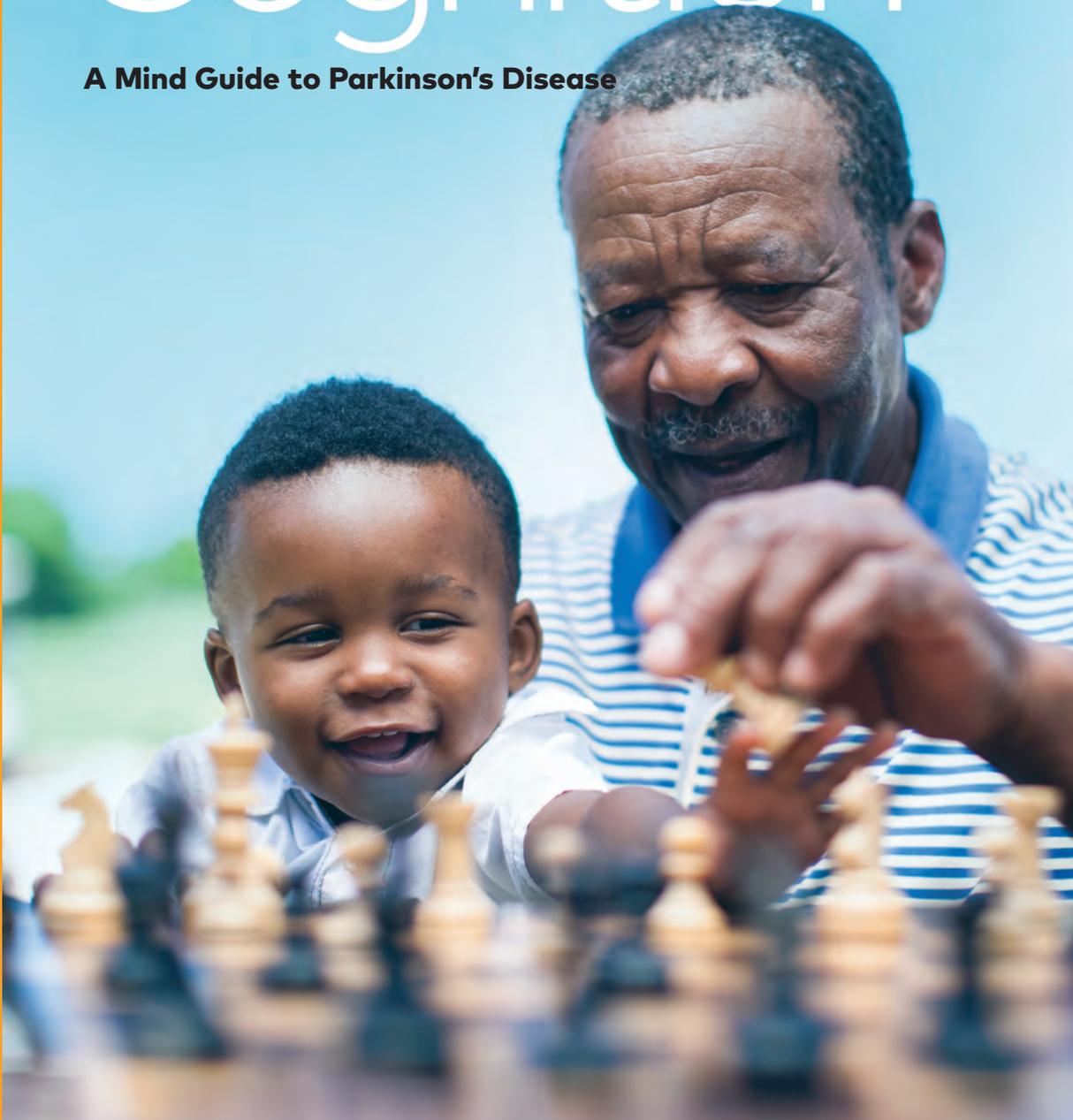


Cognition

A Mind Guide to Parkinson's Disease



Parkinson's
Foundation

About this book

GLOSSARY

Definitions for all words underlined in blue can be found in the glossary starting on page 42.

A comprehensive Parkinson's disease glossary can be found at [Parkinson.org/glossary](https://www.parkinson.org/glossary).

INDEX

An index of key words and topics can be found on page 47.

PARKINSON'S FOUNDATION RESOURCES

Certain pages include tip sheets with practical pointers for coping with cognitive changes.

You can find more helpful tips for managing Parkinson's in the books, fact sheets, videos and podcasts in our PD library at [Parkinson.org/library](https://www.parkinson.org/library).



Cognition is the act of mental processing. There are many aspects of cognition: thinking, understanding, learning, remembering, problem solving, language and more.

Why are we talking about cognition in a book on Parkinson's disease (PD)? Because about 30% of all people with PD report changes in their memory and thinking ability. These and other changes can have just as much (or more) of an impact on your quality of life as motor symptoms.

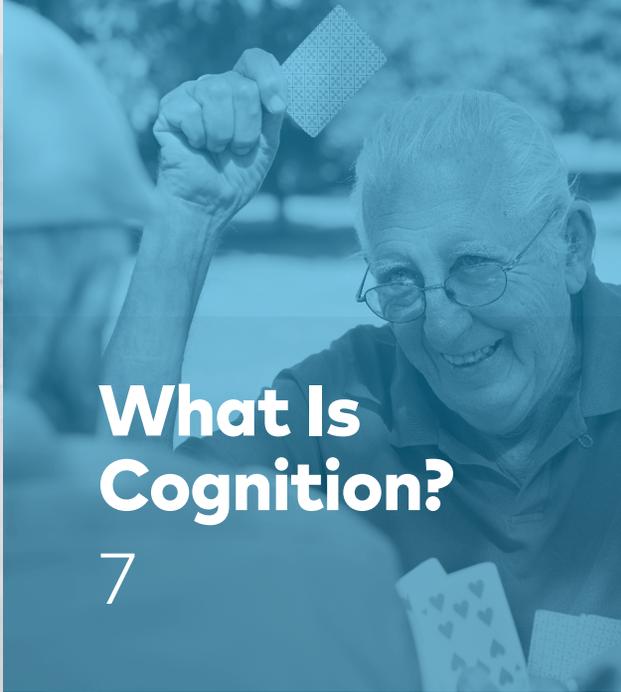
There are coping strategies in this book for people with Parkinson's and for care partners of someone experiencing cognitive changes associated with Parkinson's disease. Overall, the information, tips and stories included here will provide answers, help you organize thoughts and questions for your medical team and remind you that you are not alone on this Parkinson's journey.

Contents



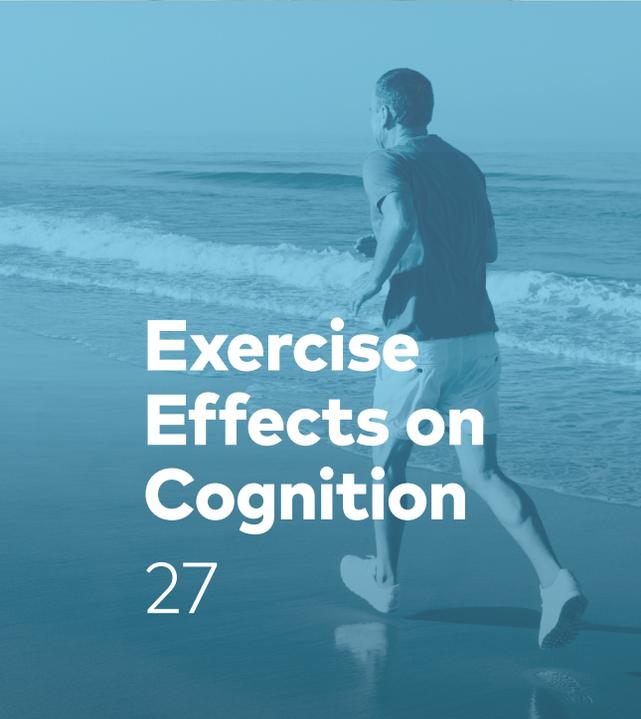
**About
Parkinson's
Disease**

5



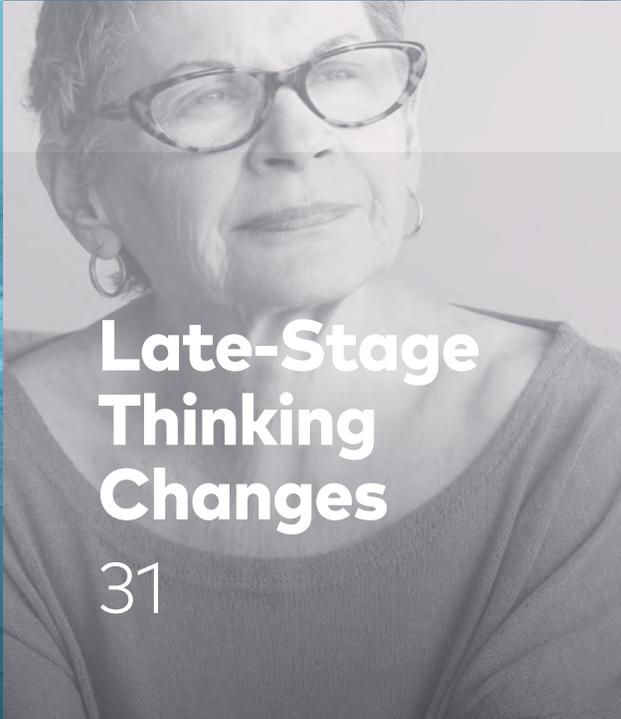
**What Is
Cognition?**

7



**Exercise
Effects on
Cognition**

27



**Late-Stage
Thinking
Changes**

31



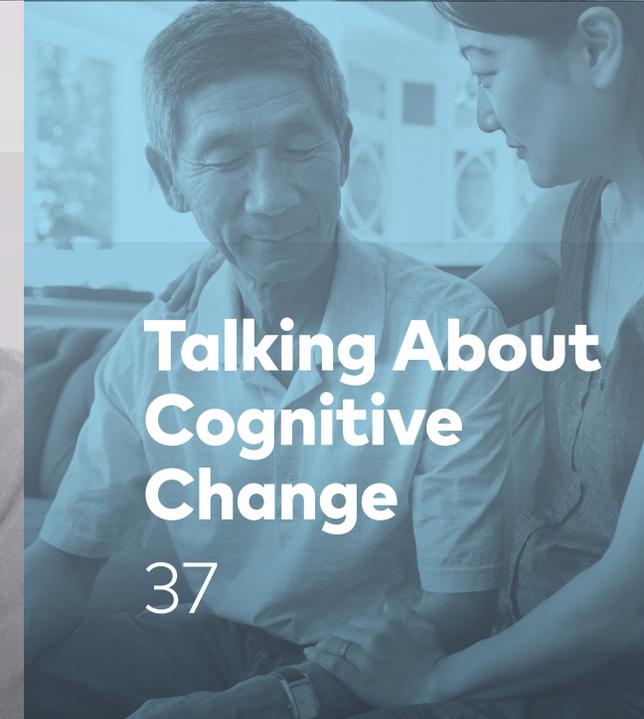
**Thinking
Changes**

14



**Treatment
Options**

23



**Talking About
Cognitive
Change**

37

Summary 42

Glossary 43

Index 48

Acknowledgements

This book was written and reviewed by:

Kate Perepezko, MSPH
Gregory Pontone, MD, MHS
Johns Hopkins University School of Medicine

Linda Minton, MPH
East End Strategic

Paula Wiener, MSW, LCSW, of the Parkinson's Foundation also contributed to the writing and review of this guide.

Thank you to Giselle Petzinger, MD, Beth Fisher, PT, PhD, Lauren Hawthorne and Michael Jakowec, PhD, of Keck School of Medicine, University of Southern California for their contributions to the section on exercise and cognition.

This book has been made possible through the generous donations of thousands of individuals affected by Parkinson's and a grant from



Design: Ultravirgo

CHAPTER ONE

About Parkinson's Disease

If you're reading this book, you are probably already familiar with Parkinson's disease, but here are some basics: Parkinson's is a progressive neurodegenerative disorder that affects about one million people in the United States and 10 million people worldwide. It is called a movement disorder because of the tremors, slow movements, stiffness and muscle cramping it can cause. But its symptoms are diverse and usually develop slowly over time.

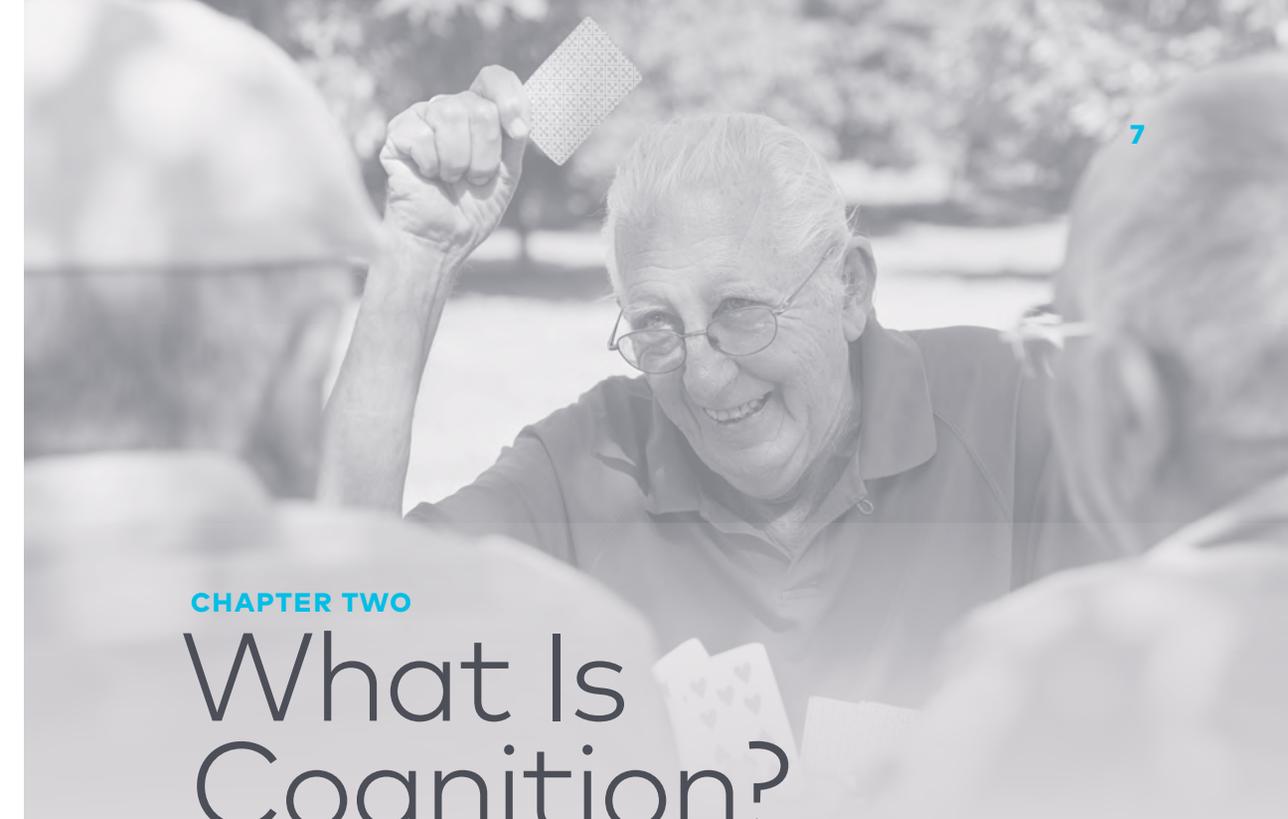
Parkinson's disease is not diagnosed with a test or a scan; instead it is diagnosed by a neurologist, who asks you questions about your health and medical history and observes your movement. Your doctor may want you to have some tests or imaging; some, like an MRI, can help rule out other conditions, while others, like DaTScan, may help confirm a Parkinson's diagnosis if there is uncertainty. The goal of treatment is to help you manage your symptoms. Good symptom management can help you to stay healthy, exercise, and keep yourself in the best possible shape. Although at this time there is no way to correct the brain changes that cause Parkinson's, we know that exercise can help you maintain your ability

6 COGNITION

to fight the disease and that staying healthy can reduce setbacks that make PD progress faster. Great care is an important part of living your best life with Parkinson's.

Lack of [dopamine](#) in people with Parkinson's was first described in the 1960s. Dopamine is a type of [neurotransmitter](#), or chemical messenger, one of several chemicals your brain cells use to send signals to one another. Soon after, dopamine-replacement therapy using [levodopa](#) became – and remains – the gold standard treatment. However, we know that the dopamine system is not the only one affected by Parkinson's. The disease process also disrupts other brain networks, including those linked to mood, behavior and thinking (cognition). You might also hear that Parkinson's is linked to a protein in the human brain called [alpha-synuclein](#). Researchers continue to study how cells and brain networks are affected in Parkinson's to improve our understanding of the disease and potential for treatments.

You and your family may have questions or fears about Parkinson's and [genetics](#). While there are several genetic mutations that can increase your risk, for the vast majority of people, Parkinson's is not inherited. There is no test that can accurately predict who will develop Parkinson's. Extensive gene and biomarker research is underway to uncover the possible factors involved in – not necessarily causes of – disease development.



CHAPTER TWO

What Is Cognition?

When most people think of Parkinson's, they think of tremors, stiffness and slowness of movement. Many people are unaware that PD is more than a motor disease: it can affect thinking, mood and behavior as well as other body systems. For people with Parkinson's and their care partners, living with the motor symptoms can be hard. However, thinking and behavior changes can be even more frustrating and challenging. These changes can have a huge impact on quality of life.

Cognition is the action or process of acquiring knowledge and understanding through thought, experience and the senses. It includes a variety of mental skills such as attention, memory, language, visuospatial abilities and other aspects of reasoning and general intellect. When you hear someone mention cognitive function or ability, it refers to the processes involved in knowing or putting together information.

What Affects My Thinking?

People tend to blame every health concern on Parkinson's, but there are many other factors in your daily life that can contribute to changes in your health status and your cognition.

TIP

Some changes to your cognition are reversible if you address the underlying cause. It is important to bring up any changes you (or a care partner) notice with your healthcare team.

Age

Many changes take place in the normal brain over time that can affect physical, behavioral and cognitive functions, such as memory and attention. Some of these issues may appear earlier in people with Parkinson's. There is also a lot of individual variability in the way we age. Furthermore, age can have an impact on disease progression for people with PD. For example, people with young-onset Parkinson's tend to have slower disease progression and frequently do not experience cognitive changes until later in the course of their disease.

Coexisting Conditions

Many conditions can impact your cognitive skills and quality of life. Some of the conditions described below are conditions associated with Parkinson's, while others occur independently.

DEPRESSION

At least 50% of people with PD experience some form of depression during the course of their illness. Unfortunately, it often goes undiagnosed and undertreated. When that happens, depression can affect cognition, and you might experience some of the following symptoms:

- Sluggish or distorted thinking
- Difficulty concentrating
- Distractedness
- Forgetfulness
- Negative thinking
- Slowed reaction time
- Indecisiveness
- Memory loss

Severe depression can even mimic the symptoms of dementia.

Fortunately, depression is generally managed successfully with psychotherapy and medication. Unlike motor symptoms, depression is most often episodic and can usually be treated to full remission. If you experience any of the symptoms above, it is a good idea to be screened for depression before assuming that Parkinson's is affecting your cognition.

TIP

For more information on depression and other mood disorders, request your free copy of *Mood: A Mind Guide to Parkinson's* by contacting the Parkinson's Foundation Helpline at 1-800-4PD-INFO (473-4636) or Helpline@parkinson.org.

SLEEP PROBLEMS

In general, people who don't sleep well can have difficulty functioning. Poor sleep can affect judgment, alertness, memory and coordination. Sustaining attention can also be challenging when you are sleep-deprived. These issues are generally magnified in people with Parkinson's because many already experience fatigue and excessive daytime sleepiness.

Sleep disturbances are common in PD and may include the following:

- Problems falling or staying asleep and early morning awakening (terminal insomnia)
- Involuntary movements and pain that interrupt sleep (e.g., REM sleep behavior disorder and muscle stiffness when medications wear off)
- Increased nighttime urination
- Nighttime agitation and vivid dreams

Sleep can also be affected by certain medications, overeating or having a cold. If you have a few bad nights, it is probably nothing to worry about. But it is important to communicate with your doctors about any prolonged changes in your sleep. A sleep study can be helpful in analyzing your sleep-wake cycle and other patterns that may contribute to energy levels and daytime functioning.

TIP

For more information on sleep disorders, request your free copy of *Sleep: A Mind Guide to Parkinson's* by contacting the Parkinson's Foundation Helpline at 1-800-4PD-INFO (473-4636) or helpline@parkinson.org.

10 COGNITION

Many sleep problems can be treated successfully with medication (adjustment of dopaminergic drugs or prescribing new medication such as sleep aids or anti-anxiety medication), behavior modification and medical devices like a CPAP machine (for sleep apnea). If you are considering over-the-counter medications, be sure to consult your doctor first. Many common sleep aids contain diphenhydramine (also the active ingredient in Benadryl), which is an [anticholinergic](#). This class of medication can contribute to confusion and cognitive slowing (see the "Medication" section on page 12).

Melatonin is a naturally occurring hormone that regulates sleep; melatonin supplements are another commonly used over-the-counter sleep aid that you can discuss with your doctor. If your sleep improves, you might notice a positive impact on activities of daily living, memory and thinking.

FATIGUE

Fatigue is a lack of energy to the extent that it makes routine physical or mental activities difficult. It is one of the most commonly reported symptoms of Parkinson's and can make it hard to enjoy your life. Fatigue's impact is generally associated with motor function and physical endurance, but fatigue can affect the speed of thinking and recall. Fatigue may increase as the day wears on, particularly if you are not sleeping well at night. However, fatigue is not just caused by lack of sleep. For some, rest does not improve fatigue. Some medications may also cause daytime sleepiness (somnolence). Ongoing fatigue can affect both motor and thinking skills.

Tell your doctor if you are experiencing fatigue. Adjusting medications, treating depression, improving sleep and incorporating exercise into your daily routine are all strategies that may help reduce fatigue.

COPING STRATEGIES to help address fatigue

- Execute your most difficult tasks in the morning or when you are most alert.
- Make time to rest your body and your mind; a catnap or meditation may refresh you.
- Break down tasks into smaller, more manageable units, so you can accomplish what needs to get done a little at a time and not feel overwhelmed or over-tired.

NEUROGENIC ORTHOSTATIC HYPOTENSION (NOH)

Orthostatic hypotension (OH) is a drop in blood pressure that happens when you go from a seated position or lying down to standing, and it can cause foggy thinking and memory problems. When it's related to a neurologic disorder like Parkinson's, it's called neurogenic OH, or nOH. This condition tends to be underdiagnosed. It is usually identified because people get dizzy or start to black out when they stand up. Early in the PD progression, you might not notice the dizziness, but you may experience the foggy thinking. If you become lightheaded upon standing, report it to your doctor. In general, asking your doctor to screen you for nOH once a year is a good idea. This is done by taking your blood pressure while lying down and then standing. A drop of 20 points in the top number (systolic) or 10 points in the bottom number (diastolic) indicates nOH.

DIABETES

Uncontrolled diabetes can negatively affect cognition. On one hand, untreated low blood sugar (hypoglycemia) can lead to confusion, difficulty speaking, drowsiness and other severe symptoms. On the other hand, over time high blood glucose levels (hyperglycemia) can damage nerves, including nerves in the brain. This increases the risk of long-term memory problems, even dementia.

Recent data from the *Parkinson's Outcomes Project* shows that even people with well-controlled diabetes have an increased risk of cognitive impairment. If you have diabetes or have been told you are at risk for diabetes, talk to your primary care provider and your Parkinson's doctor to make sure you are regularly evaluated for thinking changes.

INFECTIONS

Urinary tract infections can cause sudden confusion, as can aspiration pneumonia. If there is a rapid change in mental state, report it to your doctor right away.

NOTE

To learn more about current research and causes of dementia in PD, tune into our Expert Briefing episode *Dealing with Dementia in PD* by visiting episode archives at [Parkinson.org/ExpertBriefings](https://www.parkinson.org/ExpertBriefings).

Medication

Cognitive deficits (or thinking changes) caused by medications can have subtle or dramatic effects depending on your general health, even if you don't have Parkinson's. Some medications – both prescription and over-the-counter – can cause problems with thinking. For example, anticholinergics are found in many common sleep aids and allergy medicines (e.g., Benadryl). Anticholinergics were actually the earliest medications used in Parkinson's. They work by blocking the neurotransmitter [acetylcholine](#). They can provide modest benefit for motor symptoms, particularly tremor, and are most useful in young people with tremor-predominant PD. But they can cause significant mental side effects, including confusion, hallucinations and decreased short-term memory, so their use should be seriously discussed with your neurologist.

Opiate pain relievers (such as Vicodin, Percocet and Oxycodone) and [benzodiazepines](#) (such as Valium, Xanax, Ativan and Klonopin) have been associated with rapid changes in thinking, mood and behavior. Interactions between your Parkinson's medications and other drugs can also affect your clarity of thinking.

Reversing the side effects of medications involves careful evaluation of what drugs you currently take and the benefits you receive from them. It is always important to tell your doctors about all the medications you are taking, including supplements and anything over-the-counter. This may help to reduce the impact of drug interactions.

Biology

The same neurotransmitters (e.g., dopamine) that regulate movement also regulate our thinking and mood. Similarly, the parts of the brain, including the [basal ganglia](#), that are responsible for the motor symptoms of PD are also responsible for key mental processing functions. The same processes in the brain that lead to the more classic symptoms of Parkinson's disease can cause difficulty with memory, word choice and learning. When dopamine-producing cells in the brain die, movement AND thought processes can be affected. Changes in acetylcholine levels also have an effect on learning and short-term memory. In fact, cognitive change can appear before the onset of motor symptoms. Only looking back after a PD diagnosis do people realize the connection. This is also true for other non-motor symptoms such as depression, sleep disorders and constipation.

Genetics

Some genetic mutations related to Parkinson's disease can influence your risk for cognitive change. For example, people with a LRRK2 mutation are less likely to have cognitive symptoms of PD, while people with a GBA mutation are more likely to experience thinking changes. However, it is important to understand that these genes simply affect your risk, there are no guarantees.

How Do I Know if Parkinson's Is Affecting My Thinking?

Not everyone with Parkinson's will experience changes in thinking as a part of your disease. And for those who do, the changes are not universal. You may find yourself disorganized or distracted, having difficulty planning and making decisions or being forgetful. Since Parkinson's is usually diagnosed after age 60, it is normal to wonder if the changes you are experiencing are due to aging. Here are some questions to ask yourself to help you and your healthcare team figure out what is happening and what may be the underlying cause:

- What am I having trouble doing or remembering?
- How often am I experiencing these changes (frequency)?
- Is there anything that triggers the changes (time of day, noise, isolation)?
- Does my thinking change when I take my PD meds?
- What else could it be (medication changes, illness)?
- Was the change sudden or gradual?

It is also helpful to discuss the answers with a care partner, family member or close friend. He or she can likely add observations that will be useful for the healthcare team in making an assessment.

TIP

It can be hard to separate the symptoms of PD from normal aging. Talk to your doctor about what you are experiencing. He or she can help you identify the underlying cause and manage the symptoms.

CHAPTER THREE

Thinking Changes

Around 30% of people with PD experience cognitive change at some point in their illness. However, changes in cognition can be difficult to identify and measure because of the overlap with normal aging, other medical (or health) conditions and other factors (see "What Affects My Thinking" on page 8). And for many people, especially in the early stages of PD, the cognitive symptoms are barely noticeable and don't interfere with your life or work.

What Cognitive Problems Occur in Parkinson's?

Some people report that the most frustrating and disabling symptom of their PD is the decline in their thinking abilities. It is easier to understand and explain the physical motor symptoms of PD than the more subtle changes in concentration and thinking. Cognitive change can also hamper the ability to make decisions that affect everyday life, and it can range from mild to severe.

Early Cognitive Change

The first signs of cognitive change in PD are generally changes in memory and executive thinking abilities, like planning, organizing, scheduling, etc. (see page 16 for more information). You may find these changes annoying, and possibly overwhelming. Coping strategies (see page 19) can help you adapt to these changes and minimize some of the symptoms.

Mild Cognitive Impairment

As Parkinson's progresses, mental processing may continue to slow. Healthcare providers refer to this decrease in cognitive abilities as mild cognitive impairment (MCI). The symptoms of MCI include more frequent memory lapses, trouble multitasking and a decline in your ability to organize and plan efficiently. At this point, you and those close to you are usually aware of a change in cognition – the feeling that things may be “slipping” – but the impact on daily activities may be minor. MCI can take many forms and impact different areas of thinking. The most common form of MCI is impairment in one or two of the following areas:

ATTENTION

Attention is when you apply your mind to something, focus selectively and filter out distractions and irrelevant information. Over time, you may have problems with complex tasks that require sustained attention or shifting attention (e.g., balancing your checking account). You may require a conscious effort to focus, and it may be harder to stay on task in a multi-step process.

BRADYPHRENIA (SLOWED THINKING)

As movement slows in PD (bradykinesia), so can your mental processing. Bradyphrenia affects the time it takes to register and respond to information and is often experienced when trying to solve problems. Some people have difficulty retrieving information from memory, and there can also be a delay in responding to verbal or behavioral stimuli. At first, this may become noticeable because tasks take longer to complete. Over time, it can interfere with a broad range of daily activities and social situations.

EXECUTIVE FUNCTION

Executive functions allow you to control and coordinate your other cognitive abilities and behaviors. They guide who you are, how you organize your life, how you plan and how you execute those plans. Executive functions are divided into organizing abilities and regulation. Organizing abilities include managing time, paying attention, planning and organizing, switching focus and remembering details. Regulation includes not saying or doing the wrong thing and taking action based on experience. Problems with regulation can cause you to say embarrassing things or choose not to use your walker even though you have fallen down in the past.

Charlene and her husband had just arrived at their summer home and were enjoying lunch at their favorite local restaurant. One of the waitresses they had known for many years came to the table wearing a baseball cap to cover her hair loss from chemotherapy. Charlene, who has had Parkinson's for several years, asked the waitress if she really thought she looked good in that cap. Charlene's husband was mortified. After the waitress had taken their order, he asked Charlene why she would say such a thing. Charlene had no idea what was wrong with her comment.

NOTE

For more information on cognition and Parkinson's disease, tune into Episode 27 of our podcast *Substantial Matters: More Than Movement: Addressing Cognitive and Behavioral Challenges in Caring for PD* at [Parkinson.org/Podcast](https://www.parkinson.org/Podcast).

LANGUAGE

Many people complain of word-finding problems as they age. This can be exaggerated in people with PD. You may experience the “tip of the tongue” phenomenon and feel embarrassed during conversations if you cannot find the right word. Difficulty with language can also increase under pressure or stress. Problems naming or misnaming objects may be seen in the middle to late stages of PD. Some people report difficulty understanding complex sentences where the question or information is mixed in with irrelevant details. At this point, language often becomes simpler, using fewer words, due to problems with production and comprehension of language. Language problems are different than [dysarthria](#), which is more of a motor problem resulting in unclear articulation of speech. Unfortunately, language problems and dysarthria often co-occur in PD, combining to make it difficult to communicate effectively.

MEMORY

Structures of the brain, particularly the hippocampus and the medial temporal lobes, are important in the storage and recall of information. As Parkinson’s progresses, some people begin to have problems with short-term memory and learning new information. For example, you might have difficulty remembering what you did this morning or whether you took your pills. The level of memory deficit is often an indicator of the overall level of cognitive impairment. Difficulty retrieving memories on demand is one of the [cardinal symptoms](#) of cognitive impairment in PD. Interestingly, long-term memory – memories from the distant past – are often more preserved than recent memories. In fact, it becomes more difficult to make new memories.

Tom was diagnosed with PD a few years ago and tries to do everything he can to manage his symptoms. He exercises regularly, maintains a nutritious diet and goes to the doctor. He and his wife work together to maintain a healthy life, and his wife helps him stay on top of his medication schedule. Tom admitted to his doctor, though, that sometimes when his wife is away he forgets to take his medication on time. His doctor recommended that Tom set an alarm to remind him to take his medication and use a pill organizer so he can check to confirm that each dose was taken.

You may be familiar with a test of delayed word recall used by many neurologists: you are told a list of words, and 10 minutes later you are asked to repeat them. Interestingly, even when people with PD cannot spontaneously recall the words, they often can remember when given hints about the category that includes the specific word (e.g., animal, color, flower, etc.).

VISUOSPATIAL PROCESSING AND PERCEPTION

You may have problems processing information about your surroundings or environment, even early in the disease. Some people with PD also experience changes in the amount of contrast sensitivity in the eye, making it hard to discern objects that are similar in color (e.g., white bread on a white plate). Later in the disease, people have more trouble navigating, sometimes even becoming lost in familiar places. Visuospatial problems may contribute to the visual misperceptions or illusions that can occur in PD. You may be especially susceptible to this phenomenon in low-light situations (i.e., at night). Other visual problems associated with aging, such as macular degeneration or cataracts, can also contribute to visuospatial problems. Like PD, these conditions may progress as time goes on.

Other Considerations

We all know that physical activity helps keep a body in shape and aids in motor function, but it has also been shown to improve and maintain cognitive function. (See chapter 5, "Exercise Effects on Cognition," for more information.) In addition, it is important to stimulate the brain with activities that can help visuospatial perception, memory and other types of information processing. This is not limited to reading, puzzles and playing games, though those can be beneficial. Attending plays, concerts and museum shows may help you sustain your cognitive skills, as can learning a new language, taking a cooking class, putting together a piece of equipment or socializing. For additional benefit, cognitive tasks can be combined with physical exercises. For example, during a balance task, have someone call out a letter, and try to name animals that start with that letter.

TIP
Cognitive impairment can cause difficulties with everyday tasks. Paying bills, eating, dressing and conversation can take more effort. If you or someone you care for are experiencing difficulty with these kinds of activities, make an appointment to talk to your healthcare team.
.....

COPING STRATEGIES for daily life

When your thinking changes, your independence, ability to hold a job and general socialization can all be affected. These days we live in a culture of multitasking – life is hectic, so we're used to doing a million things at once, wherever we are. Because of both motor and cognitive changes in Parkinson's disease, it is helpful to reduce or avoid multitasking and focus on one thing at a time. It can improve your ability to complete tasks and stay focused.

Angela was diagnosed with PD a few months ago, and until recently, the only symptom she noticed was the occasional tremor in her little finger. She is a lawyer at a large company, and everyone from the office leaves the building for lunch around noon each day. Angela never had any problems keeping up with the group as they walked to the elevator. However, these days she notices that if she is talking to a colleague while she walks, she slows down and is not able to keep up with the group. She brought this up with a nurse during her routine visit. The nurse told her that sometimes people with PD have problems multitasking – for Angela, walking and talking at the same time had become a challenge. The nurse advised her that if she is in a rush to get somewhere, it would be a good idea to focus only on the walking part; then she can talk to her colleague when they arrive at their destination.

Here are some other coping strategies that may help:

- Develop a routine; patterns may be easier to follow.
- Use calendars, reminders on your smartphone and other visual and auditory cues. These can help you remember things like taking your medication or taking your identification when you leave the house.
- Exercise! It is good for the body and the mind.
- Stay engaged. Intellectual activities like reading or attending a lecture can challenge you and help your attention.
- Stimulate your brain with puzzles and by learning new activities.
- Be social. Stay connected to friends and family.
- Avoid loud rooms and distractions when possible (e.g., turn off the television or radio while you're having a conversation).
- Divide your tasks into individual steps that are easier to complete.
- Keep rooms well-lit if you experience problems with visual perception.

Diagnosis of Cognitive Change

At this time, there is no predictive tool to know who will or won't experience changes in thinking. Some people already have a decline in executive function at the time of their PD diagnosis, while others never experience a decline at all. Early in the Parkinson's journey many people report that they have trouble paying attention and finishing tasks. Complaints include being easily distracted, losing your train of thought and "muddy" thinking. These changes do not generally get in the way of day-to-day activities and responsibilities. For some, the decline increases as the disease progresses. You may be at greater risk for cognitive problems if you have more severe motor symptoms or if you already have changes in your memory or thinking.

In the middle stages of PD, complaints often reflect difficulty with problem-solving, memory, decision-making and word choice. In the later stages, some people experience more serious cognitive disturbance including confusion, visual [hallucinations](#), [delusions](#) and [agitation](#). Mental and motor decline tend to occur together as the disease progresses. As with motor symptoms, you can have good days and bad days.

If you or someone you spend time with notices any cognitive changes, it is important to discuss them with your care team. An office visit that includes an updated comprehensive history can help identify subtle or significant changes in your thinking ability. Cognitive testing, called [neuropsychological testing](#), can reveal problems in specific areas such as executive function, attention, visuospatial abilities, memory and language. With the results of this testing, the [neuropsychologist](#) can often suggest coping skills that use cognitive strengths in some areas to offset weaknesses in others.

For those diagnosed with Young Onset Parkinson's Disease (YOPD) or for those still in the workforce, it can be beneficial to get tested early to provide a baseline assessment of cognitive abilities. This can be referenced as the disease progresses should the person with PD need to apply for disability benefits, as proof of cognitive decline can highlight their need for support.

Because it can affect several areas, there is no single test that is used to evaluate cognitive change; instead, there are a variety of tools that can be used as part of a cognitive assessment. Some of these tests

can be administered in the primary care setting by your doctor, a nurse or a trained assistant; others require referral to a specialist such as a neuropsychologist or [neuropsychiatrist](#). Most of these in-office tests have a range of normal scores and a cut-off score for dementia, adjusted for age and education. However, determining whether someone actually has dementia or mild cognitive impairment requires consideration of additional clinical history and daily functioning.

Preliminary tests that might be suggested include the following:

- The **Mini-Mental State Exam (MMSE)** is an 11-question measure that evaluates five areas of cognitive function: orientation, registration, attention and calculation, recall and language. It takes less than 10 minutes and can be administered routinely as part of your PD check-up or at a primary care visit.
- The **Montreal Cognitive Assessment (MoCA)** is a 22-question measure that evaluates eight cognitive domains: memory, visuospatial ability, executive function, orientation, verbal fluency, attention, concentration and working memory. Similar to the MMSE, it takes less than 10 minutes to complete and can be administered routinely.
- The **Ascertain Dementia 8-item Informant Questionnaire (AD8)** is a brief interview that differentiates between cognitive changes due to aging and dementia. It is administered to a relative or friend (the "informant") of the person with potential cognitive change, though it can also be completed by the patient.
- The **Mini-Cog** is a three-minute instrument that can increase detection of cognitive impairment in older adults and identify patients who need more thorough evaluation.
- The **Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)** is a 16- or 26-question survey that assesses cognitive decline and dementia. A relative or friend who has known the person with Parkinson's for at least 10 years completes the survey.
- The **General Practitioner Assessment of Cognition (GPCOG)** screens for dementia in the primary care setting. Your provider will ask you and your

22 COGNITION

care partner questions; it takes less than 10 minutes.

- Tests for visuospatial acuity evaluate performance on tasks such as copying, ordering and finding things. These tests help identify where a person falls on the continuum from normal aging to dementia.

Many of the above tests are available in multiple languages. If English is not your first language, you can ask for the test(s) in your primary language.

Findings from the tests on the previous page can help monitor cognitive change. Your doctor will decide whether it is necessary to refer you to a specialist for further evaluation. Depending on test outcomes, your care team will work with you on appropriate coping strategies.

Sudden or rapidly developing changes in cognition are not typical of PD and should be evaluated for the presence of medical issues (e.g., urinary tract infection, stroke) or medication side effects. A "sudden" timeframe can be defined as over the course of hours, days or even weeks. If you are experiencing changes in your thinking and memory, make sure that your medical team screens for other conditions mentioned above. Rapid change is usually treatable and reversible. Gradual cognitive change, over the course of many years, is more likely due to your Parkinson's.

NOTE

At this time, there is no predictive tool to know who will or won't experience changes in thinking.

CHAPTER FOUR

Treatment Options

At this time, there are no treatments that can stop or reverse the course of cognitive decline and no treatments specifically for mild cognitive impairment. The goal of treatment for cognitive issues is to slow the progression of symptoms and help you develop ways to compensate. The strategies on the following pages are most effective early in the course of disease, while exercise is important throughout your PD journey (see chapter 5, "Exercise Effects on Cognition").

Medications

As mentioned earlier, some medications can affect your cognition. People react to medications differently: individual physiology, your general health, other medical conditions and other drugs you are taking can impact how you respond. Since cognitive deficits can have a great impact on independence, it is important to discuss your symptoms and experiences with your healthcare team.

Your healthcare provider can help you identify if certain medications help or interfere with your movement, attention, memory, sleepiness or motivation. For example, anticholinergics (trihexyphenidyl and benztropine) can cause confusion and memory problems, especially in elderly people. Amantadine can also cause confusion. If you experience confusion, simplifying your medication regimen is often the first step. Your provider might suggest stopping one or more of your dopaminergic medications to see if that helps. However, being "off" or having motor fluctuations can be frustrating, too, so optimizing dopamine replacement for motor symptoms is the best strategy for most people. Work with your care team to find the best medication regimen to address both your motor and non-motor symptoms. Remember, it is important to take your medication on time, every time.

Currently, there are no drugs available to address decline in executive function. However, some stimulants may help cognition by improving attention and alertness. Stimulants range from caffeine to prescription drugs like Ritalin.

There are a few medications used to treat memory problems. They are in a class of drug called cholinesterase inhibitors, which block the breakdown of acetylcholine. This means there is more acetylcholine available for communication between cells.

- Donepezil (Aricept)
- Galantamine (Razadyne)
- Rivastigmine (Exelon)

Finally, memantine (brand name Namenda) is a drug used to treat moderate to severe dementia. It regulates glutamate, a chemical messenger involved in brain function including learning and memory.

Counseling and Behavior Management

If you experience changes in cognition, you and your care partner may consider counseling to help learn coping strategies and come to terms with these changes – and any accompanying changes to your family dynamics. There are several techniques you may try with the guidance of a mental health professional.

- **Cognitive feedback:** An approach that uses prompts, cues and questions to help you reflect on your negative thoughts, understand and accept the problem, write out positive thoughts and visualize positive outcomes.
- **Cognitive restructuring:** The process of learning to identify and reframe negative thoughts and challenge the beliefs that can lie behind them.
- **Self-dialogue/role-play:** An approach that allows for you to explore how you as a person have changed as a result of Parkinson's disease. It can help you and your family adapt to your changing roles and develop more effective methods for communicating.
- **Biofeedback:** The idea that by becoming aware of what's going on inside your body, you can gain control over some of those functions and your overall health.

A counselor can also offer practice with coping strategies and compensation techniques, such as setting alarms for medication times, using a planner to remember appointments and other tips suggested in previous chapters. Simple, repeatable, reinforced steps for basic activities can foster independence and feelings of success.

As Parkinson's progresses, gentle reminders from your care partner, family or friends might become necessary, but they can help you continue to enjoy your daily activities. Similarly, memory cues can often lead to improved performance in activities of daily living. Also known as retrieval cues, they are hints to help us remember things. Sights, smells and sounds can all be memory triggers, along with key words or details.

TIP

Bear in mind that these strategies are most effective when cognitive change is mild, because you need to remember what you did in the session for it to be useful.

Other Treatments for Dementia

Studies have shown that prescription medications developed for Alzheimer's disease have benefits in PD dementia, including rivastigmine (the only FDA-approved PDD medication), donepezil and galantamine. A doctor can also recommend counseling and other therapies.

COPING STRATEGIES to help you accept and adapt to cognitive change

- Make checklists for specific tasks, such as when you take your medication, eat and exercise.
- Post notes in helpful locations around the house to help you remember to turn off the water or the stove, remind you where you put your keys, etc.
- Cue yourself to use your assistive devices. For example:

Anthony has been living with Parkinson's for more than a decade. He enjoys spending time with his wife and maintaining as much independence as he can. He has been able to adjust to most of his PD symptoms. He tries to move at his own pace, keeps up with his medication plan and exercises daily. Recently, he has been experiencing some balance problems, so he started using a walker. When he has been sitting for a long time he occasionally forgets to use his walker. He has had a couple falls because of this, which makes his wife nervous. They brought up their concerns with his physical therapist, who recommended a little trick to remind Anthony to use the walker. She coached him to place the walker within a few inches of his legs when seated, rather than off to the side, out of his line of sight. This way, when he stands up he bumps the walker, reminding him to use it.

CHAPTER FIVE

Exercise Effects on Cognition

Across medicine, researchers have long linked exercise to cognitive function or thinking. More recently, researchers are finding that exercise seems to improve aspects of how you think that are frequently affected in Parkinson's, such as executive function (see page 16). The parts of the brain that perform executive function tasks are the same parts that help you apply motor learning in different environments. What does that mean? For example, you use executive function centers of the brain when you go from walking inside the house to walking outside. You also use your executive function centers when you think about how to improve a motor skill – how to be better or faster at a task you already know how to do.

Today, we have ideas about how to exercise better. In the past, when scientists studied how exercise affected the brain they always studied basic aerobic training such as biking or walking on a treadmill, track or around the community. When you exercise aerobically, you make your heart healthier and you improve how your body uses oxygen. Studies of aerobic exercise have shown that it can help improve age-related changes in cognitive function. Scientists are now working to determine how well aerobic exercise works to slow Parkinson's disease. They are asking, "What is the right 'dose' of exercise to get the best benefits?" They are also looking at balancing the benefits of exercise versus the risk that exercising too much might increase your risk of falls or injury.

TIP

Based on findings from the Parkinson's Foundation's *Parkinson's Outcomes Project*, the largest-ever clinical study of Parkinson's, it is recommended that you get at least 2.5 hours of exercise a week for a better quality of life.

Ben tries to go for a walk every day for at least 20 minutes. He has been doing this for the last few years and has noticed that the activity helps his mood and focus. He likes to walk outside whenever possible to enjoy the nice weather. Ben used to skip his walks on days when it was raining or too cold outside because he was worried about slipping and falling. However, he noticed that he didn't feel as healthy on these days. He talked to his partner about this problem, who suggested that they go to the mall to walk. Ben started going to the mall when he didn't want to walk outside and is now able to walk every day – rain or shine.

In addition to aerobics, there are exercises that aim to improve common motor symptoms, such as problems with walking, posture and balance. These are called "skill-based exercises" or "goal-oriented movements." So far, we don't know which is better – aerobic or skill-based exercises. In fact, the answer may be that doing both works best of all, in particular for targeting cognition. Physical therapists commonly start with movements you are capable of doing, then gradually make the activity more difficult by adding challenges that force you to problem-solve, or have you do exercises with set goals. A goal might be to stay at a certain speed or finish a certain number of repetitions. This is the same approach used when you learned to swim or ride a bike.

How can you try to do both skill-based exercise and aerobic exercise together?

- Walk a course through your neighborhood with the goal of finishing in a pre-set time
- Ride a bike (stationary or on the road; alone or tandem)
- Learn to play ping pong

TIP

Mixing up skill-based and aerobic exercises offers the opportunity to get both motor and cognitive benefits.

Exercise and Neuroplasticity

We've known for years that exercise improves muscle strength, flexibility, bone density and cardiovascular health. New research is showing us that the brain isn't just a passive beneficiary of these health benefits. When you take up a new sport, you learn it, and that is about your brain – not just your muscles – learning the movements. This process of teaching your brain a new pattern (whether it is a movement, being comfortable in a new place, or even learning a way to think) is called neuroplasticity. We have actually measured in animals that exercise leads to the following Parkinson's-fighting changes:

- Exercise changes how the brain uses chemicals that signal from one cell to the next (neurotransmitters). Exercise actually made brain cells use dopamine more effectively.
- Exercise causes new blood vessels to grow, helping brain cells to get the oxygen and nutrients they need to stay healthy and participate in the activities of thinking.
- Exercise changes brain circuits by changing how brain cells are connected. By releasing brain growth factor, along with other effects, exercise helps neurons grow new connections. It also helps grow new neurons that become part of a more efficient brain network.
- Exercise helps the immune system to work more effectively. Recent research suggests that the immune system may play a part in PD, too.

It really is amazing that by doing something enjoyable to make your body healthier, you are making your brain healthier, too!

Benefits of exercise include the following:

- Increased blood flow to the brain
- Increased expression of growth factors that strengthen brain connections
- Optimized use of energy by brain cells (improved metabolism)
- Reduced potentially harmful effects of the immune system (inflammation)
- Improved effectiveness of the medicines you take to fight Parkinson's

What to remember:

- When you learn a new exercise skill (like tai chi, boxing or yoga) it helps both how you move and how you think.
- There is not just one best exercise – you should do aerobic, strength and skill-based exercises to get the best benefits. Pick exercises you enjoy!
- Learning new exercises, as well as pushing yourself to get better at the ones you already do, helps your neurons to grow new connections, resulting in learning.
- Doing cognitive exercises while you exercise can help stimulate the brain. For example, count backwards by 7s while you walk.
- Exercise is a LIFELONG COMMITMENT.
- Exercise is medicine, and we don't see any signs that there ever will be a pill to replace it.

TIP

.....
For more information on the benefits of exercise and guidance on exercises you can do, visit [Parkinson.org/exercise](https://www.parkinson.org/exercise). Also request your free copy of the publication *Parkinson's Disease: Fitness Counts* by calling our Helpline at 1-800-4PD-INFO (473-4636).
.....

CHAPTER SIX

Parkinson's Disease Dementia

Cognitive impairment in people with advanced Parkinson's involves more changes than can be attributed to normal aging. It includes difficulty concentrating and accurately completing tasks, trouble with recent memory and getting lost. If your cognitive ability declines in this way, you will likely need help with activities of daily living. This level of cognitive impairment is associated with further progression of Parkinson's motor symptoms, so those around you will notice significant physical and mental changes.

Cognitive impairment is often associated with:

- Declining daily function
- Diminishing quality of life
- Poor treatment outcomes
- Increased medical costs
- Increased mortality
- Care partner distress

A few years after her Parkinson's diagnosis, Cindy started noticing some problems remembering specific words, but it didn't really impact her day-to-day routine. Gradually, her husband, Roger, noticed that Cindy would sometimes forget to take her medicine and that she was easily distracted. Now, 15 years after her diagnosis, Cindy gets confused if anything disrupts the daily routine, and she sometimes gets aggressive if she can't find the right words to express what she means. Roger discussed these concerns with their social worker, and now he manages her medication: he sets out her pills and tells her when to take them because she can't remember anymore. He does not feel comfortable leaving her alone, so he has friends who help run errands and stay with Cindy occasionally so Roger can have time for himself.

Dementia

For some people, cognitive change may never progress beyond the early stages. Others experience progression from cognitive changes due to aging to mild cognitive impairment and cognitive impairment.

In the later stages of disease progression, cognitive deficits can also worsen, sometimes resulting in dementia. The word "dementia" comes from Latin roots meaning "away" and "mind." It is not a specific disease; rather, the term describes a group of symptoms associated with a decline in memory and thinking. It differs from mild cognitive impairment in that it affects thinking globally rather than just the one or two domains affected in MCI. People with dementia typically experience memory impairment and trouble with executive function, visuospatial processing and language.

Cognitive impairment becomes dementia when the loss of mental ability (or cognitive skills) interferes with activities of daily living and a person can no longer function in his or her daily life without relying on others. [Parkinson's disease dementia](#) is generally an indication of disease progression. Although up to 30% of people with PD have cognitive changes early in the disease, not everyone with PD will develop dementia. The risk for dementia is relatively low among people under age 65, but by age 85 the majority of people with Parkinson's experience some degree of dementia.

The likelihood of developing dementia has been associated with certain conditions. We refer to them as risk factors, but they have not been proven to cause dementia; rather, they appear to be present in people with PD dementia. These include:

- Increasing age
- PD onset at older age
- Longer disease duration
- Family history of dementia
- Motor symptom severity

Additionally, among Medicare beneficiaries with PD, dementia is most common in Black/African Americans and Hispanics.

If symptoms of dementia come on suddenly, you should report it immediately to a healthcare provider, as there is likely another cause. For example, [delirium](#) causes similar symptoms, such as disorganized thinking, unusual behavior and hallucinations. However, delirium is reversible, because there is usually an underlying medical condition, such as a urinary tract infection, or it can be a medication side effect. Delirium generally resolves quickly and may never appear again, while the symptoms of dementia are persistent and onset is gradual and permanent.

Dementia with Lewy Bodies

Dementia with Lewy bodies (DLB) is a progressive, neurodegenerative disease in which abnormal deposits of a protein called alpha-synuclein build up in multiple areas of the brain. This is the same protein build up that is found in individuals with PD, but memory and thinking problems occur later in the disease for those with Parkinson's disease dementia.

If dementia occurs before or within one year of motor symptoms, a diagnosis of DLB should be considered, especially if the person also experiences hallucinations. The lack of a strong symptom response to levodopa is another distinguishing factor. Dementia with Lewy bodies is often referred to as an [atypical parkinsonism](#), or a "[Parkinson's plus" disorder](#) (motor symptoms of Parkinson's, plus others). It is present in 5–15% of overall dementia cases. You may need to consult a movement disorder specialist to determine whether you have DLB or one of the other atypical parkinsonisms.

ALZHEIMER'S DISEASE

What is it?	The most common type of dementia and the most common neurodegenerative disorder
How common is it?	60–80% of dementia cases
Most common symptoms	Memory loss that disrupts daily life; no new memories formed Language difficulties – problems with words in speaking or writing
Main protein involved	tau
Treatment options	Early to moderate stages: cholinesterase inhibitors to treat memory problems <ul style="list-style-type: none">• donepezil (Aricept)• galantamine (Razadyne)• Rivastigmine (Exelon) Moderate to severe: memantine (Namenda) prescribed to improve memory, attention, reason, language and the ability to perform simple tasks
Risk factors	Age Family history Genetics
Functional differences	Memory does not benefit from cueing

PARKINSON'S DISEASE DEMENTIA

DEMENTIA WITH LEWY BODIES

A type of dementia that can develop in people with Parkinson's years after the PD diagnosis

A type of dementia and atypical parkinsonism in which cognitive symptoms are present before or within one year of noticing motor symptoms

Together with dementia with Lewy bodies represents the second most common form of neurodegenerative dementia

Together with Parkinson's disease dementia represents the second most common form of neurodegenerative dementia

- Problems with:
- Attention
 - Recent memory
 - Executive function
 - Visuospatial relations

Dementia before or within one year of motor symptoms
 Progressive cognitive decline
 Fluctuations in alertness and attention
 Visual hallucinations
 Parkinsonian motor symptoms such as slowness of movement, difficulty walking or rigidity

alpha-synuclein

alpha-synuclein

Same as Alzheimer's*

Same as Alzheimer's*

Age
 PD onset at older age
 Longer PD duration
 Family history of dementia
 Severe motor symptoms

Age
 Male sex
 Family history of PD
 Genetics

Memory benefits from cueing (recognition memory is more preserved than free recall)

Memory is intermediate between AD and PD

**The drugs listed are all FDA-approved to treat Alzheimer's disease (at various stages), but the same medications are used to treat other types of dementia.*

DLB is second only to Alzheimer's as the most common cause of dementia in the elderly. It can cause progressive intellectual and functional deterioration, along with frequent changes in thinking ability, level of attention or alertness and visual hallucinations. Tremor is either slight or non-existent. The parkinsonian symptoms may or may not respond to levodopa.

Alzheimer's Disease

Because Alzheimer's disease (AD) is the most common type of dementia (more than 60% of dementia cases turn out to be Alzheimer's), many people assume that if you have dementia, you have AD. This is not the case. There are some similarities between Alzheimer's and Parkinson's – they are both progressive neurodegenerative disorders that usually occur later in life – but they are distinct. Parkinson's is a movement disorder; some people will have cognition or mood issues, and a smaller number will develop dementia. Alzheimer's is a memory disease that is not characterized by movement difficulties. Although rare, Alzheimer's disease and Parkinson's disease can occur together.

Fortunately for people with PD, Parkinson's disease dementia is less disabling than AD. People with Alzheimer's have language difficulties earlier than people with Parkinson's, and no new memories are formed. People with PD also have more ability to compensate and to make adjustments based on cues.

For example, in mild to moderate PD dementia, encoding is still intact. This means that new memories can be formed. However, you might have difficulty retrieving the memories, possibly due to executive dysfunction in PD. Fortunately, hints or cues can usually help you remember, by helping your brain's search function. In part, this is why people with PD dementia often have better recognition memory than free recall. For example, in the test of delayed word recall mentioned on page 18, you might not remember the words you are told until you are given a hint about the category that includes the word (e.g., the hint "flower" would help you remember the word "rose").

CHAPTER SEVEN

Talking About Cognitive Change

Some people are comfortable talking to others about any aspect of their condition. Others find these conversations awkward or embarrassing, and this sensitivity may be even greater when it comes to cognitive change.

If you let people know about some of your difficulties early on, it may make social interaction more comfortable. You do not have to tell everyone – start with a few trusted family members and friends, and get ahead of the questions through education.

Communication

Changes in voice volume (hypophonia) and facial muscles (hypomimia, or facial masking) can make it hard for people with Parkinson's to communicate clearly. This difficulty can be even worse if it takes you longer to process information. People might begin to ignore you or jump in to finish your sentences. Even if they are trying to help, this can be frustrating. Try to have conversations one-on-one or in small groups, so you have a better chance of being heard.

Nora lives in an assisted living facility. She has had Parkinson's for many years but can still move around without help as long as she uses her walker. However, Parkinson's has affected her cognitive processing, so it can take Nora a while to respond when someone speaks to her. She was sitting in a chair in the living area when two other residents walked by and said hello to her. Because of her facial masking and the fact that she didn't respond right away, the ladies walked by commenting loudly about how stuck up she was. Nora did eventually say hi, but the ladies had already walked away.

Empathy

Studies have shown that as dopamine levels in the brain decrease, some people have trouble understanding other people's negative emotions, including anger, disgust, fear and sadness. This loss of empathy can also be experienced as the lack of a verbal filter. If you can't recognize the feelings of others, you may say things that are hurtful or embarrassing, especially if comments are made in public. This is not intentional, but it can cause strain in families, friendships, and at work. Reminding yourself and others that this is another part of Parkinson's may help ease tension and soothe hurt feelings.

Work life

Many people with Parkinson's continue to work for years after their diagnosis, but eventually you may find that your work becomes more challenging. At some point, you need to decide when and how to tell your employer. This is an individual decision based on your position, time on the job, and relationship with your supervisor. Some people tell their friends and employers right away, while others wait until their symptoms begin to interfere with their output.

Whether your motor or non-motor symptoms appeared first, you may have already had to make adjustments at work. Depending on your specific career, you need to consider the following:

- Your safety and the safety of others
- The accuracy of your work
- Whether accommodations can be made for you at work, such as adjustment of responsibilities, schedule or travel

Joe is an account manager at an advertising agency. Several years after his PD diagnosis, he started having some problems multi-tasking. He struggled to juggle multiple accounts for different companies. Joe told his bosses that he could no longer manage so many projects but that he felt he could still contribute to the company. His supervisor reassigned him to one of their larger projects so that he could work with one company only, instead of having to switch between multiple, smaller accounts. Joe feels much more confident with this arrangement.

Driving

Cognitive change can affect your ability to drive, potentially impacting both personal and public safety. To avoid hurt feelings and arguments, spouses or other close friends or family may not be the best people to have conversations around driving safety. It is best to have a driving assessment program or clinician carefully evaluate driving skills. Occupational therapists sometimes offer this assessment. Professionals can deliver the message if driving is no longer safe. Then you and your family can have a conversation about acceptable transportation options, so you can maintain active social engagement.

NOTE

If you notice thinking changes in yourself or a loved one, consider a driving evaluation to assess driving skills and safety. Check for local resources in your community or contact the Parkinson's Foundation Helpline at 1-800-4PD-INFO (473-4636) or helpline@parkinson.org.

Tips for Care Partners

Dealing with changes in mental status in someone you care about is challenging. As with motor symptoms, and as with life, there are good days and bad days. As the disease progresses, you will have to come to terms with new losses. Changes in cognition can be particularly frustrating, as there are few treatment options, and behavioral strategies and cues you used earlier in the disease are no longer effective. What was once a simple conversation about the weather or a grocery list no longer seems simple. The person with dementia may not be able to participate constructively.

As a care partner, you play an important role in the quality of life of the person with Parkinson's. Here are some tips to help you manage day-to-day life with someone with dementia:

- A smile and pleasant manner can invite cooperation.
- Do not leave someone with dementia alone. Lack of judgement and/or impulsive behaviors can create a dangerous situation.
- Use exercise, diet and rest to keep your loved one as healthy as possible.
- Give medication on time as prescribed by the doctor.
- Create and follow a routine.
- Make a list of important phone numbers, and keep a copy with you in case of emergencies.
- Keep written track of appointments, tasks and medication schedules.
- Stay calm and be patient.
- Speak slowly and use simple sentences to communicate.
- Ask one question at a time and wait for an answer. Use either/or questions instead of open-ended questions. Instead of asking, "What would you like for lunch?" try asking, "Would you like soup or a sandwich for lunch?"
- Limit distractions as you try to accomplish the daily routine. Make sure to turn the TV or radio off before asking the person to do something.
- Try not to argue. It is usually not helpful to try to reason or tell the person with Parkinson's dementia that he or she is wrong.
- Consider what may be causing a disruptive behavior. The person may be hungry, thirsty, tired, in pain, frustrated, lonely or bored.
- If the person seems to be stuck on an idea (e.g., "I have to get dressed for work"), try agreeing with her and then distracting her with something else.

NOTE

Based on the 2020 Care Partner Summit | Cumbre Para Cuidadores registration, the Parkinson's Foundation found that cognitive changes are a significant challenge for care partners regardless of length of disease, age of care partner and gender of both the care partner and PwP, with 51% of responses of spouses/partners placing cognitive changes as one of the three most challenging symptoms.

An important part of being a caregiver for someone else is taking care of yourself, both physically and mentally.

- Be kind to yourself, and acknowledge your right to feel emotionally off-balance. Remember you are experiencing normal reactions to abnormal circumstances.
- Build in regular breaks from caregiving, and make them a priority. Take time off to relax, socialize and exercise. Get outside help; this can be a family member or a paid caregiver. Your loved one can survive for a few hours and, periodically, a few days without you, even if he claims he cannot. Getting outside help early on can make the transition easier when dementia becomes more severe.
- Use a journal or other creative outlet to express your feelings.
- Determine your limits, and get help as needed. No one person is ever able to meet all of an individual's needs, and as Parkinson's progresses this becomes more and more true.
- Talk to someone. This can be a friend or family member, but a professional counselor is objective and has training and experience working with people in similar situations. The same techniques described on page 25 for people with Parkinson's can be helpful for you, too.

TIP

As time goes on, you may find that you are spending more time as a care partner than as a significant other, friend or family member. This can be a difficult adjustment for everyone involved. Remember that there are resources available to help you navigate these changes. Get your free, comprehensive care partners guide, *Caring and Coping*, by calling the Parkinson's Foundation Helpline at 1-800-4PD-INFO (473-4636).



Summary

Some people are comfortable talking to others about any aspect of their condition. Others find these conversations awkward or embarrassing, and this sensitivity may be even greater when it comes to cognitive change.

If you let people know about some of your difficulties early on, it may make social interaction more comfortable. You do not have to tell everyone – start with a few trusted family members and friends, and get ahead of the questions through education.

Glossary

Glossary terms are identified with a blue underline the first time they appear in this book.

A **Acetylcholine** A chemical messenger (see neurotransmitter) released by cholinergic nerves; involved in many brain functions, such as memory and control of motor activity

Agitation A state of anxiety or nervous excitement

Alpha-synuclein A protein in the human brain that is associated with the development of Parkinson's; it is the main component of Lewy bodies

Alzheimer's disease A progressive, neurodegenerative disorder that results in the loss of memory, thinking and language skills, and behavioral changes

Anticholinergic The earliest medications used in Parkinson's, these medications block the neurotransmitter acetylcholine; they can cause significant mental and physical side effects, so they are most useful in young people with tremor-predominant PD; some antihistamines and sleeping agents (e.g., Benadryl) are anticholinergics

Atypical parkinsonism A general term that refers to a group of neurological disorders that cause movement problems similar to those seen in Parkinson's disease, such as tremors, slow movement and stiffness; also called Parkinson's plus syndromes

B **Basal ganglia** Area of the brain responsible for motor control and elements of thinking

Benzodiazepine A class of medication that produces sedation and muscle relaxation; used to treat anxiety

Bradykinesia Slowness of movement; one of the four main motor symptoms of PD

Bradyphrenia Slowed mental processing or thinking

C Cardinal symptom Primary clinical symptom used to make a diagnosis; in Parkinson's, the three cardinal symptoms are tremor, rigidity and bradykinesia

Cholinesterase inhibitor A class of medication used to treat memory loss; these drugs prevent the breakdown of acetylcholine, which is important for learning and memory

Cognition Mental abilities involved in processing and using information, including memory, attention, thinking, problem solving, language and visuospatial abilities

Cognitive impairment Noticeable and measurable decline in cognitive abilities, including memory and thinking skills

D Delirium A reversible medical condition that involves a state of altered alertness, disorientation, disorganized thinking, unusual behavior and/or hallucinations; can be hard to differentiate from other psychiatric conditions

Delusion False, fixed, idiosyncratic beliefs, not substantiated by sensory or objective evidence; delusions are not deliberate and cannot be controlled

Dementia A progressive decline in memory and thinking that impairs one's ability to function independently

Dementia with Lewy bodies (DLB) Unlike Parkinson's disease dementia, cognitive symptoms are present before or within one year of noticing motor symptoms; the central features of DLB include progressive cognitive decline, fluctuations in alertness and attention, visual hallucinations and parkinsonian motor symptoms such as slowness of movement, difficulty walking or rigidity

- Depression** A mood disorder whose symptoms can include a persistent sad or empty mood, feelings of hopelessness or pessimism, irritability and loss of interest or pleasure in previously enjoyable activities
- Dopamine** A chemical messenger (see [neurotransmitter](#)) that is primarily responsible for controlling movement, emotional responses and the ability to feel pleasure and pain; in people with Parkinson's, the cells that make dopamine are impaired or die
- Dysarthria** Speech disorder (slurred or unclear speech) caused by problems with the strength or coordination of the muscles that produce speech, as a result of damage to the brain or nerves
- E Empathy** The ability to understand the feelings of another person from their perspective
- Excessive daytime sleepiness** A chronic condition characterized by difficulty staying awake or paying attention; may be due to underlying sleep disorders, depression and some medications
- Executive function** The brain's ability to analyze, plan, organize, schedule and efficiently complete tasks
- H Hallucination** Something you see, hear, smell, taste or feel that is not actually there
- Hypomimia** Reduced facial expression; also called "facial masking"
- Hypophonia** Soft speech, commonly from lack of coordination in vocal muscles
- I Illusion** A distortion of a sensory perception; when you misinterpret real external stimuli; e.g., mistaking hats on a coat rack for heads

L Levodopa The medication most commonly given to control the motor symptoms of Parkinson's; it is converted in the brain into dopamine

M Memory cues Verbal or environmental clues (such as smells, sounds and images) that help us recall or remember

Mild cognitive impairment (MCI) The intermediate stage between the decline of normal aging and dementia; it can involve problems with memory, language, thinking and judgment

Motor fluctuations Changes in the ability to move, often related to being in the "off" medication state when Parkinson's symptoms reemerge; also called "on-off" fluctuations

N Neurodegenerative disorder A disease characterized by the loss of cells of the brain or spinal cord, which over time leads to dysfunction and disability; Parkinson's disease, Alzheimer's disease and Lou Gehrig's disease are all examples

Neuron Brain cell

Neuroplasticity The brain's ability to reorganize itself by forming new connections; this allows the brain to compensate for injury and disease and to respond to new situations and changes in the environment

Neuropsychological tests Standardized tests to evaluate functioning in a number of areas including executive function, memory, mood and daily activities; these tests can be repeated over time to evaluate change

Neuropsychiatrist A physician who combines the specialties of neurology and psychiatry to treat and manage the emotional (mental health) and cognitive symptoms of neurological diseases

- Neuropsychologist** A licensed psychologist with expertise in how behavior and cognitive (thinking) skills are related to brain structure and symptoms
- Neurotransmitter** A chemical messenger, such as dopamine or acetylcholine, that transmits nerve impulses from one nerve cell to another, allowing them to communicate with each other
- Non-motor symptom** A symptom of Parkinson's that affects something other than movement, such as sleep, mood, behavior, sensory function (sense of smell, vision, pain) or autonomic function (urinary, gastrointestinal and sexual function); typically does not respond to dopamine-replacement therapy
- P Parkinson's disease dementia** A type of dementia that affects attention, recent memory, executive function and visuospatial relations; it usually develops years after the PD diagnosis
- Parkinson's plus syndrome** See atypical parkinsonism
- Physiology** How your body parts and systems function
- R Rapid eye movement (REM) sleep behavior disorder** A sleep disorder in which you physically act out dreams
- V Visuospatial perception** The ability to perceive objects and the spatial relationships among objects
- Vivid dream** A dream that is very realistic and can be caused by awakening during the dream

Index

- Acetylcholine 12, 24, 43–44, 47
 Alzheimer's disease 34–36, 43, 46
 Amantadine 24
 Anticholinergics 10, 12, 24, 43
 Aricept 24, 34
 Ativan 12
 Attention 7–9, 15–16, 19–21, 24, 44–45, 47
 Benadryl 10, 12, 43
 Benzodiazepines 12, 43
 Benztropine 24
 Bradyphrenia 16, 44
 Cholinesterase inhibitors 24, 34, 45
 Confusion 10–12, 20, 24
 Delusions 20, 44
 Dementia with Lewy bodies 33–35, 43–44
 Depression 8–10, 12, 45
 Diabetes 11
 Diphenhydramine 10
 Donepezil 24
 Driving 24
 Executive function 15–16, 20–21, 24, 27, 32, 45–47
 Exelon 24, 34
 Exercise 5, 10, 17–19, 23, 26–30, 40–41
 Fatigue 9–10
 Galantamine 24, 34
 Genetics 6, 13, 34–35
 Hallucinations 12, 20, 33–35, 44
 Illusions 18, 45
 Klonopin 12
 Language 1, 7, 17, 20–21, 32, 36, 43–44, 46
 Melatonin 10
 Memantine 24, 34
 Mild cognitive impairment 15, 20, 23, 32, 46
 Namenda 24, 34
 Neurogenic orthostatic hypotension (nOH) 11
 Neuroplasticity 29, 46
 Neuropsychiatrist 20, 46
 Neuropsychological testing 20
 Neuropsychologist 20, 47
 Oxycodone 12
 Parkinson's disease dementia 32–35, 44, 47
Parkinson's Outcomes Project 11, 28
 Percocet 12
 Razadyne 24
 Ritalin 24
 Rivastigmine 24, 34
 Sleep problems 9
 Trihexyphenidyl 24
 Valium 12
 Visuospatial processing 7, 18, 20–21, 32, 44, 47
 Xanax 12
 Vicodin 12

ABOUT THE PARKINSON'S FOUNDATION

The Parkinson's Foundation makes life better for people with Parkinson's disease by improving care and advancing research toward a cure. In everything we do, we build on the energy, experience and passion of our global Parkinson's community. A wealth of information about Parkinson's and about our activities and resources is available on our website, Parkinson.org.

YOUR FEEDBACK MATTERS!

We'd like to know what you think of our publications and programs. Please take a few moments to fill out our online feedback form. Your answers will be used to improve our resources and will benefit people with Parkinson's, caregivers, families and others in the Parkinson's community. Thank you for your help.

ONLINE FORM: Parkinson.org/feedback

YOUR GENEROSITY MAKES THIS PUBLICATION POSSIBLE.

The Parkinson's Foundation is proud to provide this booklet and other educational materials at no cost to people around the globe. If you found this book helpful, please consider a gift so that we may continue to fight Parkinson's on all fronts: funding innovative research, providing support services and offering educational materials such as this publication. Thank you for your support.

DONATE ONLINE: Parkinson.org/donate

DONATE BY MAIL: Parkinson's Foundation
200 SE 1st St, Suite 800
Miami, FL 33131

DONATE BY PHONE: 1-800-4PD-INFO (473-4636)

TAX ID: 13-1866796

The information contained in this publication is provided for informational and educational purposes only and should not be construed to be a diagnosis, treatment, regimen or any other healthcare advice or instruction. The reader should seek his or her own medical or other professional advice, which this publication is not intended to replace or supplement. The Parkinson's Foundation disclaims any responsibility and liability of any kind in connection with the reader's use of the information contained herein. ©2018



200 SE 1ST STREET, SUITE 800
MIAMI, FLORIDA 33131

1359 BROADWAY, SUITE 1509
NEW YORK, NEW YORK 10018

HELPLINE:
800.4PD.INFO (473.4636)
HELPLINE@PARKINSON.ORG

PARKINSON.ORG