



Navigating Cognitive Changes in Parkinson's Disease

A Guide for Patients and Families

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Thinking about Brain Health

Parkinson's disease (PD) traditionally is called a "movement" disorder because of its classic features: tremor occurring primarily at rest, slowness of movement, stiffness and, particularly later in the disease, walking and balance problems. But it's also a non-movement disorder.

Some of the most common and prominent symptoms include mood and sleep changes, constipation and fatigue. Thinking and memory (cognitive) changes can be part of the disease, too.

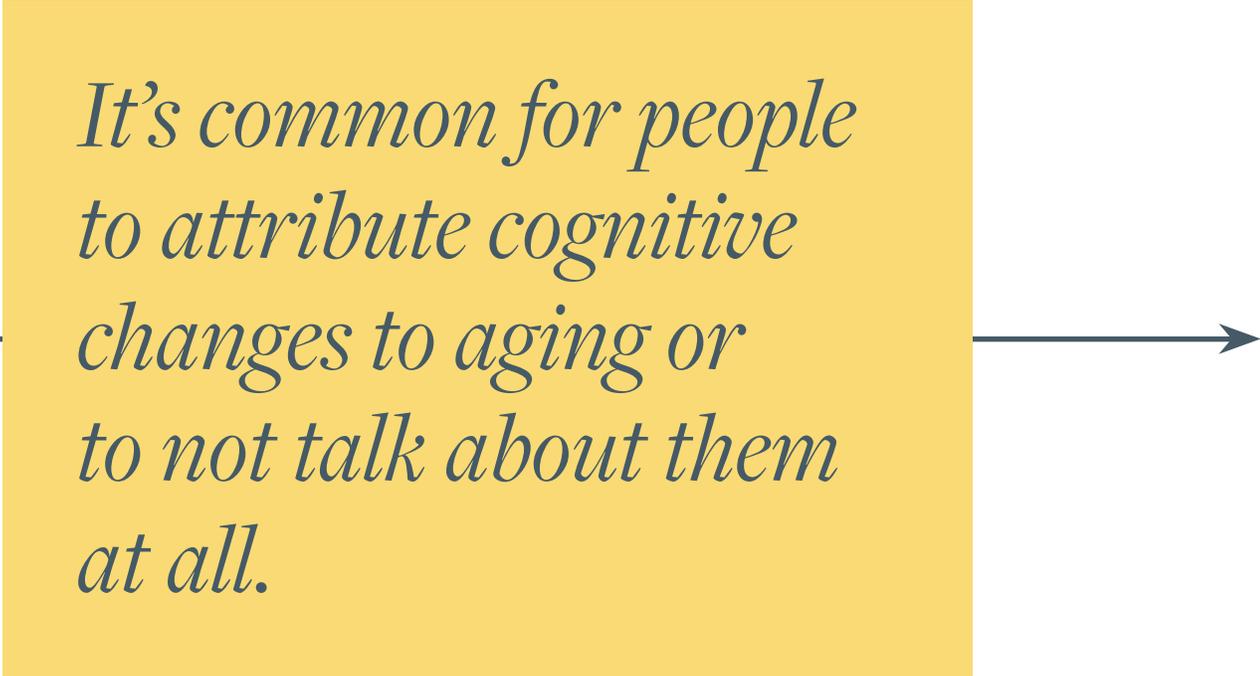
Not everyone with PD experiences cognitive issues and, as with all Parkinson's symptoms, when and how they occur is unique to each

person. But many people with Parkinson's and their families say changes in thinking and memory are among the most concerning potential symptoms of the disease. These symptoms are, unfortunately, also some of the least talked about. Doctors may focus on movement problems, especially in the early years after a diagnosis. And patients and families may be unsure about what they're experiencing. It's common for people to attribute cognitive changes to aging or to not talk about them at all, because they don't want to think about what may (or may not) lie ahead.

But avoiding discussion can increase fear, misperception and misinformation — and lessen quality of life. It also can slow much-needed

research into why these changes happen and how to treat and ultimately prevent them. By opening the conversation, you can take steps to keep your brain healthy and recognize changes if they happen.

We created this guide in collaboration with people and families who live with Parkinson's and related disorders and the expert clinicians who care for them. It is intended to help you understand your experiences, start a dialogue about brain health and connect to ongoing research. Whether you want to know the bare minimum, everything there is to know, or — like many people — you're somewhere in between, we hope you take the information and practical tips that speak to you, wherever you are in your journey with PD or cognitive changes.



It's common for people to attribute cognitive changes to aging or to not talk about them at all.

What Is Cognition?

Cognition is the work our brain does to collect, process, remember and respond to information. It's anything we do that requires thought or memory: getting ready for work, chatting with friends, reminiscing about childhood or setting goals for the future. There are different aspects of cognition:



Attention

Attention is focusing on one thing while tuning out everything else. You need to pay attention to watch a movie, drive a car or be part of a group conversation.



Memory

Memory is the storage of information to recall or use later. Different systems store different types of memories. Long-term memories are kept for days, weeks, years or decades, and include facts (who the president is), life experiences (where you went to school or when you got married) and skills (how to ride a bike or brush your teeth). Short-term memory holds small bits of data for short periods (such as a phone number that you forget after you write it down). Working memory is for information that you are actively using (storing numbers in your head while you work with them to solve a math problem, for example).



Executive function

Executive function includes multitasking, problem-solving, organizing, planning and decision-making. These parts of cognition control and coordinate other brain functions and behavior. Doctors call these executive functions because they're similar to the responsibilities of an executive who runs multiple departments of a company.



Language

Language is the system we use to communicate through speaking and writing. It involves naming objects (calling a tree a "tree," for example), understanding words' meanings, finding the words you need to speak smoothly and without pauses, and using sounds and phrases to accurately express yourself.



Visuospatial skills

Visuospatial abilities help you create a mental picture of your surroundings and tell where you are in relation to other objects. These skills enable you to give directions, judge the distance between your car and the one in front of you, and find your way home after a walk around the neighborhood.

As we get older, cognition naturally changes because our brains change. Vocabulary and general knowledge tend to increase, but it can be harder to understand and learn new information as easily or as quickly. Using a smartphone or playing a new card game, for example, may take more mental effort. Memory may not work as well as it did in previous years. Many people have difficulty recalling new acquaintances' names, forget why they walked into a room or misplace items, such as eyeglasses.

Because Parkinson's also can affect cognition, it can be hard to know what's normal aging and what's part of the disease. Bret Parker, a lawyer and co-chair of The Michael J. Fox Foundation (MJFF) Patient Council, says, "Sometimes I can't tell if my brain just isn't as sharp as it used to be because I'm getting older or because of Parkinson's."

Cognitive changes from Parkinson's often are different or more than you'd expect with age. As you get older, it may be normal to leave your keys in the door, forget something at the grocery store or miss an occasional bill payment. But age alone doesn't usually cause a person to forget what their keys are for or how to use them, how to get to and around their usual grocery store, or how to balance the checkbook and transfer money between bank accounts.

To get a sense of what is or isn't typical, you might ask friends in your age group (both with and without Parkinson's) if they have similar experiences and gauge how you're doing with your daily activities. (See page 8: *Keeping Track of Cognitive Changes.*)

Cognitive changes from Parkinson's often are different or more than you'd expect with age.

Boosting Brain Health

Whether you're experiencing cognitive changes or you worry about the possibility, you can take steps to keep your brain as healthy as possible. Researchers have not yet proven ways to prevent or slow cognitive changes, but the current evidence suggests that what's good for your body is good for your brain. Practice these heart- and brain-healthy activities:



Exercise regularly

Any aerobic exercise (such as cycling, boxing or dancing) is beneficial for general well-being and brain health. No matter your age, fitness level or Parkinson's symptoms, you can be active. Work with your doctor and physical therapist to find an exercise you enjoy, feel safe doing and will do regularly.



Be socially active

Spending time with friends and loved ones and meeting new people not only prevents isolation that can come with Parkinson's, but also gives you a chance to put your brain to work. At social gatherings, for example, you can practice learning new names and discuss current events.



Eat a healthy, balanced diet

There is no specific "Parkinson's" or "brain" diet. Aim to eat a variety of fruits and vegetables, whole grains and, for non-vegetarians, more fish and poultry than red meat. Limit sugary, processed foods. The Mediterranean and MIND (Mediterranean-DASH Intervention for Neurodegenerative Delay) diets incorporate these concepts. (For more, read our [Guide on Diet and Parkinson's.](#)) 



Get involved in the community

By taking an active role in the Parkinson's or local community, you can give and receive support and make connections. There's something for every schedule, interest and comfort level. You can attend a neighborhood event or join a Parkinson's support group, advocate for Parkinson's policies or participate in research.



Train your brain

Your brain is a bit like your muscles; it needs a regular workout to stay in shape. Play “brain games” online or on your smartphone, do a crossword or jigsaw puzzle (get a group together so you can socialize too!), learn to speak a second language, take music lessons or start a hobby that challenges you in a new way.



Reduce stress

Everyone experiences stress in different ways and to different degrees. Common stressors may involve work, family or balancing the two. Stress can worsen Parkinson's symptoms and cause thinking and memory changes. Identify your stressors and find ways to relieve them. Meditate, practice mindfulness, go for daily walks, or spend time gardening or relaxing in nature.



Sleep well

Researchers believe we store memories and rejuvenate our bodies during sleep. Not getting enough rest can make it harder to manage Parkinson's and think clearly. (Most of us have felt the fogginess and slowness that follows a poor night's sleep.) Make sure you get enough sleep each night for someone your age and maximize sleep by: keeping a regular schedule for going to bed and getting up, creating a routine to relax before bedtime (taking a bath or reading a book), limiting daytime naps and electronic screen time before bed, and watching how much and what you drink as well as how close to bedtime you exercise. If you have trouble sleeping — a common problem in PD — ask your doctor about ways to improve your rest and if medications or other therapies might help. (For more, check out our [Practical Guide on Sleep and Parkinson's.](#)) 



Take care of medical conditions

Diabetes, high blood pressure and high cholesterol can damage your brain's blood vessels and lead to thinking and memory problems. If you live with one of these diseases, work with your doctor to control it with diet, exercise and medication.



Check on mood and motivation

Depression, anxiety and apathy (lack of motivation) — non-movement symptoms of Parkinson's — can cause or contribute to cognitive change. Medication, talk therapy and exercise can ease depression and anxiety. Keeping a daily schedule and working toward specific goals can help apathy. If your mood or motivation are low, talk to your doctor or a loved one. And watch for times when depression, anxiety or apathy might increase, such as right after you're diagnosed, during a hospitalization or around the holidays.



Review your medications

Certain prescription and over-the-counter medications, such as the PD drug Artane (trihexyphenidyl), pain or sleeping pills, and Benadryl (diphenhydramine), can cause confusion in some people. At regular intervals (every visit or any time a medication changes), go through your medication list in detail with your doctor. For any drug that could cause cognitive difficulties, ask whether you can stop it or decrease the dose. Always speak with your doctor before making changes or adding over-the-counter medications, supplements or herbal products.



Drink alcohol in moderation

Too much alcohol can cause cognitive changes as well as walking and balance problems. Stick to the daily amount (or less) recommended by the Dietary Guidelines for Americans. (These vary for men and women.) If approved by your physician, consider an occasional glass of red wine for heart health benefits.



Don't smoke cigarettes

Cigarette smoking is associated with Alzheimer's, stroke and other diseases that cause thinking and memory problems. If you smoke, make a plan with your doctor to stop. Nicotine patches, gum or lozenges as well as prescription medications may help.



Keeping Track of Cognitive Changes

Many people with Parkinson's and their families ask what signs and symptoms are concerning. Dave Iverson, a broadcast journalist and founding member of MJFF's Patient Council remarks, "We've all had moments of losing our car keys, but what about leaving the burners on?" He adds, "When should we and our loved ones be worried, and what should we track?" Using the list below, consider the activities you do on a regular basis and whether there has been a major change in many or most of them:

+ *Paying attention*

Do you have trouble participating in or following the flow of group conversations? Is it harder to read books or watch movies because of difficulty following storylines or plots?

+ *Making decisions and solving problems*

Is it nearly impossible to make decisions, such as what to do with a free afternoon? Do you make poor decisions, such as not wearing your seatbelt or spending large amounts of money you don't have? Do you have difficulty solving problems, such as how to reroute through a traffic jam or what to do about dinner when there is no food in the house?

+ *Remembering*

Do you forget important appointments or social engagements? Do you regularly forget who called and why? Do you lose track of the season or time of year? Do you often need reminders of how to do things that were previously second nature, such as how to turn on the television or use the computer?

+ *Taking medication*

Are you able to describe which medications you take for what and when? Do you need help from your spouse or care partner to take the right medications at the right time?

+ *Behaving*

Have you or others noticed changes in your manner? What about your personality or mood? Are you more outspoken or withdrawn than you used to be?

+ *Managing money*

If you manage the household finances, do you pay bills on time, write checks correctly and balance the checkbook? Have you started regularly buying things you can't afford or don't need, such as magazine subscriptions from telemarketers or "As Seen on TV" items?

+ *Working*

Do you have trouble focusing or need more time than usual to complete tasks? Is it hard to switch between tasks? (If you get called away from one project to another, is it harder than normal to get back into the first?) Do you have difficulty multitasking, or juggling several things at once? Are you disorganized? Is it hard to follow instructions?

Even if you answered yes to several of these questions, you don't necessarily have a significant problem. But if you or your loved ones notice differences in how you think, remember, act or do regular daily activities, talk with your doctor. Together, you can evaluate what's happening and figure out the best path forward.



Cognitive Changes in Parkinson's

Not everyone with Parkinson's experiences thinking and memory changes. But for those who do, they can happen at any point, from before diagnosis to decades into life with the disease.

Symptoms vary widely. They may be subtle and barely noticeable, mild and manageable, or significant and life-altering for the person experiencing them and their family. Some people continue to work full-time, but rely on calendars, post-it notes or phone alarms to stay on schedule. Others, whose cognitive changes progress to dementia, need help with some or all of their daily activities, such as showering, dressing, using the bathroom and eating meals.

When Parkinson's affects cognition, it typically impacts executive function (multitasking, organizing, decision-making) and attention more than memory. But as with every PD symptom, each person experiences cognitive change differently. Engineer and business executive Ken Cater, an MJFF Patient Council member, says about his difficulty multitasking, "I used to prioritize a hundred things a day and now I can only do two or three." Patient activist and artist Hadley Ferguson, another MJFF Patient Council member, describes her challenges: "Information in my brain used to feel neatly organized, as if in filing cabinets, and I knew exactly which cabinet to go to for what. Now, it's like all the folders have been dumped into one big pile on the floor.

Sometimes I dig through that mental pile so long I forget what I'm looking for."

Researchers are investigating why and how Parkinson's causes thinking and memory problems. Altered brain chemicals and brain cells likely play a role. PD affects several brain chemicals, including dopamine, acetylcholine, serotonin and norepinephrine, which support thinking, attention and memory. In brain cells that are responsible for cognition, the protein alpha-synuclein can misfold and clump into Lewy bodies, which researchers believe damage the cells. (Lewy bodies also are seen in brain cells that control movement, and these may contribute to the tremor, slowness and stiffness of Parkinson's.)

"I used to prioritize a hundred things a day and now I can only do two or three."

— Ken Cater,
MJFF Patient Council

Mild Cognitive Impairment

At the earliest and mildest stages, Parkinson's cognitive changes don't noticeably interfere with everyday life. Such early changes are greater than expected with age, but you can typically work around them to do everything you need and want to do. This is called "mild cognitive impairment" (MCI).

A person with Parkinson's, their family or their physician might be the first to recognize MCI. Mild cognitive impairment can occur any time — even early — in the course of PD, so it's important for doctors to regularly ask about and look for cognitive changes. If your doctor doesn't ask, it's important for you to raise any concerns. Because Parkinson's non-movement symptoms and certain medications and medical conditions can impact cognition, your doctor may:

+ ***Ask about sleep and mood changes***

Sleep problems, depression, anxiety and apathy (lack of motivation) — common Parkinson's non-movement symptoms — can mimic or worsen cognitive changes. Each condition requires its own evaluation and treatment. Carey Christensen, patient advocate and MJFF Patient Council member, says, "The anxiety I felt around my Parkinson's caused me to lose my ability to multitask, and I've met many other patients and families who've had similar experiences. Treating depression and anxiety can make a real difference on cognitive symptoms."

+ ***Review medications and supplements***

Some over-the-counter and prescription medications can affect cognition, especially when they are first started or the dose is increased. Eugenia Brin, retired research scientist and MJFF Patient Council member, says, "I had a month-long episode in which my husband said I was 'all

scattered around.' I saw my doctor and figured out that about a month before he had increased my dose of amantadine. Once I stopped taking the extra dose, the symptoms went away." Make sure your doctor is aware of all supplements and over-the-counter medications you take, even those you use occasionally.

+ ***Look for "reversible" causes***

Certain conditions, such as vitamin B12 deficiency, low thyroid levels, untreated sleep disorders and infection, can cloud thinking. (Urinary tract infection and pneumonia are common causes of sudden confusion in people with progressing Parkinson's.) Treatment often improves cognition, so your doctor may order blood or urine tests, brain or body scans, and even a sleep study to look for these conditions. Having surgery, undergoing general anesthesia and being in the hospital also can impact thinking and memory.

+ ***Do memory and thinking tests***

To check cognition, your doctor will perform tests in the office, which include naming objects, remembering words and other short tasks.

Depending on these results, your doctor might recommend neuropsychological testing for a more thorough and detailed examination.

MCI in Parkinson's usually affects executive function and attention more than memory. (See page 3: *What Is Cognition?*) But it looks different for different people. Some people experience slower thinking or trouble finding the right words, while others have difficulty planning their day or recalling recent events. A schoolteacher may have difficulty handling multiple lesson plans and an accountant might not be able to perform complex calculations as easily. Retirees may find it harder to pursue hobbies, map out a day's activities or follow a recipe.

As with all Parkinson's symptoms, treatment of MCI is individualized. Doctors typically recommend that you keep your brain active (See page 5: *Boosting Brain Health*) and work with an occupational therapist, speech therapist or cognitive rehabilitation specialist to strengthen cognitive skills and work around your challenges. (Your physician can refer you to one of these experts.) Your doctor also will want to treat any other medical condition or symptom, such as a urinary tract infection, depression or sleep problem, which could potentially worsen cognition. Currently there are no U.S. Food and Drug Administration (FDA)-approved medications to treat mild cognitive impairment, but research in this area is ongoing.

About 25 percent of people with Parkinson's have MCI. Over time, mild cognitive impairment can stay the same, get better or worsen. For some, mild cognitive impairment eventually develops into dementia. Dementia has similar cognitive changes as MCI but to a more significant degree and with a noticeable effect on daily activities.

“The anxiety I felt around my Parkinson's caused me to lose my ability to multitask.”

— Carey Christensen,
MJFF Patient Council member



Dementia in Parkinson's Disease

For many people with Parkinson's and their families, dementia is one of the most concerning potential symptoms of disease. "A common question I hear from patients is, 'I'm not going to get Alzheimer's, am I?'" says Jennifer Goldman, MD, MS, Section Chief of Parkinson's Disease and Movement Disorders at Shirley Ryan AbilityLab and Professor of Physical Medicine and Rehabilitation and Neurology at Northwestern University.

Goldman continues, "Because there are fears and stigma associated with dementia, both doctors and patients may be hesitant to talk

about it.” But her research shows that many people with Parkinson's and their care partners want to know about dementia and other cognitive changes, and they want to know early so they can prepare and be proactive.

Katie Amodeo, MD, a movement disorder specialist at the University of Rochester, says, “Doctors use the word ‘dementia’ as a broad term for thinking and memory changes that are significant enough to affect a person's ability to do any or all of their daily activities, socialize with other people or work.” Dementia describes symptoms rather than a specific disease, so it has many possible causes. Alzheimer's disease (AD) is the most common, but other diseases, including Parkinson's and a related condition called dementia with Lewy bodies (DLB) also can cause dementia.

Parkinson's disease dementia (PDD) and dementia with Lewy bodies share symptoms and brain cell changes (clumps of alpha-synuclein protein called Lewy bodies). Because of these overlapping characteristics, PDD and DLB are grouped together under the umbrella term “Lewy body dementia.” Doctors and researchers distinguish Parkinson's disease dementia and dementia with Lewy bodies primarily based on when movement symptoms occur in relation to dementia. People with PDD start with movement symptoms and a diagnosis of Parkinson's disease. Many years or decades later, they develop dementia. Those with DLB show movement symptoms and dementia at the same time or within a year of each other.

The features of Lewy body dementia include:

+ ***Dementia***

Lewy body dementia affects thinking, attention, executive function and visuospatial skills more than memory. (This contrasts with dementia in Alzheimer's, which causes short-term memory loss as an early and prominent symptom.) People with Lewy body dementia may have trouble following steps in a process, such as baking a cake; grasping new information, such as how to play a board game; or seeing information in three dimensions to interpret road signs or give verbal directions while driving. Previously simple tasks, such as getting dressed or washing dishes, may become confusing. A person might do things in the wrong way or order, such as trying to put their leg in a shirt's armhole or putting pajamas on over clothing when getting ready for bed. Barbara Emery Mendel, who chairs a Parkinson's care partner support group and whose husband Lee lives with Lewy body dementia, says “the dishes end up half as dirty” when Lee does them. Ava Butler, an organizational development consultant, says that when her husband Richard, who also had Lewy body dementia, did dishes, he would put them away “wherever he wanted in the house.” Enjoyable activities may be more challenging, too. One of the first changes Barbara noticed in Lee was that he couldn't keep score in golf — “he put random numbers in the wrong boxes on the scorecard.” Jana Hood, a retired educator who assists her local PD support group Summit for Parkinson's, says her husband Charlie, an avid reader and writer, stopped reading novels and writing in his journals in early years with Lewy body dementia.

Memory loss can occur in Lewy body dementia, but it's usually later, less severe and different than Alzheimer's. Whereas someone with Alzheimer's likely will not remember a piece of information even when given prompts or clues, a person with Lewy body dementia might recall when explicitly asked or given specific examples. For instance, they might not volunteer that your sister called, but if you ask specifically whether anyone called or if there are messages, they may remember.

+ ***Movement symptoms***

Lewy body dementia causes the same movement symptoms as Parkinson's — slowness, stiffness, tremor, and walking and balance problems. Because people with Parkinson's disease dementia typically have lived with Parkinson's for years or decades before dementia occurs, their movement symptoms often are progressing, sometimes causing significant walking or balance difficulties. People who have dementia with Lewy bodies may have milder movement symptoms that come on before cognitive symptoms (and in some people, not at all). This can lead to a misdiagnosis of Parkinson's or another condition that is corrected when both sets of symptoms (movement and cognitive) emerge.

+ ***Fluctuating attention or alertness***

A person with Lewy body dementia may seem completely “with it” one day and confused and sleepy the next. This can be especially taxing for spouses. Barbara Mendel relates her experience with husband Lee's fluctuations: “I sometimes felt like I was going crazy because I saw things at home that no one else did and he'd appear ‘fine’ to

everyone but me.” Fluctuations may be more severe in DLB than in PDD.

+ ***Seeing things that aren't there (hallucinations)***

With visual hallucinations, a person sees things or people that aren't there. Hallucinations are realistic images of children, people or animals; a person may or may not recognize they're not real. They can come and go, sometimes disappearing for a few days or weeks and then recurring for several days in a row. Hallucinations may be non-bothersome or frightening. One person may see kids playing in the backyard. Another might watch porcelain figurines “do a little dance.” Still others find intruders in their homes, which can lead them to call the police or look for (or use) weapons to defend themselves. In DLB, hallucinations often happen earlier in the disease course and prior to treatment with any Parkinson's medications. In PDD, they happen later, and Parkinson's medications (especially amantadine or dopamine agonists such as Mirapex, Neupro or Requip) may bring them on. These drugs and certain illnesses, such as urinary tract infections, can worsen hallucinations in both DLB and PDD.

+ ***Believing things that aren't true (delusions)***

Delusions are strong beliefs about things that are not true. Often they are paranoid in nature. A person might think a loved one is an imposter, a partner is being unfaithful or children are stealing money. In some cases, hallucinations can stimulate or worsen delusions. For example, a woman may have a vision of a visitor whom she believes is her spouse's mistress. As with hallucinations,

delusions tend to occur earlier, more significantly and spontaneously (not brought on by Parkinson's medications) in DLB as compared to PDD.

+ ***Sleep, mood or behavior changes***

People with Lewy body dementia may act out their dreams, which is known as REM sleep behavior disorder. Lewy body dementia also causes mood changes, such as depression or anxiety, and behavioral problems, such as agitation, aggression or apathy (lack of motivation). If a person with DLB first presents with mood or behavior changes without movement or thinking changes, the initial misdiagnosis may be depression, anxiety or a psychiatric condition. As the disease unfolds and other symptoms manifest, doctors can make the correct diagnosis, but this can be a lengthy and frustrating process.

Dementia can range from mild to moderate to severe, and Lewy body dementia progresses over time. Everyone's symptoms and needs are unique.

Someone with early, mild dementia may be able to live alone with help for grocery shopping, household cleaning and bill paying. A person with advanced dementia, on the other hand, may require around-the-clock care from family members, loved ones or skilled professionals in a care facility.

Not everyone with Parkinson's experiences dementia. Estimates vary, but about 40 percent of people with Parkinson's have dementia, and small studies suggest this number may be higher in people who have had Parkinson's for 20 years or more. Certain factors may increase risk for dementia: a longer course of PD, significant movement problems (more walking and balance problems rather than tremor), mild cognitive impairment, seeing things that aren't there (hallucinations) or believing things that aren't true (delusions). Changes in brain chemicals and brain cells (misfolding of the alpha-synuclein protein into Lewy bodies) play a role in dementia, and researchers are studying the exact mechanisms and causes.

“A common question I hear from patients is, ‘I’m not going to get Alzheimer’s, am I?’”

— Jennifer Goldman, MD, MS,
Shirley Ryan AbilityLab and Northwestern University



Treatment of Dementia

If you or your loved ones notice cognitive changes, talk to your primary care physician or your Parkinson's doctor. Or make an appointment with a neurologist or another doctor who specializes in memory disorders such as Alzheimer's.

Many academic centers (treatment hubs affiliated with a medical school) have clinics dedicated to evaluating and treating thinking and memory problems. If you don't live near or can't find an academic center, ask your primary care physician or others in the Parkinson's community for a recommendation.

Many health care professionals, therapies and strategies can help with dementia. The key is finding the right combination for you.

Health care professionals

A team of experts, each of whom contributes unique expertise, delivers the most comprehensive care for dementia. Every person's team looks different, but may include:

- + **Movement disorder specialist:** a neurologist with additional training in evaluating and treating Parkinson's and other movement disorders; some have the experience to treat Lewy body dementia while others will recommend referral to a cognitive specialist for dementia management.
- + **Cognitive specialist:** a neurologist, geriatrician or other doctor who has supplemental training in diagnosing and managing Alzheimer's disease, Lewy body dementia, and other conditions that affect memory and thinking.
- + **Physical or occupational therapist:** an expert who helps with movement symptoms, such as walking and balance problems, and builds individualized exercise programs; occupational therapists also can suggest strategies and equipment for doing activities of daily living (such as showering, dressing and eating) more easily and safely.
- + **Speech therapist:** also known as a speech-language pathologist; a specialist who evaluates and treats speech and swallowing problems, often with voice and breathing muscle exercises, as well as behavioral strategies and diet modifications; these experts also provide tactics and exercises for people with cognitive and language difficulties.
- + **Social worker:** a professional who provides supportive counseling and education about managing disease; connects people to community resources, such as support groups; and assists with future care planning (a move to assisted living or another residence, or completion of advance directive paperwork to detail your care and financial wishes, for example).
- + **Palliative care specialist:** a physician who can, at any time in the course of disease (not just near the end of life) help manage troublesome symptoms, coordinate communication and align goals of care between a patient, family and the professional team.
- + **Psychiatrist:** a doctor who specializes in treating mental health symptoms such as depression, anxiety, behavioral changes, hallucinations and delusions; can prescribe medication and other therapies to ease symptoms.
- + **Psychologist:** a professional who offers talk therapy, or psychotherapy, to treat depression, anxiety and other conditions. Talk therapy explores behaviors and thoughts and aims to change negative patterns that may be interfering with daily functioning or quality of life. (Talk therapy can be used with or without medication prescribed by a psychiatrist.)

Consider naming one of your physicians (your primary care doctor or movement disorder specialist, for example) the care team "quarterback." This person can oversee care and communication across all team members.



Top Myths about Dementia

Misconceptions about dementia are widespread. With the facts, you can understand more about dementia and help others understand, too. A few common myths:

+ *Dementia is a normal part of aging*

Some changes in memory and thinking are normal with aging. But severe memory loss or thinking problems that make it impossible to do daily activities or live alone are not an expected part of life.

+ *All dementia is Alzheimer's*

There are many different types of dementia. Because Alzheimer's is the most common cause, many people think it's the only one. But there are many others. Lewy body dementia is the second most common cause of neurodegenerative (progressive) dementia. Other conditions, such as strokes or blood vessel (vascular) disease and vitamin deficiencies, also can cause dementia.

+ *Dementia does not have a treatment*

There are many treatments and strategies to ease symptoms and limit the impact of dementia on a person's life. But no therapy has yet been proven to slow or stop the progression of dementia.

+ *Dementia only causes memory loss*

Memory loss is the telltale sign of Alzheimer's. But dementia affects other parts of the brain too, causing thinking problems (such as difficulty multitasking or making decisions), communication challenges (trouble organizing and expressing one's thoughts clearly), and mood and behavior changes. In Lewy body dementia, changes in thinking, attention or visuospatial skills can be the first and most significant symptoms of dementia.

+ *There is a test to diagnose dementia*

Doctors diagnose dementia based on a person's symptoms and physical examination, as well as an assessment of thinking and memory skills. They may perform blood or spinal fluid tests or brain scans to look for other conditions that can cause dementia symptoms. On their own, though, these tests cannot conclusively diagnose dementia. (At this time, the only way to definitively diagnose dementia is to look at the brain at autopsy.) Researchers are actively searching for ways to objectively diagnose and track dementia.

Therapies

Medication can lessen symptoms and improve quality of life, but no treatment has yet been proven to slow or stop disease progression. Symptoms and examples of commonly used treatments include:

+ **Thinking and memory changes**

Treatments: Aricept (donepezil), Exelon (rivastigmine), Namenda (memantine), Razadyne (galantamine)

These medications were originally developed to treat Alzheimer's disease. Aricept, Exelon and Razadyne boost the brain chemical acetylcholine, which supports memory and thinking; Namenda works on the glutamate brain chemical pathway. Exelon is the only one FDA-approved to treat PDD, but doctors often use the others "off label" in people with Lewy body dementia. These medications may temporarily boost cognition; lessen behavioral changes, such as agitation; decrease hallucinations and delay the need for alternative living situations, such as a long-term care facility.

+ **Movement problems**

Treatments: levodopa/carbidopa (Duopa, Parcopa, Rytary, Sinemet, Sinemet CR)

For stiffness, slowness and tremor, doctors may prescribe Parkinson's medications, such as levodopa. Physicians aim to use the lowest effective dose to control symptoms without causing side effects, such as hallucinations or delusions. In people with Lewy body dementia, these medications may be more likely to cause or

worsen hallucinations and delusions, so doctors use them cautiously. Physical and occupational therapy also may help, especially with walking, balance and fine motor issues (problems using utensils or tying shoelaces, for example).

+ **Mood and behavior changes**

Treatments: Celexa (citalopram), Prozac (fluoxetine)

Depression and anxiety are common with dementia, and they can manifest as decreased mood or motivation, irritability or anger. As dementia progresses, some people become agitated or aggressive. Doctors first recommend non-medication strategies, such as maintaining a soothing environment (avoiding loud television and violent or political programs, for example) and talking calmly to a loved one who is upset. If symptoms continue, your doctor may prescribe medication or recommend consultation with a psychiatrist. There are many different antidepressants and researchers have studied only a few specifically in Parkinson's and dementia. When treating people with these conditions, doctors select carefully from the wide variety of drugs available, often using them "off label." Anti-anxiety drugs also may be helpful, but many have potential side effects such as sleepiness or confusion, so they generally are used sparingly in dementia.

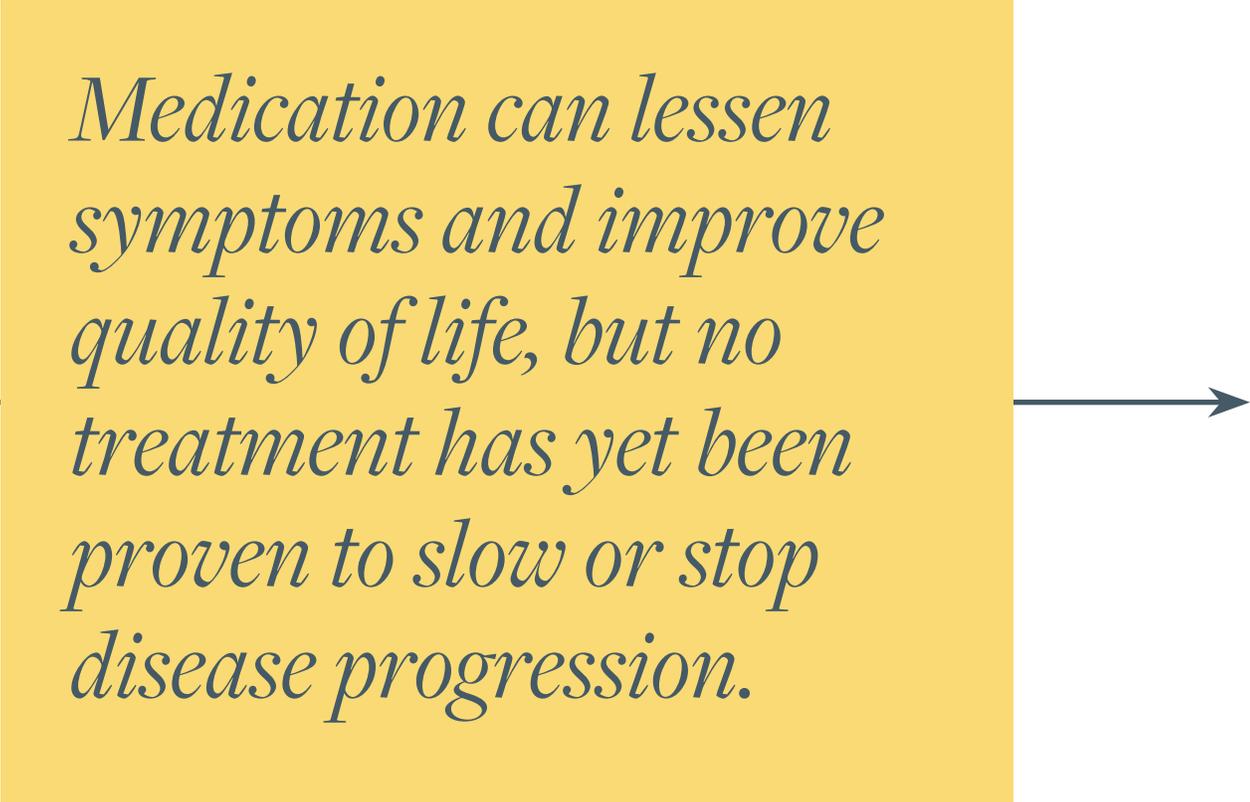
+ **Hallucinations and delusions (psychosis)**

Treatments: Clozaril (clozapine), Nuplazid (pimavanserin), Seroquel (quetiapine)

Doctors often avoid these medications in Lewy body dementia because of the potential for significant side effects, including increased risk of

death in elderly people with dementia. But when hallucinations or delusions jeopardize a person's (or their care partner's) safety or well-being, doctors may prescribe them. As with any medication, you and your doctor must weigh the potential benefits (fewer or less severe hallucinations and delusions) against the possible side effects (sleepiness, confusion and potentially more significant effects). Nuplazid is FDA-

approved to treat hallucinations and delusions in Parkinson's, but doctors sometimes use it and the others "off label" in people with Lewy body dementia. Because many of these drugs (called atypical antipsychotics) block the brain chemical dopamine and can worsen movement symptoms, it's important to avoid them if possible.



Medication can lessen symptoms and improve quality of life, but no treatment has yet been proven to slow or stop disease progression.



Tips for Managing Hallucinations and Delusions

For some people and their families, hallucinations and delusions can be the most difficult part of the disease. Tips for managing these symptoms:*

+ *Respect and reassure*

It's nearly impossible to convince someone that what they see or believe isn't real. And arguing about hallucinations or delusions can lead to frustration and loss of trust. For hallucinations, ask the person to describe what they see. This helps them focus, and lets you understand what they are feeling (anxious and afraid about a scary person in the home, for example) and how to respond. For delusions, don't dismiss the belief but don't completely buy into it either. Ask non-intense, probing questions to learn more about what the person believes and why. Sometimes this helps a person understand how they came to a particular conclusion and why it may be mistaken. Remind your loved one that they are safe and secure and that you are on their side.

+ *Reframe and redirect*

Aim to turn the negative into positive and, if possible, cast the experience in a different light. Ava Butler found it helpful to respond to her husband Richard's hallucinations about "bad guys" with statements such as: "It first looked like a bad guy, but he's actually very friendly." Or, "I saw that guy before, and he's really harmless and here to keep us safe."

Direct attention and discussion away from the hallucination or delusion. Draw your loved one's gaze away from a hallucination by, for example, gently approaching from the opposite side. Transition conversation to a related topic. For instance, if your spouse sees a band playing on the balcony, you might ask about an instrument they used to play.

+ *Encourage a peaceful environment*

Create a calm atmosphere. Consider a sage or lavender diffuser or air freshener, keep the television off or watch an uplifting show together, and keep routine and order in the home and schedule. If your loved one needs glasses or hearing aids, make sure they use them. (Decreased vision and hearing can promote hallucinations.)

+ *Work through the experience together*

As you ask for more description and context about a hallucination or delusion, find creative ways around it. If your loved one sees intruders, for example, you might encourage them to tell the intruders to "back off" and leave you alone. Or, you could ask where the intruders are and then walk slowly and calmly toward them saying, "It's time to go now." Some also find it helpful to open a door and usher unwanted visitors out; but use caution as offering an exit around a person with hallucinations or delusions could be unsafe.

+ *Be mindful of your emotions*

Frustration, anger and anxiety are normal feelings when living with a loved one who has dementia. But if unchecked, these emotions could make managing symptoms even tougher. Talk to your doctor and your loved one's doctor and, if helpful, other care partners or a therapist, about how to process your feelings, particularly during moments of hallucinations and delusions.

*Adapted from Ava Butler's book, *Parkinson's: A Love Story with Dementia for Dessert*.

Strategies

You and your loved ones can take steps together and individually to work through cognitive challenges:



Find a knowledgeable physician

Look to a doctor who has expertise in treating memory and thinking problems. If the first doctor you see isn't a good fit or you aren't comfortable working with him or her, try another. Barbara Mendel says, "Find someone who understands there are many types of dementia and can talk with you in a frank, open manner." Ask questions, take notes, and advocate for your loved one and yourself.



Be patient and flexible

It may be more difficult or take longer to perform daily activities, do hobbies and even answer questions. If your loved one is a bit slower, give them extra time and space. Allow more time to reply to questions. Let them know you're there if needed, but don't hover or interfere just to speed things up. If you're a little slower than you once were, be kind to yourself. Don't rush or push to do things the same way you once did; instead, try new approaches.



Communicate openly and honestly

Anna Greenfield, a writer and Hilarity for Charity grant board committee member whose mother Donna lives with early-onset dementia, says families should have "clear and open talks about dementia." She explains that her mom was "so ashamed about her diagnosis and her beginning symptoms that we never had a frank talk about the kind of care she would want or how she wanted the end of her life to be." As early as possible, acknowledge your loved one's experience and talk about dementia in a straightforward way. Ava Butler adds, "No matter what's happening, respect your loved one and don't talk down to them like a child or about them in the third person." As disease progresses and a person's ability to communicate changes, find new and different ways to converse. You may need to adjust how you ask questions (such as changing from open-ended to yes-no) or look to music or another shared interest to connect.



Educate yourself and others

Yael Wyte, MSW, a social worker with the Alzheimer's Association, offers this advice: "Ask your doctor for credible, trusted resources to learn more about dementia and your loved one's condition."

Ava Butler adds, "Learn as much as you can. Educate yourself, even on topics that you don't want to learn about and may have trouble understanding."

Because many people are unfamiliar with Parkinson's cognitive changes and dementia (especially types other than Alzheimer's), you may encounter misinformation or misperceptions. With facts, you can dispel common misconceptions. (See page 19: *Top Myths about Dementia.*)



Use adaptive strategies

Find creative ways around the difficulties you encounter. Some solutions may be simple and others may require more innovation and imagination. An erasable white board may help track the date and the day's activities. Labeling items and light switches around the house may remind you of what does what. You might need detailed instructions near the phone for how to make a call, or you might want to buy a phone with pictures and one-touch dialing. In homes with people who wander, door alarms can be beneficial.



Ask for and accept help

You aren't alone and don't have to face dementia on your own. As disease progresses, you may need more help managing symptoms, putting a home care or supervision plan in place, or thinking about the most suitable living arrangement. Your doctor, a cognitive rehabilitation specialist and social worker can help you work through changing symptoms and confusing areas of insurance and health care. Your loved ones, friends and family can assist with day-to-day needs. Be specific with how and when you need help. Ask an adult child to drive your spouse to their weekly exercise program, a family friend to spend a few hours with your loved one so you can run errands or take an exercise class, and a neighbor to pick up your groceries or bring dinner.



Join a support group

Many groups — both online and in-person — offer a way to learn about others' paths and connect with people like you. Some are designed for care partners. Even though dementia is variable, there are many common experiences. Sometimes knowing that other people are on a similar journey can make dementia feel less lonely and isolating. If a support group isn't for you, find encouragement in your family, church, exercise class or wherever there are people who care about you.



Participate in research

Many people say they can gain control of their disease by lending their voice to research. But there can be challenges; a patient or family may not be open about their diagnosis, symptoms might make participation difficult or family members might worry about what they could learn (whether they carry genetic mutations that increase dementia risk, for example). People with (and without) Lewy body dementia can complete a profile on Fox Trial Finder (foxtrialfinder.org), MJFF's clinical trial matching tool, to be matched to recruiting trials. You also can find studies through clinicaltrials.gov or other disease organization's websites. Always discuss potential research participation with your personal physician and be wary of any treatment advertised as research that charges you or your insurer. (Research studies should not have an associated cost, but some companies and clinics offer stem cells or other unproven therapies for a fee.)

Patients, families and care partners of people with cognitive changes and dementia are critical to advancing research, and there are many ways to get involved. Studies are available online or in person, one time or over many visits. Some involve testing a therapy, undergoing a brain scan or donating tissue to find ways to diagnose and track disease. There also are studies that aim to learn more about the care partner's experience and needs.



Plan ahead

It's a good idea for everyone (whether you have Parkinson's or dementia or are just getting older) to think about the future. Although the time may never come when you need to stop driving or move out of your home to get the best care, think about how you'd like to approach these situations. For example, you may want to agree you'll stop driving (or undergo a driving assessment) if you have a near miss or your spouse or children notice changes in your driving abilities. Your doctor can help you and your family agree upon a plan. As you have these conversations, complete advance directives, legal documents that detail the medical treatments you'd want if you couldn't speak for yourself (CPR or a breathing tube if your heart or lungs stop, for example).

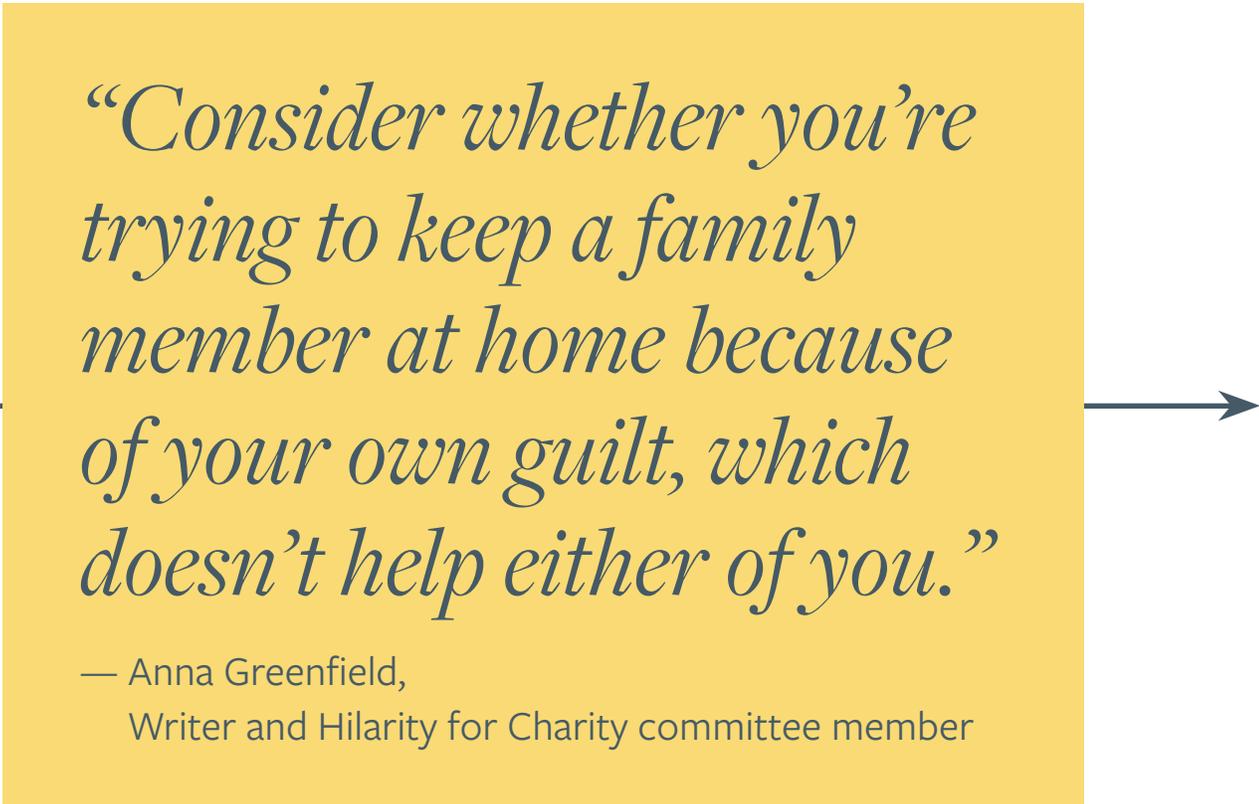


For care partners, take care of yourself

Caring for another person can be a full-time job. But don't neglect your needs. You can't take care of someone else unless you first care for yourself. See your own physician regularly and speak up about caregiving challenges during your loved one's doctor visits. Exercise, keep up your hobbies and see friends to avoid isolation. Get support by talking to friends, family, other care partners and, if helpful, a therapist or counselor.

Watch for care partner burnout, which may show up as irritability, depression or sleep problems. Know your limits. There may come a time when you need a break, or you can no longer safely care for your loved one on your own or in your home. Ask your loved one's doctor about "respite care," which offers temporary relief for care partners, and think about other living arrangements, such as assisted living or a memory care facility. Anna Greenfield says, "Consider whether you're trying to keep a family member at home because of your own guilt, which doesn't help either of you." Matthew Patterson, a television writer and Hilarity for Charity grant board committee member whose father Robert lived with Alzheimer's disease, shares

a similar message: "My mom cared for my dad at home into advancing stages, but the decision to move him in his last two years helped preserve her well-being." There are several types of living facilities, which offer varying levels of assistance and care, and some specialize in caring for people with dementia. Your loved one's doctor and a social worker can help you determine the necessary amount of care and discuss the different options and costs. Once you narrow your choices, visit at a few different times (during a meal and a group activity, for example) and talk with staff about your loved one's symptoms (thinking changes, hallucinations or decreased mobility) to ensure the location is a good match.



“Consider whether you’re trying to keep a family member at home because of your own guilt, which doesn’t help either of you.”

— Anna Greenfield,
Writer and Hilarity for Charity committee member



How to Communicate about Cognitive Change

Discussing cognitive changes or a diagnosis of dementia with others isn't easy. But the people who are closest to you may have already noticed changes and want to offer support. You're in charge of these conversations and you decide what information to share with whom and when. Consider talking with your:



+ *Loved ones, family and friends*

Many people hide their symptoms or diagnosis because they're ashamed or they don't want to be "discovered." No one wants to be seen or treated differently or have others feel sorry for them. But when people sense something's wrong, they often create their own explanations. Sharing your story can give you the freedom to attend social or family gatherings without fear of being found out. Hiding not only makes symptoms worse, it also can be lonely and isolating. And it's good for brain health to be connected to others.



+ *Spouse or partner*

Some people worry that after opening up to their significant other they will be treated differently, criticized or watched more carefully, and that any minor (normal) memory lapse will be questioned. Claudia Revilla, a research ambassador and MJFF Patient Council member, says, "I travel and do a lot of other things by myself but sometimes it feels like if

I forget one thing at the supermarket, my husband thinks there is a problem." Significant others — who often are the first to see change — worry about hurting their partner's feelings or, in Parkinson's, "pointing out progressing disease." But acknowledging the situation can bring you both relief and the opportunity to work through it together.



+ *Bosses, managers or colleagues*

In many cases, there is no legal obligation to disclose your symptoms or diagnosis in the workplace and employers generally are not permitted to take adverse actions against employees because of health issues. Some people prefer a proactive approach, wanting to communicate on their own terms and timing, and to suggest solutions, such as schedule changes or the use of technology to assist. Other people, whose jobs involve major decision-making and quick response time, or potentially impact others' safety (doctors or police officers, for example) may have a responsibility to speak up. No matter your situation, know your rights, the possible implications of your disclosure and what accommodations you may be able to request ahead of time.

Because each relationship is unique, each discussion will be unique. The MJFF Patient Council offers tips for your conversations:



+ Use humor

Many people find humor helpful in broaching and managing sensitive subjects. Bret Parker often jokes with his wife, “I forgot to take out the trash again... must be the Parkinson’s!” He adds that he doesn’t take this serious symptom lightly, but humor keeps the lines of communication open.



+ Acknowledge fear

Future unknowns — especially around your thinking and memory — are scary. But naming your fears tends to make them shrink rather than grow. Talking about your feelings can help you connect with others (many of us share the same fears) and work through them.



+ Be positive and proactive

Don’t sugarcoat your reality or the facts. (The fact that millions of people and families live with dementias that don’t yet have a cure may help you feel less alone and help others see the tremendous need for research.) But do focus on where and how you can take control and find ways to live better with disease.



+ Develop your own vocabulary

Words such as “dementia” and “psychosis” (a term for hallucinations and delusions) may not only be hard to define, they also may be associated with stigma and strong emotions, which can inform a person’s reaction to the information you’re sharing. You don’t have to tiptoe around or avoid certain words, but it may be beneficial to have alternative ways to describe symptoms. Barbara Mendel explains that as her husband Lee’s Lewy body dementia progresses, he is “unlearning” how to do things, such as use a computer and cellphone. When talking about her mom’s dementia, Anna Greenfield says, “The brain stops sending impulses to the body, which makes the hands, speech and other processes stop working.” Ava Butler described her husband Richard’s hallucinations as “not the nice 1960s kind” or “the bad guys.”



Ongoing Research in Dementia

Researchers are working to better understand, measure and treat cognitive changes and dementia. And because Parkinson's disease, Lewy body dementia and Alzheimer's disease share symptoms, brain changes and genetic risks, breakthroughs in one disease can lead to insights and benefits in another. Researchers aim to:

+ ***Build understanding***

Precisely how and why cognitive changes happen and who is most at risk are big unanswered questions. Clues may lie in misfolded proteins and genetic risks that are associated with dementia.

In dementia, normal proteins misfold and clump in brain cells, and researchers believe these proteins contribute to or cause cell damage or death. In Lewy body dementia, the misfolded protein is alpha-synuclein, which forms clusters called Lewy bodies. (Lewy bodies also are found in the brain cells of people with Parkinson's disease.) In Alzheimer's disease, the characteristic misfolded proteins are tau and beta-amyloid. Researchers also find misfolded beta-amyloid in the brains of people with Lewy body dementia as well as older people without thinking or memory problems. And the brains of some people with Alzheimer's have Lewy bodies, too. Learning more about the role of Lewy bodies, beta-amyloid and tau in Parkinson's, Lewy body dementia and Alzheimer's not only will deepen disease understanding, it also may lead to treatments to slow or stop progression.

Genetic links are another route to more knowledge and potential treatments. Age and environmental factors are likely the biggest contributors to dementia in most people, but researchers have found several genetic mutations (such as GBA, or glucocerebrosidase, in LBD and APOE4 in Alzheimer's) that increase risk. Studying these mutations and their cellular pathways helps scientists learn how disease happens. Following people with and without mutations to see who develops disease can show what factors protect from and lead to disease.

+ *Develop diagnostic tests*

At this time, no test can definitively diagnose or differentiate between the various types of dementia. Researchers are evaluating patient questionnaires and physician rating scales, brain wave tests, and other ways to measure and track mild cognitive impairment and dementia. They're also developing brain imaging scans to see misfolded proteins in the living brain, since these proteins currently can only be seen in autopsied brain tissue. Tests for dementia would allow earlier and more accurate diagnoses. They also would speed research by getting the right patients in the right trials and determining more quickly and clearly whether an investigational therapy works.

Studies such as MJFF's Parkinson's Progression Markers Initiative (PPMI) collect data on volunteers with and without Parkinson's over time to search for a way (a measurement of alpha-synuclein or a specialized brain scan, for example) to diagnose and track PD and predict who will develop cognitive changes. In a similar manner and for similar reasons, separate studies follow people with Alzheimer's and Lewy body dementia. And Biomarkers Across Neurodegenerative Diseases (BAND) — a collaboration between MJFF, the Alzheimer's Association, Alzheimer's Research UK and the Weston Brain Institute — encourages researchers to compare dementia-causing diseases in order to distinguish and better treat them.

+ ***Improve treatments***

Clinical trials are testing treatments for mild cognitive impairment, therapies to slow or stop progression of Lewy body dementia and Alzheimer's, and methods to ease associated symptoms such as mood changes, sleep disorders and hallucinations. A variety of therapies are in various phases of clinical trial testing. Examples include non-invasive brain stimulation (transcranial magnetic stimulation and transcranial direct current stimulation), brain exercises, new medications, and novel therapies such as plasma (part of the blood that contains brain-boosting proteins) from young people without disease. Researchers also are evaluating several repurposed drugs (medications FDA-approved for one condition, now being tested in another) for potential to slow or stop progression of Alzheimer's, Lewy body dementia or Parkinson's. Examples include the cancer medication nilotinib, the cholesterol drug

simvastatin, the diabetes treatment liraglutide and the respiratory medication ambroxol. And scientists are targeting misfolded proteins with novel therapies to slow or stop disease progression, including oral medications that prevent clumps from forming and infusions that boost the immune system to clear clumps. At the time of this writing, nine anti-alpha-synuclein therapies are in clinical trials to slow or stop Parkinson's disease. Because of alpha-synuclein's involvement in Lewy body dementia, there is reason to believe success in Parkinson's could translate to a therapy for Lewy body dementia, too. Anti-amyloid therapies have, unfortunately, largely failed in Alzheimer's; but this helps researchers better understand disease and develop different treatments. Multiple efforts now focus on identifying the disease and intervening before symptoms arise, and targeting other disease pathways and proteins such as tau.

Information in this guide was accurate at the time of publication in September 2019. For the latest on Parkinson's cognitive changes and dementia, visit michaeljfox.org.

NOTE: The medical information contained in this article is for general information purposes only. The Michael J. Fox Foundation for Parkinson's Research has a policy of refraining from advocating, endorsing or promoting any drug therapy, course of treatment, or specific company or institution. It is crucial that care and treatment decisions related to Parkinson's disease and any other medical condition be made in consultation with a physician or other qualified medical professional.

Appendix

While not a comprehensive list, the books and websites below offer information on symptoms, personal experiences and ongoing research in Parkinson's disease, Lewy body dementia and Alzheimer's disease.

Books

- + *A Caregivers Guide to Lewy Body Dementia*
Helen Buell Whitworth and James Whitworth
- + *Navigating Clinical Trials*
The Michael J. Fox Foundation
for Parkinson's Research
- + *Parkinson's 360*
The Michael J. Fox Foundation
for Parkinson's Research
- + *Parkinson's: A Love Story with Dementia for Dessert*
Ava S. Butler
- + *Treasures in the Darkness: Extending the Early Stage of Lewy Body Dementia, Alzheimer's, and Parkinson's Disease*
Pat Snyder

Websites

- + The Michael J. Fox Foundation
for Parkinson's Research
michaeljfox.org
- + Lewy Body Dementia Association
lbda.org
- + Alzheimer's Association
alz.org
- + Hilarity for Charity
hilarityforcharity.org
- + Fox Trial Finder
foxtrialfinder.org
MJFF's clinical trial matching tool that matches volunteers with recruiting clinical trials.
- + clinicaltrials.gov
A searchable database of clinical trials in all diseases being conducted across the world.

Thank you to the people, families and clinicians touched by Parkinson's disease and dementia who contributed their experience and expertise:

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