (Remeron ®), quetiapine (Seroquel ®), and clozapine (Clozaril ®).

- ❖ ***Depression:*** EDS can be a symptom of depression. Some antidepressant medications are thought to have stimulating properties and may therefore be helpful if EDS is thought to be a manifestation of depression. Such antidepressant medications include fluoxetine (Prozac ®), bupropion (Wellbutrin ®), and venlafaxine (Effexor ®).

Excessive Movement During Sleep

If you answer “yes” to any of the following questions, you should read the material in this section to better understand the possible causes of excessive movement during sleep.

- *Do you or your bedpartner notice that your legs jerk spontaneously at night?*
 - *Do you frequently experience nightmares with a chasing or attacking theme?*
 - *Have you been told that you act out your dreams, screaming, punching or kicking?*
 - *Have you or your bedpartner ever been injured while you “act out your dreams?”*
- ❖ ***Sleep Disorders:*** Primary sleep disorders that have features of excessive movements during sleep include obstructive sleep apnea (activity is related to the frequent snorts, gasps, and turning in bed), periodic limb movements of sleep (PLMS) and REM sleep behavior disorder (RBD).
- ❖ ***Medications:*** Parkinson medications are usually effective for PLMS and can both improve or worsen RBD. Some antidepressant medications, such as venlafaxine (Effexor ®) and mirtazapine (Remeron ®), have been known to cause or worsen RBD. The effects of *dopaminergic medications* and cholinesterase inhibitors on RBD is controversial.
- ❖ ***Depression:*** Depression rarely causes or contributes to excessive motor activity at night.

Overview of Common Sleep Disorders

The following section will provide an overview of general sleep disorders that are often experienced by individuals with PD. It is not thought that these disorders are directly related to PD but are coexisting problems that can complicate proper care and treatment.

Obstructive Sleep Apnea Syndrome (OSA)

Causes: Normally during sleep, the back of the throat (*oropharynx*) remains open, so that there is no restriction to airflow or *snoring*. However, when the oropharynx is small and/or crowded, its walls can become sucked together during sleep and cause obstructive sleep apnea syndrome. When the walls of the oropharynx are sucked together too much, air turbulence results and produces snoring. (Although many people believe snoring is caused by obstruction in your nose, it is most frequently due to problems in your throat). If the walls of the throat are sucked together completely, air cannot pass through and breathing is interrupted.

When a person stops breathing for a period of time, it is known as an *apneic event* or *apnea*. You can think of this process as if you are sucking through a wet paper straw; as the walls of the straw are pulled together, you are less able to suck air out. During an apneic event, a person continues to try to breathe, however the obstruction in the throat stops air from entering the lungs and the oxygen level in the bloodstream progressively drops. The brain responds by temporarily waking the person (which is called an *arousal*), resulting in the throat opening and return of airflow into and out of the lungs. The person appears to choke or gasp with a loud snort when this occurs. Within seconds, the person falls back to sleep, and the cycle begins again with soft snoring, then louder snoring, then an apneic pause, and then the snort and arousal. This process can occur dozens or hundreds of times per night but are rarely recalled by the individual.

The term OSA can thus be explained by *obstructive* (referring to the restriction of airflow in the throat) *sleep* (referring to the state when this occurs) and *apnea* (referring to the disrupted breathing episodes). OSA can be described as “positional” and “non-positional”. *Positional OSA* refers to the presence of symptoms only when sleeping on one’s back. OSA is almost always worse in this position, since this results in the back of the tongue sagging downward from gravity. *Non-positional OSA* refers to the presence of OSA when sleeping in any position.

Repeated arousals caused by OSA do not allow enough deep sleep for the brain to feel alert and sharp during the day. This explains why people with OSA feel that they sleep well and often deny that they even snore. However, they usually do not feel rested when they wake up in the morning and are often sleepy during the day.

Disrupted breathing during sleep can also be seen with a disorder known as *upper airway resistance syndrome (UARS)*. This disorder is basically like OSA except without apneic events. Arousals also occur but are caused strictly by loud snoring. Most people with UARS are sleepy during the day, which is why they seek treatment.

Risk factors: Risk factors for OSA include increasing age, male gender (although OSA is also common in women), a narrow oropharynx from birth, large tonsils and obesity with excess tissue in the neck. The risk of OSA rises as a person's collar size increases. Those with collar sizes above 17 are especially at risk for OSA. It is not clear if patients with PD have a higher risk of OSA in general, but the rigidity and slowness of movement can make it difficult for patients to change positions during sleep. This can be particularly troublesome for those with positional OSA, since turning over from the back to the side can be difficult.

Symptoms/Manifestations/Problem: The main symptoms related to OSA are loud disruptive snoring, snorts and gasps while sleeping and sleepiness during the day, which is known as excessive daytime sleepiness (EDS). Many patients experience some degree of forgetfulness and depression related to OSA. Untreated OSA clearly affects daily functioning and increases the risk of heart disease and stroke. Proper treatment of this disorder can improve thinking, mood and quality of life. Treatment also allows better sleep for bedpartners, who commonly become anxious and concerned from apneic episodes.

Diagnosis: Patients who experience such symptoms should be evaluated by a physician trained in sleep medicine and undergo a *polysomnogram (PSG)*, otherwise known as a "*sleep study*."

Treatment Options: The most effective way to treat OSA for many patients is nasal *continuous positive airway pressure (CPAP)*. This small device (a little larger than a telephone) is connected by a long tube to either a mask that is worn over the nose or soft tubes inside the nostrils. It takes room air and pressurizes it so that it acts like an air splint and keeps the oropharynx open during sleep. If the pressure of air is set properly and the patient tolerates using CPAP, it is 100% effective at eliminating snoring and OSA. While most patients are not overly enthusiastic about using CPAP initially, they soon report better sleep at night, feeling more rested in the morning and being more alert during the day.

Other options for treating OSA include an *oral appliance* and surgery to the back of the throat. An oral appliance is a small device that is placed inside the mouth and keeps the jaw gently pulled forward. The base of the tongue is therefore also pulled forward, which can lessen snoring and OSA. This form of treatment is successful for some OSA patients who find it effective and tolerable. Surgical options include tonsillectomy, *uvulopalatopharyngoplasty (UPPP)* and *radiofrequency ablation (RFA)*. Tonsillectomy can be successful if large tonsils are present. UPPP involves surgery to the oropharynx, in which tonsillar tissue is removed and the back of the roof of the mouth is trimmed off. The trimming involves removal of the uvula, which is the small piece of tissue that hangs down

in the back of the throat. UPPP is effective in approximately half of the patients who undergo this procedure. RFA involves a procedure in which a probe is placed in the back of the tongue and radiofrequency waves shrink the tissue. While this may be effective for stopping snoring, it is not usually helpful in treating OSA. These surgical options are usually reserved for those patients who cannot tolerate using CPAP.

For those patients who have positional OSA, another form of treatment known as positional therapy (otherwise known as the “tennis balls-in-a-T-shirt technique”) can be effective. Patients can either purchase specially made T-shirts with a pocket in the back, or make one by sewing an old sock or a long sleeve to the middle of the back of a T-shirt. Patients then place 4 or 5 tennis balls in the pocket in the back, which effectively keeps them from sleeping comfortably on their back. While many individuals chuckle at the thought of this type of therapy, it is far cheaper and sometimes easier to use than CPAP. If positional therapy is not effective, CPAP can be prescribed.



Key Point: Excessive daytime sleepiness in PD can be due to a primary sleep disorder, such as sleep apnea, as well as a side effects of anti-PD medications.

Central Sleep Apnea

Causes: Central sleep apnea (CSA) refers to apnea that occurs unrelated to any obstruction in the back of the throat, but rather due to either brain or heart dysfunction. A patient with CSA will have a waxing and waning type of breathing with intermittent periods of deep breathing, shallow breathing and apnea. The cycle between these three types of breathing occurs over and over again. Most patients arouse momentarily during the deep breathing phase of CSA. These repeated arousals can cause insomnia as well as excessive daytime sleepiness (EDS). Since PD is a disorder of the brain, CSA can occasionally occur. CSA can also be related to significant heart dysfunction such as congestive heart failure. Some patients have both OSA and CSA.

Risk Factors: The primary risk factors for CSA are a disorder of the brain and/or a disorder of the heart.

Symptoms/Manifestations/Problems: Patients with CSA can experience insomnia, excessive daytime sleepiness, or both. In some patients, EDS is profound.

Diagnosis: Patients who have the symptoms noted above should be evaluated by a physician trained in sleep medicine and undergo a polysomnogram (PSG).

Treatment Options: The evaluation and treatment of CSA can be challenging. While some patients may benefit from CPAP, other forms of therapy may be necessary such as oxygen, medications, a device similar to CPAP known

as bi-level positive airway pressure, or a combination of these. In some patients, two nights of PSG may be necessary to adequately try these different forms of therapy.



Key Point: It is important to discuss all sleep changes with your clinician. If necessary, sleep studies can be ordered to better determine the cause of such changes.

Restless Legs Syndrome

Causes: Restless legs syndrome (RLS) is a common sleep disorder that is seen in many patients with PD. Typical symptoms include an irresistible urge to move the legs that is usually accompanied by a creepy-crawly, nervous or uncomfortable feeling or pain in the legs. These symptoms occur at rest, primarily at night. Movement of the legs tends to temporarily relieve the uncomfortable sensation, but symptoms soon return. These symptoms can also be present in the day, particularly when riding in a car for an extended period of time or when traveling by air. RLS often runs in families. Some patients go through life unaware that their symptoms are due to a treatable disorder. RLS can be classified as either *idiopathic*, meaning that there may be a family history but no other found cause, or secondary, meaning that it is related to another medical disorder.

Although the precise cause of RLS is not yet known, there is evidence that the brain chemical known as *dopamine* and iron metabolism are involved. RLS can be particularly troublesome in patients who have iron deficiency. In any patient whose RLS symptoms are difficult to treat, or if there has been recent surgery or loss of blood from a stomach ulcer or lesion in the large intestine, it is important to have a *ferritin* level checked. Ferritin reflects the amount of iron stored in the body, which can be measured by a blood test.

Risk Factors: The primary risk factors for RLS include family history and iron deficiency. Other factors include kidney failure and disorders that affect the spinal cord and/or nerves to the legs.

Symptoms/Manifestations/Problems: The main features of RLS include an urge to move the legs usually accompanied by creepy-crawly, nervous or uncomfortable feeling or pain in the legs. These symptoms occur while at rest and are temporarily relieved by moving the legs or walking. There is a tendency for symptoms to occur primarily at night. Patients with severe RLS may also experience symptoms during the day and may report symptoms in their arms as well as the legs.

Diagnosis: The diagnosis of RLS is based on reported symptoms and/or a sleep study. Individuals who experience such symptoms should seek an evaluation with a physician knowledgeable in the diagnosis and management of

RLS. Most neurologists and sleep medicine specialists are well trained in RLS diagnosis and treatment.

Treatment Options: For the vast majority of patients with RLS, their symptoms are treatable. The first issue is determining whether a patient has an idiopathic or secondary form of RLS. There are four classes of medications that can be effective for RLS. These include drugs that affect dopamine such as carbidopa/levodopa (Sinemet ®), pramipexole (Mirapex ®) or ropinirole (Requip ®), certain benzodiazepine type sleeping tablets such as temazepam (Restoril ®) or clonazepam (Klonopin ®), certain anti-seizure medications such as gabapentin (Neurontin ®), and opiate analgesics such as codeine, propoxyphene (Darvon ®), or oxycodone (Oxycontin ®). All of these are prescription drugs and some can be habit-forming. Therefore, use of medications must be monitored closely by a physician.

Carbidopa/levodopa (Sinemet ®) before bed may initially relieve RLS, but in many patients the symptoms return during the day. Additional doses of the drug earlier in the day can worsen the problem. This phenomenon is known as augmentation. As you can imagine, augmentation can be a serious problem in those patients with RLS and PD who are treated with large doses of carbidopa/levodopa (Sinemet ®) for their motor symptoms. Management is difficult and may involve changing from carbidopa/levodopa (Sinemet ®) to a dopamine agonist or the addition of other medications for RLS such as gabapentin or an opiate analgesic.



Key Point: Restless leg syndrome is commonly reported in patients with PD and is often treated with dopamine agonists, such as Pramipexole (Mirapex ®) and Ropinirole (Requip ®).

Periodic Limb Movements of Sleep

Causes: Periodic limb movements of sleep (PLMS) refers to leg jerks that occur during sleep. These jerks tend to occur in a rhythmic fashion, usually every 15-90 seconds. Many, but not all, patients with RLS also experience these symptoms. PLMS is quite common in patients with PD as well as healthy older adults. The same disorders that cause RLS (such as iron deficiency or kidney failure) can cause or contribute to PLMS.

Risk Factors: Risk factors are the same as RLS including family history, iron deficiency, kidney failure and disorders that affect the spinal cord and/or nerves to the legs.

Symptoms/Manifestations/Problems: The primary feature of PLMS is the periodic limb jerks during sleep. Although similar jerks can occur during wakefulness, which patients can easily identify, they are obviously unaware of the jerks during sleep. Therefore, PLMS symptoms are usually

observed by their bedpartners. Some bedpartners have counted how many seconds occur between each jerk, which is remarkably consistent for each individual. Surprisingly the jerks do not usually cause significant arousals from sleep and are rarely a cause of insomnia or EDS. However, they can be very disturbing to a bedpartner

Diagnosis: Unlike RLS, which is purely based on a patient's symptoms, the diagnosis of PLMS is based on the findings obtained during a sleep study. Importantly, those patients who have frequent jerks but few arousals do not require any treatment. For the occasional patient who does experience frequent arousals with insomnia or excessive daytime sleepiness, treatment is appropriate.

Treatment Options: The same medications used for RLS can be effective for PLMS.



Key Point: Periodic limb movements are often confused with a tremor of the leg(s). Periodic limb movements are jerks that occur during sleep. PD resting tremor is more of a rhythmic movement that should always cease during sleep.

REM Sleep Behavior Disorder

Causes: REM sleep behavior disorder (RBD) is a sleep disorder in which individuals seem to “act out their dreams.” This disorder tends to affect older men, although both genders at almost any age can develop RBD. Most individuals with RBD experience unpleasant dreams, often with chasing or attacking themes. This can result in injuries to themselves and/or their bedpartners. RBD is quite common in patients with PD; in fact, many patients develop RBD years or decades before any other symptom of PD appears.

Humans and most animals in the world exist in three “states of being”—wakefulness, rapid eye movement (REM) sleep, and non-rapid eye movement (NREM) sleep. Most dreaming occurs in REM sleep. Normally in REM sleep, certain circuits in the brain are activated so that almost all muscles in the body are paralyzed except for those that move the eyes, a small muscle in the ear, and the diaphragm. The diaphragm is the large muscle just below the lungs that allows one to breathe during wakefulness and sleep. Soft sounds from the mouth and small jerks of some muscles tend to occur normally in REM sleep. However, shouting, screaming and more complex movements of the arms and legs do not. When the circuits in the brain that control muscle *paralysis* are affected by a *neurological* disorder, patients become able to scream, swear and flail their limbs during sleep.

Risk Factors: Male gender and particularly PD are risk factors for RBD.

Symptoms/Manifestations/Problem: The primary concern with RBD is the potential for injury to the patient and bedpartner. The dreams often

have a chasing or attacking theme, with the person defending against assaults. When the individual is awakened, the description of the dream tends to match the behaviors that have occurred. Since most REM sleep tends to occur in the latter half of the sleep period (i.e., after 12 midnight), RBD most often occurs during the early morning hours. However, behaviors can happen at any time of the night, sometimes twice or more in the same night. Bruises, skin abrasions, fractured bones, and even blood clots in or near the brain can occur from violent movements during sleep. Bedpartners can also be seriously injured with punches and kicks. It is therefore important for patients to be evaluated and treated if RBD is suspected.

Diagnosis: While the diagnosis of RBD is often obvious from the patient's report, a sleep study is usually needed to confirm the diagnosis. Normally during REM sleep, there is little or no muscle activity observed during a sleep study. However, individuals with RBD typically demonstrate increased muscle tone and even dream enactment behavior. Patients with OSA can have symptoms similar to those with RBD however, treatment for these two disorders are very different. A polysomnogram (PSG) is therefore very important to ensure that patients are properly diagnosed and treated.

Treatment Options: All patients and their bedpartners should take measures to minimize the potential for injury. Simple examples can include placing foam padding on the floor next to the bed, placing foam padding on the headboard, and either moving furniture with sharp edges away from the bed or cover the edges with padding. Some spouses choose to sleep in separate beds, which is unfortunate but sometimes necessary.

Certain medications can be used to minimize unpleasant dreams and reduce the potential for injury. The medication clonazepam (Klonopin ®) has been the most effective agent and individuals generally tolerate this medication with no significant side effects. However, in older persons, impaired balance, daytime sleepiness and sexual dysfunction may occur. Melatonin is also another effective option. Many other medications have been tried for RBD but the response has been quite variable.



Key Point: Safety is a major concern for patients who experience RBD symptoms and their bed partners. Violent movements, such as punches and kicks, often lead to serious injury.

Narcolepsy-Like Conditions

Causes: *Narcolepsy* refers to a disorder of the brain in which patients have difficulty staying awake during the day. Most patients with narcolepsy begin experiencing symptoms as a child or teenager. While the precise cause of narcolepsy is not yet known, a lack of a brain chemical known as *hypocretin* has recently been identified as a key factor. Although narcolepsy itself is not related

to PD, it has recently been observed that some patients with PD develop narcoleptic-like symptoms. It may be very difficult to distinguish this from sleepiness due to medications. Medications used for typical narcolepsy may therefore be effective for patients with PD and related sleepiness.

Risk Factors: Narcolepsy-like sleepiness appears to be more common in Parkinson patients with advancing disease, dementia or hallucinations.

Symptoms/Manifestations/Problem: The four main symptoms of typical narcolepsy are excessive daytime sleepiness (EDS), *cataplexy* (sudden attacks of muscle weakness, triggered by laughter or other *emotions*), *sleep paralysis* (the inability to move for seconds or minutes upon awakening or falling to sleep), and *hypnagogic or hypnopompic hallucinations* (dream imagery that occurs before falling sleep (hypnagogic) or right after waking from sleep (hypnopompic)). Cataplexy does not generally occur in the narcoleptic-like sleep disorder described in PD.

Diagnosis: The diagnosis of narcolepsy is usually based on an overnight polysomnogram (PSG) followed by a nap study the next day. The nap study is known as the Multiple Sleep Latency Test (MSLT), in which patients are given four or five nap opportunities during the day. Falling asleep quickly on the MSLT is a characteristic of narcolepsy. The diagnosis of narcolepsy is established if one goes into REM sleep during two or more of the naps. Although this test is sometimes performed in sleepy patients with PD, often the diagnosis of a narcolepsy-like syndrome is made by a physician experienced in this area without further testing.

Treatment Options: Many patients with narcolepsy experience a benefit from scheduled naps during the day. The mainstay of treatment of daytime sleepiness in narcolepsy is stimulant medications, including modafinil (Provigil ®) and methylphenidate (Ritalin ®). These medications are used in selected sleepy patients with PD.



Key Point: Patients who experience narcolepsy or narcoleptic-like symptoms should not operate motor vehicles unless properly managed with medications.

Psychophysiologic Insomnia and Inadequate Sleep Hygiene

Causes: Psychophysiologic insomnia refers to the tendency for past experiences to impair the ability to fall and stay asleep. Current stressors, *anxiety* and depression may worsen this problem. Behaviors such as consuming caffeinated beverages or chocolates in the afternoon or evening, smoking or consuming alcohol late in the day, and watching the clock during the night are all examples of *inadequate sleep hygiene*. Since psychophysiologic insomnia and inadequate sleep hygiene are so common in the normal population, many patients with PD experience these problems as well.

Risk Factors: Psychophysiologic insomnia is particularly common among those who are anxious and worry excessively.

Symptoms/Manifestations/Problems: The primary symptom of psychophysiologic insomnia and inadequate sleep hygiene is difficulty falling and staying asleep. Patients with psychophysiologic insomnia also tend to worry in bed and often remark “it is hard for my brain to slow down or rest at night.”

Diagnosis: The diagnosis of these sleep disorders are based on the patient’s symptoms and lifestyle habits.

Treatment Options: Cognitive therapy, behavior modification, relaxation techniques and if necessary, medications can be effective for patients with psychophysiologic insomnia. For those with inadequate sleep hygiene, lifestyle changes are vital. These can include restricting caffeine to only the morning hours, refraining from using tobacco and alcohol, and removing the clock from the bedside. These tips and others are outlined in the sleep hygiene table at the end of this chapter. Several excellent self-help books have been developed for managing insomnia, with our preference being, “No More Sleepless Nights” by Peter Hauri, PhD, and Shirley Linde, PhD.



Key Point: Depression and anxiety can cause serious impairment to one’s sleep. It is important to identify and treat mental health issues so that proper sleep can be resumed.

Advanced and Delayed Sleep Phase Syndromes

Causes: Advanced and delayed sleep phase syndrome, also known as *circadian dysrhythmias*, refer to shifts in the *biological* time clock. This shift can cause sleep to occur during an earlier time in the evening (advanced sleep phase syndrome) or later time in the night (delayed sleep phase syndrome). Since phase shift disorders are common amongst the general population, patients with PD may experience them as well.

Risk Factors: There appears to be a *genetic* tendency for individuals to be either a “night owl” or “early riser.” Advancing age is clearly a risk factor for advanced sleep phase syndrome.

Symptoms/Manifestations/Problems: In advanced sleep phase syndrome, patients struggle to remain awake in the evening and tend to retire to bed between 4-8 pm. They tend to awaken, often feeling refreshed and unable to fall back to sleep, between 1-5 am. Patients with delayed sleep phase syndrome often describe the inability to fall asleep until 1-5 am, and are unable to awaken and feel refreshed until at least 9 am - 1 pm.

Diagnosis: The diagnosis can often be made simply by a consistent tendency to fall asleep too early or too late. Sleep physicians often obtain support for these disorders by having patients complete sleep logs or wear a wrist actigraph. An actigraph, a small device that is worn like a wristwatch, records movement throughout the day and night. The abrupt cessation of movement typically corresponds with the onset of sleep, and the abrupt return of movement typically corresponds with the onset of wakefulness.

Treatment Options: Treatment can be challenging, and patients are often best served by working with a sleep medicine specialist. Bright light therapy, melatonin, sedative/hypnotics, or a combination of these can be effective.



Key Point: Going to bed at the same time every night and waking up the same time every morning can assist in getting adequate and restful sleep at night.

Conclusion

Sleep plays a vital role in maintaining mental health and performance for all human beings. It is especially important for individuals with PD, who require significant levels of energy to function at their greatest ability. Sleep disorders can be directly related to both PD and mental health disorders. It is pertinent that all sleep changes be brought to your clinician's attention for proper assessment and possible treatment.

Sleep Hygiene: Rules for Better Sleep

Daytime Tips

1. Wake up the same time everyday. Set an alarm if you have to.
2. Get out of bed right after you wake up. Too much time spent in bed can lead to more waking up at night.
3. Limit daytime naps. They can make sleep at night more difficult.
4. Eat regular, healthy meals. Eat at the same time every day. Three to four small meals are better than 1-2 large meals.
5. Do not drink coffee, tea, sodas or cocoa after noon. They contain caffeine and can interfere with normal sleep.
6. Do not drink alcohol after dinner. It may help you fall asleep faster, but makes sleep shallower later in the night. Alcohol can also make snoring and sleep apnea worse.
7. Use caution when taking headache and cold medicines. Some contain stimulants that can affect sleep.
8. Stop smoking. Cigarette smoking stimulates the body and makes sleep difficult.
9. Increase or start doing daily exercise. Regular exercise helps to deepen sleep. The best time to exercise is early in the morning. Avoid heavy exercise 2 hours before bedtime.

Nighttime Tips

1. Get into bed only when you are sleepy.
2. Do not use over-the-counter sleeping medications. They may help you to fall asleep faster, but they do not help you to get deeper sleep. They can also make snoring and sleep apnea worse.
3. Develop a sleep ritual. Do something relaxing before bed such as reading or listening to music. This tells your body that it is time to settle down.
4. A warm shower or bath an hour before bedtime can help you to fall asleep.
5. If you tend to worry about things while lying in bed, make an effort to do your worrying outside of bed. Before going to the bedroom, make a list of things to deal with tomorrow.
6. If you are hungry at bedtime, eat a small snack or drink a glass of milk. Do not eat sugary snacks or chocolate or drink tea or coffee. Large meals before bedtime can worsen sleep.
7. Use your bed only for sleep or sexual activity. Do not do anything else in bed such as reading, watching TV, arguing, catching up on work, smoking, etc.
8. Keep the bedroom dark and the temperature comfortable.
9. Block out noise as much as possible. Occasional loud noises disturb sleep even in people who cannot remember them in the morning. The hum of a fan can help cover up some noise.
10. Do not watch the clock and worry about lost sleep. Turn the clock face away.
11. Do not try to force sleep. If you cannot fall asleep, get out of bed, move to another room and watch TV, Read, or listen to soothing music until you are sleepy. Go back to bed. If you are still unable to sleep, get out of bed again and repeat the cycle until you are able to sleep.

About the Authors



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Chapter 7

Mental Health Tips for the Caregiver

Written by: Lisette Bunting Perry, RN, MScN

I AM A CAREGIVER

Thoughts by Phyllis, caregiver in Philadelphia, Pennsylvania

Where am I?
Where did I go?
What happened to me?
I am a Caregiver
That's who and what I am
Non-stop 24-7
A Caregiver
Get my meds
I need a drink
What's for lunch?
I had an accident
Oh well, more laundry, then when the kids were toddlers...
What time is dinner?
You just finished lunch
Where is me – lost for now
I am a Caregiver
Lunch with Jeanne – not today
Can't go anywhere
The collar & the rope are fastened to my very being
I feel the noose around my neck
Yes, I am a caregiver
What did I do to deserve this constant pressure & responsibility?
What did he do to deserve Parkinson's Disease???
My children & grandchildren are the oxygen that allow my soul to breath and go on
But, is it the Parkinson's?
Lash out, lash out
One bash to the head
You're stupid & don't understand
You have no compassion
You need classes to learn
My mouth is silent
His is raging
On & on and on
You don't listen
You don't understand
No, I don't understand
Life isn't fair
Nastiness is spewing out of your mouth
Like an erupting volcano
Another bash to the other side of the head
My very being is in pain
Where is your compassion?
I give my all and then give more
Another sleepless night
The exhaustion is physical
The mental tired is most draining
Another blow to the head
The tone of voice & words are so hurtful
It's not fair
I realize now it doesn't have to be

Caregiver Distress in Parkinson Disease

In her poem, *I am A Caregiver*, Phyllis shares with us her emotional life as a caregiver. Phyllis cares for her husband who has had PD for 10 years. They remain committed to each other through their 44 years of marriage.

The demands, complaints and verbal abuse Phyllis experiences in the caregiver role are evident in her words. The reader can sense the *anxiety* and despair experienced by her husband and his unrealistic fear of abandonment. Phyllis shares with us her caregiving experience by writing “the collar & the rope are fastened to my very being”. However, she reminds us that her strength comes through her commitment to family when she writes “my children & grandchildren are the oxygen that allow my soul to breath and go on.”

Like many caregivers, Phyllis has found the *non-motor symptoms* of *Parkinson disease* (PD) to be more disturbing to the caregiving relationship than the *motor symptoms*. In the previous chapters, non-motor symptoms of *depression*, anxiety, *psychosis*, *dementia* and sleep disturbances have been skillfully described for you.



Key Point: *Non-motor fluctuations* of PD, such as depression and anxiety, are often more disturbing to the patient and caregiver than motor symptoms, such as walking difficulties and tremor.

Role of the Caregiver

Throughout our lives we work, spend time with family and friends and enjoy hobbies. The new role of “caregiver” brings along the responsibility of 24-hour care. This can often lead to isolation and a feeling of loss. How can caregivers successfully balance caregiving responsibilities while meeting their own personal needs?

The medical literature provides us with numerous studies of *caregiver burden* and caregiver distress. It tells us the following about caregiving for patients with PD:

- The majority of caregivers are spouses-primarily wives
- Most caregivers care for PD patients in the home
- Caregivers experience high levels of depression
- Caregiver stress increases with progression of PD motor symptoms
- Caregivers report fatigue, sadness and less satisfaction with life
- Caregiver depression is predicted by the severity of psychiatric symptoms in the PD patient
- *Delusions* and agitation contribute to emotional distress in caregivers

Unfortunately these studies are of little help to you without specific suggestions as to how to manage the caregiver role and reduce related stress. It is of no surprise that the non-motor symptoms of PD, such as delusions and agitation, are reported to be the most debilitating and difficult symptoms to manage as a caregiver. Identification and treatment of *mental health* changes in PD are of significant clinical importance for reducing caregiver burden. This, in turn, increases the likelihood that the caregiver will successfully maintain the PD patient in the community.

Patients and family members commonly view the psychiatric symptoms of PD as personal weaknesses. They have often stated, “I just need to pull myself up by the boot straps.” In addition, many patients and family members are not willing to share their loved one’s problems of *hallucinations*, sadness, despair, or anxiety with healthcare professionals due to feelings of embarrassment. This is especially true if the PD patient is expressing sexual thoughts that are not real and are focused towards a family member. These types of thoughts are not uncommon in PD and reflect symptoms that can be successfully treated.



Key Point: Immediately report all mental health changes to the clinician. This not only allows for appropriate treatment but, reduces caregiver burden.

Your Health Care Team

You, as a caregiver, are part of the healthcare team. The first step in coping with the psychiatric non-motor symptoms of PD is to inform clinicians of symptoms that are not evident during brief office visits. In sharing your concerns with the healthcare team, a solution is often found to treat the symptoms and reduce the burden of care.

You can also be active in learning about PD and available therapies to treat both motor and non-motor symptoms. Treatment of PD is becoming more complicated with multiple classes of medications and new surgical therapies. It is helpful to find an experienced team of professionals who are specialized in the field of movement disorders. An experienced healthcare team of physicians, nurses, social workers, *occupational therapists*, physical therapists, pharmacists, psychologists and *speech –language pathologists* will support you in your role of caregiver.

Make the most of the time you have with healthcare providers by being active during office visits. This will increase the quality of care provided to the PD patient and can reduce the amount of time you spend managing care. The following are suggestions for working with your treatment team:

- Make a list of healthcare concerns and focus on the most troublesome symptoms.
- Bring a list of all current medications to every appointment.
- Keep a history of medications that have been tried and discontinued. For example, some patients have experienced hallucinations on *dopamine agonists*, such as Mirapex. This is important information and can prevent a similar drug from being prescribed.
- Make a copy of current medications for your healthcare provider to place in the medical record.
- Make of list of medications that need to be refilled before the next visit.
- Be familiar with generic and trade names of all medications being prescribed. Your pharmacist can help you develop this list.
- Check with your pharmacy plan to see if they will fill a prescription for a 90-day supply of medication. This will reduce time and effort in obtaining new prescriptions and reduce the likelihood of running out of a drug before the next refill is available.
- If your healthcare provider increased the number of tablets to be taken in a day, request a new prescription.
- Call before a problem becomes a crisis. Most healthcare providers would rather receive a phone call than see you take a trip to the emergency room.
- Make a list of all healthcare providers involved in the care of the PD patient and give each healthcare provider a copy of the list. This will assist with coordination of care.
- Be prompt to clinic appointments.
- Please do not cancel at the last minute. Other patients are on a waiting list to be seen.
- Use phone calls to focus on a specific problem, be brief.



Key Point: As the caregiver, you are a vital member of the healthcare team.

Taking Care of You

Life as a caregiver is difficult. The only way you can continue to be a caregiver is by taking care of yourself. Many spouses express guilt over the thought of not providing 24-hour care for an ill partner. However, many caregivers do not recognize the benefits of a break, which can renew their strength and commitment.

There are several ways to provide care for a family member while you take a much-deserved break. The break from care does not need to be a week or several days. It can be accomplished in taking several hours a day to run errands or have lunch with friends. The following are examples of ways to arrange care:

- Arrange for in-home care from a licensed and bonded home care agency.
- Have a relative or friend come stay with your loved one while you are away.
- Use respite care services offered by community nursing homes.
- Have your loved one attend an adult day care center several days a week.

The cost of respite care should not be a limiting factor in your decision to pursue care for your family member. Many private, public and government agencies provide funding for respite care. Most medical centers within the Department of Veterans Affairs will provide up to 4 weeks a year of respite care services for qualified veterans. Check with your local Alzheimer's Association for funding for respite care. The Alzheimer's Association's web site offers excellent resources. The web site can be found at the end of this article.



Key Point: Caregiving breaks are essential. Make use of available resources that can assist in caring for your loved one while you take time for yourself!

Improving Communication

Providing direct care to a family member with PD can change the way family members relate to each other. The strain of lost goals, diminished job opportunities and added responsibilities can result in worry, tension and frustration. The importance of good communication is essential for effective caregiving. Keeping the PD patient involved in decision-making, as much as possible, will allow for better communication of both your needs.

Many caregivers are reluctant to ask for help. Asking for help is not being weak; it is being realistic in what you can accomplish on your own. When someone offers to help, give him or her a specific task they can assist with. Let someone do your laundry, vacuum your home, get your groceries or make you beds. People are happy to help if they know what you need. Sit down and make a "wish list" of things people can volunteer to help you with. Share this list with your family and friends.

It is not uncommon for family communication to suffer with the progression of a loved one's disease. Family meetings can assist family members who do not live with the patient to better understand the complexity of care. These meetings can be informal with only family members present. However, if communication is difficult, a social worker or clergy member can assist in bringing family members back together during stressful times. Family meetings give the caregiver an opportunity to review the care plan, outline resources and ask for help. They offer opportunities for individuals to discuss how they feel and reduce stress on family relationships. Regular family meetings will assist in keeping communications open with the primary caregiver.



Key Point: Maintaining open lines of communication between family members is fundamental in reducing caregiver burden. Family meetings are excellent ways for the caregiver to express both the needs of the patient as well as their own needs.

The Value of You

Value yourself for what you bring to the caregiving relationship. Remember you are not alone. Find ways to express your *emotions*. Try to do the following activities:

- Write poetry
- Sing
- Write your story and share it with other caregivers
- Find humor in the simple things
- Go to a caregiver support group
- Attend a PD support group
- Have a family meeting
- Meet with your Minister, Priest, or Rabbi

Do not allow yourself to become lost during the caregiving process. Find other caregivers who can offer support based on their own experiences. Years ago, as a PD nurse in Baltimore, I was responsible for coordinating support groups throughout the state of Maryland. There were two couples that met at a group and became close friends. Both husbands had PD and their wives cared for them in their respective homes. Several times a week, the couple that owned a van would pick up the other couple and go to lunch at McDonalds. This was quite an event for the second couple, who could not leave the house without a wheel chair. It took much effort for both wives to plan for the outing however, the couples cherished the time they had together and would laugh as they described their outings. Maintaining a social life does not need to end due to caregiving responsibilities. Opportunities for socialization will change and it may take more effort to get out of the home. However, it is important to make socialization a priority for both you and your loved one.



Key Point: It is important for caregivers to preserve their own sense of self. Remember your interests and passions before becoming a caregiver. Take time to enjoy life!

Staying Realistic

Be realistic in what you can accomplish. Caring for someone with PD is difficult due to unpredictable aspects of the disease. The motor and non-motor symptoms can change with each dose of medication. PD patients can be mobile one minute and immobile the next. *Moods* change and behavior can become erratic, making caregiving activities difficult to plan. It is important to build flexibility into your caregiving techniques. And, don't forget to give yourself a pat on the back for a job well done.



Key Point: Caregiving is never predictable and requires great flexibility!

Healthy Habits

Your ability to provide care is dependent on maintaining your own health. As we discussed earlier, caregivers report fatigue, sadness and less satisfaction with life. Ask yourself the following question:

**“What would happen to your loved one
if you were hospitalized or ill?”**

Below is a list of healthy habits you can do for yourself. Keep this list in a place where you will see it everyday.

- Get the rest you need
- Eat a well balanced diet
- Drink plenty of water
- See a doctor regularly
- Manage your weight
- Take your medications as prescribed
- Express your feelings
- Participate in activities that make you feel good
- If you feel depressed, seek treatment

Remember, you are the most important person in the caregiving relationship. Take care of yourself!



Key Point: You must take proper care of yourself before you can take care of anyone else.

Support at Home

The home is the center of care and services can be arranged to assist home management during the advanced stages of PD. Healthcare professionals can support the caregiver and patient in arranging community support and resources. There is a listing of web sites to assist caregivers in identifying community resources in Appendix B.



Key Point: Home care and support is available. Talk to your healthcare provider about how to arrange such service.

Conclusion

Much has changed with the addition of Parkinson disease to your life. You are now a caregiver. Grieving for your loss is normal and expected. The risk of experiencing depression in the course of your caregiving role is a real possibility. Now is the time to care for yourself, express your emotions, ask for help and learn more about PD. Find a team of healthcare professionals to assist you in providing care. Find support from friends, family, clergy and other caregivers. Use the information in this chapter to help improve care for your own mind, body and spirit.

National Family Caregivers Association

10 Tips for Caregivers

Reprinted from "10 Tips for Caregivers" with permission of the National Family Caregivers Association, Kensington, MD, the Nation's only organization for all caregivers.

1. Choose to **take charge** of your life, and don't let your loved one's illness or *disability* always take center stage.
2. Remember to **be good to yourself**. Love, honor and value yourself. You're doing a very hard job and you deserve some quality time, just for you.
3. **Watch out** for signs of depression and don't delay getting professional help when you need it.
4. When people offer to help, **accept the offer** and suggest specific things that they can do.
5. **Educate yourself** about your loved one's condition. Information is empowering.
6. There's a difference between caring and doing. **Be open to technologies and ideas** that promote your loved one's independence.
7. **Trust your instincts**. Most of the time they'll lead you in the right direction.
8. Grieve for your losses, and then allow yourself to **dream new dreams**.
9. **Stand up for your rights** as a caregiver and a citizen.
10. **Seek support** from other caregivers. There is great strength in knowing you are not alone.



About the Author



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Appendix A

Glossary

****PLEASE NOTE:** Glossary terms are identified as *italicized red* words the first time they appear in each chapter.

-A-

Acetylcholine: a chemical in the brain (neurotransmitter) that regulates movement, memory, learning and emotions

Acetylcholinesterase inhibitors: medications that increase the level of acetylcholine in the brain and are commonly used to treat cognitive disorders

Advanced sleep phase syndrome: sleep disorder in which there is a tendency to fall asleep early in the evening (usually before 9 pm) and arise early in the morning (usually before 6 am)

Anticipatory anxiety: prolonged state of anxiousness in anticipation of a feared or concerning event or situation

Anxiety: a feeling of nervousness, worried thoughts and physical distress

Apnea: cessation of breathing

Apneic event: episode of stopped breathing

Arousal: being awake

Attention deficit disorder (ADD): a biological condition that is characterized by inattention, hyperactivity and/or impulsivity

Auditory hallucinations: state of hearing voices or sounds that are not real

-B-

Basal ganglia: part of the midbrain responsible for controlling movement and is linked with emotional and thinking centers of brain

Behavioral therapy: psychological techniques that help manage or shape a person's behavior

Benign: meaning mild or harmless

Benzodiazepines: class of anti-anxiety medications

Biological: related to chemical changes

Bradykinesia: term reflecting the slowness of movement seen in patients with Parkinson's disease

Bradyphrenia: term reflecting a slowness in one's ability to think and process information and is often seen in Parkinson's disease

-C-

Cardinal symptom: a principal or essential symptom of a disease or syndrome

Caregiver burden: the emotional and physical strain involved in caring for someone with a chronic, disabling illness

Cataplexy: sudden attacks of muscle weakness triggered by laughter or other emotions

Central sleep apnea (CSA): sleep disorder in which there are repeated episodes of stopped breathing and low levels of oxygen in the bloodstream during sleep that is related to brain or heart dysfunction

Chronic depression: typically defined as consistent depression lasting more than 2 years

Circadian dysrhythmias: sleep disorder in which an individual's biologic clock has shifted

Clinical neuropsychologist: a specially trained psychologist who focuses on brain functioning

Cognitive: related to memory, thinking and/or language

Cognitive fluctuations: frequent changes in thinking ability, level of attention, and/or alertness commonly seen in patients with dementia with Lewy bodies (changes can last from minutes to weeks)

Cognitive remediation: a specialized type of psychotherapy designed to help patients learn behavioral strategies to compensate for their cognitive problems

Continuous positive airway pressure (CPAP): method for treating obstructive sleep apnea, in which a small device pressurizes air from the bedroom through a long tube and mask that is worn over the nose or inside the nostrils

Cortical dementia: significant cognitive impairment that is caused by pathologic changes in the cortex or outer "shell" of the brain and is characterized by deficits in memory, language, and learned movements (ie; Alzheimer's disease)

-D-

Deep brain stimulation: surgical treatment for Parkinson's disease that involves putting electrical stimulators deep within the brain

Delayed sleep phase syndrome: sleep disorder in which there is a tendency to fall asleep very late at night (usually after 12 midnight) and arise late in the morning (usually after 9 am)

Delirium: a state of altered awareness with agitation, hallucinations and confusion

Delusions: fixed thoughts or ideas that are not based on reality

Dementia: chronic loss of mental capacity due to an organic cause typically involves progressive changes in memory, behavior, personality and motor function, and may also be associated with psychological symptoms such as depression and apathy

Dementia with Lewy bodies: a progressive degenerative disease or syndrome of the brain that shares symptoms of both Alzheimer's disease and Parkinson's disease and is characterized by fluctuating cognition, hallucinations and parkinsonism

Depression: a feeling of sadness and/or loss of interest or pleasure, usually with negative thinking

Disability: a decrease in ability to perform day-to-day activities

Disinhibition: inability to control one's impulses or behavior (loss of impulse control)

Dopamine: a neurotransmitter that regulates movement and emotions

Dopamine agonist: class of medication used to treat Parkinson's disease and includes pergolide (Permax ®), ropinirole (Requip ®), and pramipexole (Mirapex ®)

Dopaminergic medications: medications that increase the level of dopamine in the brain and are typically used to treat Parkinson's disease (ie; carbidopa/levodopa and dopamine agonists)

Dysarthria: a group of speech disorders caused by disturbances in the strength or coordination of the muscles that produce speech as a result of damage to the brain or nerves

-E-

Electroconvulsive therapy (ECT): treatment for depression that uses electrical stimulation to produce a seizure in a patient under general anesthesia

Emotion: the expression of a feeling that can be observed by others

Excessive daytime somnolence (EDS): sleepiness during the daytime; tendency to fall asleep or struggle to remain awake during the day

Executive function: the cognitive functions responsible for problem-solving, flexible thinking, organizational ability, priority-setting, time-management and decision-making

-F-

Ferritin: measure of iron stored in the body; low ferritin is associated with restless legs syndrome and periodic limb movements during sleep

Freezing: temporary, involuntary inability to move

Frontal lobe: region of the brain responsible for complex thinking and also involved with emotions

Function: ability to perform daily activities

-G-

Generalized anxiety: feelings of nervousness and excessive worrying that is present most of the time

Genetic: related to heredity or family genes

Gustatory hallucinations: state of tasting a substance that is not real or present

-H-

Hallucinations: deceptions or tricks played by the brain that involve the body's senses (seeing, hearing, tasting, feeling and smelling)

-I-

Idiopathic: meaning a disease with no known cause

Inadequate sleep hygiene: behaviors that are not healthy for sound sleep, such as watching the clock in the bedroom, consuming caffeinated beverages or chocolates, smoking, consuming alcohol, etc.

-L-

Lewy bodies: abnormal 'clumps' of protein that accumulate in the cells of the brain and are often seen with PD and DLB (see definition for dementia with Lewy bodies)

-M-

Major depression: depression lasting two weeks or longer with at least five of the classic symptoms

Melancholy: sadness or depression

Mental health: appropriate mental and emotional well-being that allows one to cope with daily stressors

Mental illness: a severe change in one's mental or emotion well-being

Mini-Mental State Examination: a widely used paper-and-pencil test used by clinicians to assess one's memory and thinking abilities

Minor depression: depression lasting two weeks or longer with at least two (but no more than five) of the classic symptoms

Mood: the feelings inside a person that he/she reports to others

Mood stabilizers: medications used commonly in both neurology and psychiatry, especially for bipolar disorder and behavioral problems

Motor fluctuations: long-term complication of dopaminergic drug therapy that can produce fluctuating motor symptoms of PD throughout the day with bothersome "OFF" periods

Motor symptoms: PD symptoms that affect movement including tremor, stiffness, impaired balance, rigidity and generalized slowness

Multiple sleep latency test (MSLT): primary sleep test that measures the degree of sleepiness during the day

Multi-task: performing two or more tasks simultaneously or "doing two things at once"

-N-

Narcolepsy: sleep disorder in which individuals experience excessive daytime sleepiness with sudden onsets of sleep

Neurological: term used to describe diseases or conditions that affect the brain and nervous system

Neurons: a cell that conducts electrical neural impulses from one part of the body to another

Neuropsychiatric: term used to describe a combination of neurological and psychological issues

Neurotransmitters: chemical substances found throughout the body that transmit nerve impulses from one cell to another cell

Non-motor fluctuations: long-term complication of dopaminergic drug therapy that can produce fluctuating non-motor symptoms of PD throughout the day with bothersome “OFF” periods

Non-motor symptoms: secondary symptoms of PD that are not related to changes of the motor system (ie; pain, numbness, anxiety, sadness, restlessness, drooling, sweating, urinary changes, heart palpitations, dizziness)

Non-positional obstructive sleep apnea: obstructive sleep apnea that occurs in any sleep position

Non-restorative sleep: sleep that does not adequately restore the mind and body and prevents one from feeling refreshed in the morning

Norepinephrine: a neurotransmitter that regulates attention, impulsivity, heart rate and the body’s ability to manage stress

-O-

Obsessive-compulsive disorder: an anxiety disorder with unusual, frequent thoughts that do not make sense to the patient and are upsetting, often with repetitive behaviors that are an attempt to manage the anxiety caused by these thoughts

Obstructive sleep apnea (OSA): sleep disorder in which there are repeated episodes of stopped breathing and drops in oxygen saturation in the bloodstream during sleep due to restriction of airflow in the oropharynx

Occupational therapist: a rehabilitation professional that assists individuals in relearning the skills and techniques needed to perform activities of daily living and optimize independence

Olfactory hallucinations: state of smelling a substance that is not real or present

Oral appliance: method for treating obstructive sleep apnea, in which a small device is placed inside the mouth that acts to pull the lower jaw forward

Oropharynx: back of the throat region

-P-

Panic attack: a specific, short-lived episode of intense anxiety with physical symptoms such as shortness of breath, chest pain and stomach upset

Paranoia: extreme distrust and suspicion

Parkinsonism: broad term used to describe parkinson-like symptoms (resting tremor, slowness, poor balance, walking problems, etc.)

Parkinson disease: a progressive neurological disorder that has no known cause or cure and is characterized by a resting tremor, rigidity, slowness and poor balance

Periodic limb movements of sleep (PLMS): regular jerks of the legs during sleep

Polysomnogram (PSG): overnight sleep study

Positional obstructive sleep apnea: obstructive sleep apnea that only occurs in certain positions, particularly while sleeping on the back

Psychological: related to thoughts and feelings

Psychophysiological insomnia: a sleep disorder in which an individual struggles to fall and stay asleep usually due to worrying about past or current problems

Psychosis: broad medical term used to describe a loss of contact with reality that involves hallucinations and/or delusions

Psychotherapy: a form of treatment for mental illness that explores one's feelings, thoughts and behaviors through discussion with a trained therapist (ie; counseling, group therapy)

-R-

Radiofrequency ablation (RFA): method for treating obstructive sleep apnea, in which a probe is placed in the back of the tongue, and radiofrequency waves are transmitted to shrink the tissue in the back of the tongue

REM sleep behavior disorder (RBD): sleep disorder in which a person seems to act out dreams

Restless legs syndrome (RLS): sleep disorder in which an uncomfortable or creepy-crawly feeling occurs in the legs while at rest, primarily at night, and causes an irresistible urge to move the legs

Retain insight: the ability to understand reality despite current hallucinations or delusions

-S-

Serotonin: a neurotransmitter that regulates mood, emotion, sleep and appetite

Schizophrenia: a psychiatric illness that can involve hallucinations and delusions

Shuffling: small, baby steps

Sign: what someone else notices about a patient (ie; clinician's observations)

Sleep paralysis: inability to move the arms and legs for seconds or minutes upon awakening or falling to sleep

Sleep study: a sleep study, or polysomnogram, that continuously measures and records brain and body activities during sleep

Snoring: sound resulting from air turbulence in the oropharynx during sleep

Social avoidance: avoiding social situations due to feelings of anxiety, fear and/or embarrassment around others

Speech-language pathologist: a specialist trained in language and communication disorders

SSRI: medications that increase the level of serotonin in the brain and are most commonly used to treat depression and anxiety

Subcortical dementia: cognitive impairment that is caused by changes in deep brain structures and is characterized by deficits in memory retrieval, visuoperceptual abilities, and frontal lobe executive functions

Substantia Nigra: a region of gray matter in the brain where dopamine cells deteriorate and cause Parkinson's disease

Sundowning: a condition in which elderly individuals become confused and disoriented towards the end of the day

Symptom: what a patient reports about him or herself

-T-

Tactile hallucinations: state of feeling a sensation that is not real or present

-U-

Upper airway resistance syndrome (UARS): sleep disorder in which there are repeated episodes of restricted breathing without drops in oxygen saturation in the bloodstream during sleep due to restriction of airflow in the oropharynx

Uvulopalatopharyngoplasty (UPPP): surgical method for treating obstructive sleep apnea, in which tonsillar tissue and part of the back of the roof of the mouth is removed

-V-

Visual hallucinations: state of seeing a person or object that is not real or present

Visual illusions: state in which a real object is misperceived as a different or altered object

Visual misperceptions: another term for visual illusions

Visual-perceptual skills: the ability to process and understand visual information (ie; distance between objects)

Vivid dreaming: state of dreaming in which the dreams are vivid, lifelike and disturbing at times

-W-

Working memory: ability to hold new information in your memory while you perform another task

Appendix B

Resources

Book Resources

The 36-Hour Day: A Family Guide to Caring for Persons With Alzheimer Disease, Related Dementing Illnesses, and Memory Loss in Later Life by Nancy L. Mace, Peter V. Rabins.

The Anatomy of Hope: How People Prevail in the Face of Illness by Jerome Groopman.

Lucky Man by Michael J. Fox.

Saving Milly by Morton Kondracke.

Internet Resources

www.aarp.org

This is the homepage for the American Association of Retired Persons. AARP is a non-profit organization for people age 50 and over dedicated to enhancing quality of life during the aging process. The website provides information on AARP services and benefits.

www.alz.org

This is the homepage for the Alzheimer's Association. This site offers various resources for caregivers of individuals suffering from any form of dementia. Resources are available to assist in selecting respite care services and dealing with caregiver stress. Contacts for support groups are also available on this site.

www.caregiver.org

This site is the homepage for the Family Caregiver Alliance, which focuses on services in California but provides general information useful to all caregivers. This site provides facts and statistics on caregiver burnout and reinforces the importance of self-care.

www.lewybodydementia.org

This is the homepage for the Lewy Body Dementia Association. This site provides information on dementia with Lewy bodies for patients, caregivers and family members. It also posts their national newsletter and provides other valuable resources and internet links.

www.eldercare.gov

The U.S. Administration on Aging sponsors this site that allows individuals to find information and referral services for their state and area agencies on aging. These programs can help you identify appropriate services in your local community.

www.familycareamerica.com

This web site is managed by Family Care America and was founded to assist corporate America in supporting employees in caregiving roles. The web site provides resources for finding nursing care, respite care, home care, durable medical equipment and elder care attorneys. Enter your zip code to find resources in your area.

www.medicare.gov

This is the official government webpage for Medicare services. This website can answer questions on the various programs including Medicare, Medigap and Medicare Managed Care Plans.

www.michaeljfox.org

The Michael J. Fox Foundation for Parkinson's Research is "dedicated to ensuring the development of a cure for PD." This site also offers general information on PD as well as national outreach and research initiatives.

www.mwpcf.org

The Melvin Weinstein Parkinson's Foundation is a not-for-profit organization that raises money to purchase equipment and supplies necessary to maintain a safe and healthy environment for Parkinson's patients. This website reviews the organization's mission and charitable programs.

www.thefamilycaregiver.org

This is the homepage of the National Family Caregivers Association (NFCA). The NFCA exists to support caregivers and advocate for caregivers' needs. NFCA supports a philosophy of self-advocacy and self-care that is based on the belief that caregivers who choose to take charge of their lives and see caregiving as but one of their facets, are in a position to be happier and healthier individuals.

www.parkinson.org

This is the homepage of the National Parkinson Foundation, Inc. This website offers a wide-range of information for PD patients, families and clinicians. Electronic copies of educational materials are available as well as contact information for national PD centers of excellence.

www.parkinsonsaction.org

The Parkinson's Action Network (PAN) is the unified education and advocacy voice of the Parkinson's community, fighting to ease the burden and find a cure. This website provides information on the PAN mission as well as general PD resources.

This website is managed by the National Parkinson's Foundation and includes passages written by PD caregivers.

www.pdcaregiver.org

This web site discusses the ups and downs of caring for a patient with PD. The contributors are caregivers who have thoughtfully recorded their experiences to share with others.

www.pdf.org

The Parkinson's Disease Foundation provides information and education to the Parkinson's community through materials, conferences and engaging in advocacy work.

www.ssa.org

This is the official site for the Social Security Administration and provides information on Social Security Retirement and Disability benefits, including Medicare and Medicaid programs.

www.wemove.org

WE MOVE is a not-for-profit organization committed to educating and informing healthcare professionals, patients, and the public about movement disorders. This web site provides specific information on PD and related disorders.

www.va.gov/padrecc

This national PADRECC website can provide veterans with information on the VA system and its network of PD centers of excellence. It also provides links to other valuable PD and movement disorder websites for veteran and non-veteran patients and families.

Appendix C

The VA/NPF Connection

The VA and NPF Connection

On June 1, 1999, the National Parkinson Foundation (NPF) signed a memorandum of understanding with the Department of Veterans Affairs to establish the NPF/VA *Alliance to Cure Parkinson's Disease*. This affiliation agreement marks the first time a private voluntary health agency and a federal agency have joined efforts at this level, with the common goal of solving the remaining medical mysteries of Parkinson's disease.

Another primary goal of this affiliation is to better educate physicians, pharmacists and allied health professional who practice within the VA system about the diagnosis and treatment of PD; accomplishing this mission will ensure that patients who are served by the Veteran's Administration receive state-of-the-art care.

The VA Parkinson's Disease Research, Education and Clinical Center (PADRECC) Network

In addition to aligning itself with the National Parkinson Foundation, the Department of Veteran's Affairs intensified its commitment to veterans with Parkinson's disease by creating the Parkinson's Disease Research, Education and Clinical Center (PADRECC) Network. In 2001, six centers of excellence were established at VA facilities in Philadelphia, Richmond, Houston, West Los Angeles, San Francisco and Portland/Seattle. The PADRECCs are designed to treat veterans diagnosed with PD and related movement disorders throughout the collective VA healthcare system. They are also dedicated to performing breakthrough research as well as delivering national education and outreach. The PADRECC teams are considered leaders in the field of Parkinson's disease and are honored to serve the veterans of this country.

*For more information on the PADRECC network and resources,
please see the national website or call your closest PADRECC facility.*

www.va.gov/padrecc

Philadelphia PADRECC

(215) 823-5934 or
toll-free (888) 959-2323

Richmond PADRECC

(804) 675-5931 or
toll-free (800) 784-8381 X5931

Houston PADRECC

(713) 794-7841

San Francisco PADRECC

(415) 379-5530

Portland/Seattle PADRECC

Portland: (503) 721-1091
Seattle: (206) 277-4560

West LA/Southwest PADRECC

(310) 478-3711 X48001

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