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Thinking, Memory and Parkinson's Disease

A Guide for People with
Parkinson's and Their Loved Ones



THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH



Thinking about Brain Health

Parkinson's disease (PD) is called a "movement" disorder because of its classic features: tremor, slowness, stiffness, and sometimes later in the course, walking and balance problems. But it's also a "non-movement" disorder. It can bring mood or sleep changes, constipation, fatigue or other symptoms. For some, thinking and memory (cognitive) changes can be part of Parkinson's, too.

Not everyone with PD experiences cognitive changes. As with all symptoms, if, when and how they occur is unique to each person. But many people and their loved ones say that thinking and memory changes are among the most concerning possibilities.

And they're tough to talk about. Michael J. Fox says, "A Parkinsonian condition I rarely contemplated before now, much less spoke of, is cognitive change: loss of

memory, confusion...What am I thinking, and *how* am I thinking." Opening a discussion with loved ones and doctors — while not always easy — can help guide you in finding strategies to boost brain health or work around changes if they arise.

Wherever you are with Parkinson's, we hope you'll find the tips and information in this resource useful. We hope they help you learn more about thinking and memory in Parkinson's, start a conversation about brain health, or connect to research.

As you read through this guide, take what works for you and put aside anything that doesn't. Some people want the basics; others, all there is to know. You may want to start with certain sections, skim the entire guide, or read it cover to cover. The best approach is the one that works for you.

What Is Cognition?

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



ATTENTION

Attention is focusing on one thing while tuning out everything else. Attention allows you to watch a movie, drive a car, or participate in group conversation.



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 ones around you, and find your way home after a walk around the neighborhood.



EXECUTIVE FUNCTION

Executive function includes multitasking, problem-solving, organizing, planning and decision-making. These are called executive functions because they're like the activities of a CEO, who oversees various parts of a company.



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. These 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 brief periods. (An example is a phone number you can forget after you write it down.) Working memory is for information that you are actively using, such as numbers you are working with to solve a math problem or add a tip to a bill.



LANGUAGE

Language is what we use to communicate through speaking and writing. It involves naming objects (calling a tree a "tree," for example), understanding words' meanings, and finding the words you need to speak smoothly and without pause.

Is It Age or Parkinson's?

As we get older, our brains change. And thinking and memory change, too. 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 isn't as sharp as it used to be because I'm getting older or because of Parkinson's."

Changes in 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 someone 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 gauge what might be age and what might be Parkinson's, consider asking friends your age (both with and without PD) if they have similar experiences. (See **page 10**: Keeping Track of Changes).



"Sometimes I can't tell if my brain isn't as sharp as it used to be because I'm getting older or because of Parkinson's."

— BRET PARKER, 53
MJFF PATIENT COUNCIL CO-CHAIR | NEW YORK,
NEW YORK

Boosting Brain Health

Whether you worry about or experience thinking and memory changes, 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 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.



CONNECT WITH OTHERS

Spending time with friends and loved ones and meeting new people can help prevent isolation and loneliness. And it also can give you a chance to put your brain to work. At social gatherings, for example, you can learn new names and discuss current events.



EAT A HEALTHY, BALANCED DIET

While there is no specific diet for Parkinson's, studies suggest that the Mediterranean and MIND (Mediterranean-DASH Intervention for Neurodegenerative Delay) diets may support brain health and provide benefits in PD. Aim to eat a variety of fruits and vegetables; whole grains; and unprocessed, non-sugary foods. And limit red meat. (For more, read MJFF's *Diet and Parkinson's Disease* guide at michaeljfox.org/dietguide.)



GET INVOLVED IN THE COMMUNITY

By taking an active role in the Parkinson's or local community, you can make connections. You also can give and get support. There's something for every schedule, interest and comfort level. You can attend a neighborhood event, join a Parkinson's support group (check out MJFF's online Buddy Network at parkinsonsbuddynetwork.michaeljfox.org), or advocate for PD.



SLEEP WELL

Researchers believe we store memories and rejuvenate our bodies during sleep. Not getting enough rest can worsen Parkinson's symptoms and make it hard to think clearly. (Most of us have felt the fogginess and slowness that follows a poor night's sleep.) Make sure you get the right amount of sleep each night for someone your age. And maximize sleep by keeping a regular schedule, creating a routine to wind down before bed, limiting daytime naps as well as screen time before bed, and exercising regularly (but not too late in the day). 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 MJFF's *Sleep and Parkinson's* guide at michaeljfox.org/sleepguide.)



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 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.



MONITOR MOOD AND MOTIVATION

Depression, anxiety and apathy (lack of motivation) — Parkinson's non-motor symptoms — 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 during a hospital stay or around the holidays.



TAKE CARE OF MEDICAL CONDITIONS

Diabetes, high blood pressure and high cholesterol can affect the 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 or medication.



REVIEW YOUR MEDICATIONS

Certain prescription and over-the-counter medications — such as the PD drug trihexyphenidyl, pain or sleeping pills, and Benadryl (diphenhydramine), can cause confusion. At regular intervals (every visit or any time a medication changes), go through your medication list with your doctor. If you are taking a drug that might cause thinking or memory changes, ask if you can stop it or decrease the dose. Always speak with your doctor before making changes to your medications or starting over-the-counter drugs, supplements or herbal products, including medical marijuana.



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

Smoking is associated with Alzheimer's, stroke and other diseases that can 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.



PROTECT YOUR BRAIN

Head injuries and concussions may increase the risk of cognitive changes. Always use a helmet when riding a bike, wear your seatbelt, and do your best to avoid falls.

Thinking and Memory 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.

These symptoms vary from person to person. They may be subtle and barely noticeable, mild and manageable, or more significant 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 may need help with some or all daily activities, such as showering, dressing, and preparing or eating meals.

If Parkinson's affects cognition, it typically impacts executive function and attention more than memory. (See **page 2**: What Is Cognition?). But everyone experiences this differently. Engineer, business executive and MJFF Patient Council Member Ken Cater says, "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, says, "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 thinking and memory problems happen in Parkinson's. Changes in brain chemicals and brain cells likely play a role. PD affects several brain chemicals that support thinking, attention and memory. And in brain cells that are responsible for cognition, a normal protein — alpha-synuclein — can misfold and clump into Lewy bodies. Researchers believe these clumps may damage the cells.



MILD CHANGES

At their earliest and mildest, thinking and memory changes don't interfere with everyday life. They 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 mild changes. These 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. To evaluate and understand thinking and memory changes, your doctor may:

+ Ask about sleep and mood changes

Sleep problems, depression, anxiety and apathy (lack of motivation) — common Parkinson's non-motor symptoms — can mimic or worsen cognitive changes. Each condition has a different evaluation and treatment. Carey Christensen, patient advocate and MJFF Patient Council Member, says, "The anxiety I felt around my Parkinson's caused me to temporarily 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."

+ Do memory and thinking tests

Your doctor may perform memory tests in the office. These might include naming objects, remembering words and other short tasks. Sometimes, it's also beneficial to have neuropsychological testing, a more thorough and detailed examination of thinking and memory.

+ 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. (Medical marijuana, for example, may impact thinking and memory.)

+ 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. Your doctor may order blood or urine tests, brain or body scans, and even a sleep study to look for these conditions. Having surgery or general anesthesia (being "put to sleep") and being in the hospital also can impact thinking and memory.

Mild cognitive impairment in Parkinson's usually affects executive function and attention more than memory. (See **page 2**: What Is Cognition?) But it looks different for



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

— CAREY CHRISTENSEN, 63,
MJFF PATIENT COUNCIL MEMBER | STANWOOD, WASHINGTON

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 a hard time 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 is individualized. Doctors typically recommend that you keep your brain active (See **page 4**: Boosting Brain Health) and work with an occupational therapist, speech therapist or cognitive rehabilitation specialist to strengthen brain 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 in Parkinson's. Sometimes doctors prescribe thinking and memory medications, such as Exelon (rivastigmine) or Aricept (donepezil), to help. (For more on these medications, see **page 16**.) Research in this area also is extremely active. (Read more on **page 25**.)

About 25 percent of people with Parkinson's experience mild changes. Over time, changes may stay the same, get better or worsen. For some, MCI may eventually progress to more significant changes that affect daily activities.



“KEEP PLUGGING ALONG”

Pamela Bland, age 72, a retired nurse and educator, has been living with Parkinson's for over two decades. In the last few years, she and her husband Dana noticed “slight” thinking and memory changes and that “a lot of things are confusing that weren't confusing before.” Pam no longer does the bills, and she has some trouble using her smartphone, remembering appointment times, and finding her words.

But Dana is there to help. As her care partner, he says, “I don't want to tell her every little thing to do.” He adds, “She's a smart, intelligent woman. She's in charge. But I don't want her to fall down or hurt herself either. Where's the line between nitpicking and being helpful?”

Pam and Dana regularly talk about what's working and what's not, how they both feel, and how to stay positive. And Dana, a self-described busybody, also makes sure to take time for himself. Once a week, he cycles outdoors with friends before going to dinner with them and Pam. This time socializing, he says, helps “clear his mind.”

About their journey, Dana says, “It's a challenge, but we're fortunate to have good support. Things just change. Life changes!” Pam adds, “It's not so bad; you just have to keep plugging along.”



Hear more from Pam and Dana on MJFF's podcast: michaelfox.org/cognitionpodcast.



KEEPING TRACK OF CHANGES

Many people and families wonder what to watch for and what changes might be 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?" Consider whether there have been changes in these areas:

+ **Attention**

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

+ **Problem-solving**

Is it nearly impossible to make decisions, such as what to do with a free afternoon? Have you made less-than-ideal decisions, such as spending large amounts of money you don't have? Do you have trouble 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?

+ **Memory**

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 computer?

+ **Medication taking**

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?

+ **Behavior**

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?

+ **Money management**

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?

+ **Work**

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, it doesn't necessarily mean there is a significant problem. But if you or your loved ones notice changes, it's important to talk with your doctor. Together, you can evaluate what's happening and figure out the best path forward.

MODERATE OR SIGNIFICANT CHANGES

For many people with Parkinson's and their loved ones (as well as many people without PD), the possibility of significant cognitive changes (dementia) is one of the biggest concerns. "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 learn about possible cognitive changes, and they want to learn early so they can be proactive.

Katherine Amodeo, MD, movement disorder specialist at Westchester Medical Center-MidHudson Regional Hospital and assistant professor of neurology at New York Medical College, 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 is the most common, but there are others, including including Parkinson's disease dementia (PDD) and a related condition called dementia with Lewy bodies (DLB).

Parkinson's disease dementia and dementia with Lewy bodies share symptoms and brain cell changes (clumps of alpha-synuclein protein called Lewy bodies). Because of these overlaps, PDD and DLB are grouped together under the umbrella term "Lewy body dementia" (LBD). Doctors and researchers distinguish Parkinson's disease dementia and dementia with Lewy bodies primarily based on when movement and cognitive symptoms occur. People with PDD start with movement symptoms and a diagnosis of Parkinson's disease. Many years or decades later, they develop significant cognitive changes. Those with DLB show movement and significant cognitive symptoms at the

same time or within a year of each other.

Symptoms of Lewy body dementia may include:

+ **Thinking and memory changes**

Lewy body dementia affects thinking, attention, executive function and visuospatial skills more than memory. (This contrasts with Alzheimer's, in which short-term memory loss is 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 directions. 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 care partner support group and whose husband Lee lived with Lewy body dementia, says "the dishes ended up half as dirty" when Lee did 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."

Hobbies may be more challenging, too. One of the first changes Barbara noticed was that Lee 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, 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 in Alzheimer's. Whereas a person with Alzheimer's has trouble forming new memories, someone with Lewy body dementia has difficulty retrieving them. So they might remember if given a prompt or clue. For

instance, they may not volunteer that anyone called while you were out, but if you specifically ask, they may remember that your sister telephoned.

+ Movement changes

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 live with PD for years or decades before significant cognitive changes occur, their movement symptoms may be progressing or they may have considerable walking or balance problems. People who have dementia with Lewy bodies may have milder movement symptoms that come on before or shortly after cognitive symptoms. (Or sometimes not at all.) In some, this may lead to an initial misdiagnosis of Parkinson's or a related condition.

+ 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.

+ Experiencing things that aren't there (hallucinations)

With visual hallucinations, a person sees things that aren't there. Hallucinations often involve children, people or animals. A person may or may not recognize they aren't 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 and prior to treatment with 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. Certain illnesses, such as urinary tract infections, can worsen hallucinations in both DLB and PDD.



“A Parkinsonian condition I rarely contemplated before now, much less spoke of, is cognitive change: loss of memory, confusion, delusions, and dementia. What am I thinking, and how am I thinking?”

— MICHAEL J. FOX

+ 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 bring on or worsen delusions. For example, someone might have a vision of a visitor who they believe is having an affair with their spouse.

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. They also may experience 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 experiences mood or behavior changes without movement or thinking changes, the initial misdiagnosis may be depression, anxiety or another mood disorder. 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 significant, and it generally progresses slowly over time. Everyone's symptoms and needs are unique. Someone with early, mild symptoms may be able to live alone with help for grocery shopping, household cleaning and bill paying. A person with advancing symptoms, 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 significant changes. Estimates vary, but about 40 percent of people experience 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: 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, and researchers are studying the exact mechanisms and causes. (See **page 25** for the latest in research.)



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

— JENNIFER G. GOLDMAN, MD, MS
SHIRLEY RYAN ABILITYLAB AND NORTHWESTERN
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TOP MYTHS ABOUT DEMENTIA

+ **It's 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 difficult to do daily activities or live alone are not an expected part of getting older.

+ **It's always Alzheimer's**

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

+ **There is no treatment**

Many treatments and strategies can ease symptoms and improve quality of life for people with significant cognitive changes. And in 2021, the FDA approved Aduhelm (aducanumab), the first Alzheimer's drug to treat brain changes with the goal of slowing progression. (Read more about Aduhelm on [page 17](#).) This milestone boosts support for ongoing research toward treatments to slow changes in other dementias and Parkinson's, too. (See [page 25](#) for more.)

+ **It causes only memory loss**

Short-term memory loss is the telltale sign of Alzheimer's. But dementia affects other parts of the brain, too. It can cause thinking problems (difficulty multitasking or making decisions), communication challenges (trouble organizing and expressing 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.

+ **There is a test to diagnose it**

Doctors diagnose dementia based on a person's symptoms and physical examination, as well as an assessment of thinking and memory. Sometimes they also perform lab tests or brain scans to look for changes that happen with dementia or for other conditions that change thinking and memory. These tests cannot, on their own, diagnose dementia. But, in some cases, they might support your doctor in making the right diagnosis. Researchers are looking for new and better ways to diagnose and track cognitive changes. (Read about this work on [page 25](#).)

Caring for Cognitive Changes

If you or your loved ones notice thinking or memory changes, talk to your primary care physician or your Parkinson's doctor. Or make an appointment with a neurologist or other doctor who specializes in diseases of memory and thinking, 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, treatments and strategies can help. The key is finding the right combination for you.

HEALTH CARE PROFESSIONALS

A team of experts can deliver comprehensive and personalized care. Everyone's health care team looks different, but may include:

- + **Movement disorder specialist:** a neurologist with additional training in Parkinson's and other movement disorders; some have the experience to treat Lewy body dementia while others will recommend referral to a cognitive specialist.
 - + **Cognitive specialist:** a neurologist, geriatrician or other doctor who has supplemental training in 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 daily activities (such as showering, dressing and eating) more easily and safely.
 - + **Speech therapist:** also known as a speech-language pathologist; these specialists help with speech and swallowing problems; their treatments may include voice and breathing exercises, or behavioral or mealtime strategies; they also can provide tactics and exercises for people with cognitive and language changes.
 - + **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 care and financial wishes, for example).
 - + **Palliative care specialist:** a clinician who can, at any time in the course of disease (not only near the end of life) help manage troublesome symptoms, and coordinate communication and align goals of care between the patient, family and professional team.
 - + **Psychiatrist:** a doctor who specializes in 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 to change negative patterns that may be interfering with daily functioning or quality of life. (Talk therapy can be used with or without prescription medication.)
- 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.

MEDICAL TREATMENTS

Medication can lessen symptoms and improve quality of life for people and families living with cognitive and other changes. Examples of commonly used treatments for certain symptoms:

+ Movement problems

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

For stiffness, slowness and tremor, doctors may prescribe Parkinson's medications. They aim to use the lowest dose that controls symptoms without causing side effects. 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. They may cause decreased mood or motivation, irritability, anger or other changes. As disease progresses, sometimes people also may act agitated or aggressive. Doctors may first recommend non-medication strategies, such as maintaining a soothing environment (avoiding loud, violent or political television programs, for example) and talking calmly to a loved one who is upset. If symptoms continue, your doctor may prescribe medication or suggest consultation with a psychiatrist.

There are many different drugs for depression or anxiety, but 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 (successfully) "off label." (This means that although they are FDA-approved for depression or anxiety, they may not be FDA-approved for treating these conditions in people with Parkinson's or dementia.) Some anti-anxiety drugs can potentially cause sleepiness or confusion, so doctors use them cautiously.

+ Hallucinations and delusions (psychosis)

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

Not everyone with Parkinson's or everyone with cognitive changes experiences psychosis. In those who do, symptoms range from non-bothersome (a hallucination of a friendly animal or small child, for example) to scary and disruptive.

When symptoms are significant, especially if they do not lessen with non-medication strategies (see **page 22: Managing Hallucinations and Delusions**) doctors may prescribe medication.

Nuplazid (pimavanserin) is the first and only FDA-approved medication for psychosis in people with Parkinson's. (In the future, Nuplazid also may be an option for people with multiple forms of dementia who have hallucinations and delusions. At the time of publication, the drug maker is working to seek FDA approval for this use.) Nuplazid works on the brain chemical serotonin to ease hallucinations and delusions. Because it doesn't impact the other brain chemicals, such as dopamine, it doesn't worsen motor symptoms. (Nuplazid is a pill you swallow, but it also can be opened and sprinkled on food for people who have difficulty swallowing.)

Other drugs, such as Seroquel (quetiapine) or Clozaril (clozapine), also may help psychosis. (These were the only treatments available before Nuplazid.) They can mildly affect dopamine and therefore slightly worsen symptoms. But for some people, one of these medications may be the best option.

Some psychosis drugs, such as Haldol (haloperidol), block dopamine and increase movement symptoms. People with Parkinson's or Lewy body dementia should not take these medications.

Before taking any medication, it's important to discuss the potential benefits (fewer or less severe hallucinations and delusions) and risks (sleepiness, confusion, or potentially even increased risk of death in elderly people) with your doctor.

+ Thinking and memory changes

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

These medications were originally developed to treat Alzheimer’s disease. Donepezil, rivastigmine and galantamine boost the brain chemical acetylcholine, which supports memory and thinking. Namenda works on the glutamate brain chemical

pathway. Of these medications, Exelon (rivastigmine) is the only one FDA-approved to treat Parkinson’s disease dementia. But doctors often use the others “off label” in people with PDD and DLB.

These drugs 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.

ALZHEIMER’S DRUG APPROVAL SIGNALS PATH FOR PARKINSON’S THERAPIES

In 2021, the FDA approved Aduhelm (aducanumab) for people with early, mild Alzheimer’s. While questions remain about the drug’s ability to reduce the confusion and memory loss that mark Alzheimer’s disease, this approval marks several significant firsts in the field of brain research. Aduhelm is the first new Alzheimer’s treatment in almost two decades. It’s also the first to treat Alzheimer’s underlying brain changes, rather than targeting symptoms.

The brain changes Aduhelm goes after are abnormal clumps of a protein known as amyloid. Researchers can visualize and measure these clumps using a specialized brain scan, providing an objective biological marker — a biomarker — of the Alzheimer’s disease process in brain cells. In clinical trials, Aduhelm decreased amyloid protein, although it did not consistently improve thinking and memory. The FDA approved the drug based on this biomarker data and requested additional trials to test its ability to increase cognitive functioning.

Parkinson’s and related conditions, such as Lewy

body dementia, are tied to similar brain changes as Alzheimer’s — in this case, clumps of the protein alpha-synuclein. The Aduhelm approval lends confidence to ongoing research targeting these protein clumps to slow symptom changes over time. Currently, more than a dozen therapies against alpha-synuclein are in active clinical trials.

Scientists also are working urgently to find Parkinson’s biomarkers, such as brain scans to visualize alpha-synuclein or spinal fluid tests to measure the protein. Biomarkers would speed research by helping scientists see quickly and clearly whether a new treatment works. The Michael J. Fox Foundation supports these efforts through its Parkinson’s Progression Markers Initiative (PPMI), a global study of thousands of people with Parkinson’s and their loved ones who have enabled deeper disease understandings as well as the launch of several ongoing Parkinson’s drug trials. PPMI is now open to new volunteers, both with and without Parkinson’s. Learn more and join at michaeljfox.org/ppmi. (Read about the latest research on [page 25](#).)



STRATEGIES AND TACTICS

Tips for navigating thinking and memory changes:



FIND THE RIGHT DOCTOR FOR YOU

Look to an expert in memory and thinking problems. If the first doctor isn't a good fit or you aren't comfortable working with them, 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 — again and again, if necessary — until you have the information you need. Take notes, summarize what you hear to ensure understanding, and advocate for your loved one and yourself.



LEARN AND TEACH OTHERS

"Ask your doctor for credible, trusted resources to learn more about your loved one's condition," suggests Yael Wyte, MSW, a social worker with the Alzheimer's Association. 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 cognitive changes (especially other than Alzheimer's), you may encounter misinformation or misconceptions. (See **page 14**: Top Myths about Dementia.)



GET CREATIVE

Find ways around the difficulties you encounter. Keeping 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.

Detailed instructions for how to make a call (or switching to a phone with pictures and one-touch dialing) may simplify telephone use. And adding door, window or bed alarms might make home safer for people who wander.



LEAN ON SUPPORT

Many groups — both online and in-person — offer a way to learn about others' paths and connect with people like you. Some are designed specifically for care partners. (MJFF's online Buddy Network offers a place to connect with people who live with Parkinson's, their loved ones and their care partners. Learn more and join at parkinsonsbuddynetwork.michaeljfox.org.)

Even though disease and symptoms vary, there are many common experiences. Sometimes knowing that other people are on a similar journey can make yours feel less lonely or isolating. And sharing what you've learned can help others.

If a support group isn't for you, find encouragement from your friends, family, church or exercise group, or, if helpful, a therapist or counselor.



BE PATIENT, FLEXIBLE AND KIND

Your life may be different now. It may be more difficult or take longer to perform daily activities, do hobbies and even answer questions. Don't rush or push to do things the same way you once did. Instead, give extra space and time, and try new approaches.

Focus on what you can do instead of what you can't. If the international travel you enjoyed is no longer possible, maybe you can take a local car trip instead, for example.

Be kind and compassionate toward yourself and each other. You might make silly mistakes because you're tired or stressed and bigger mistakes because you don't know any better. There may be days when you don't feel much joy or motivation. That's normal and okay.



TALK OPENLY AND RESPECTFULLY

Speaking honestly about your situation lets others talk about it as well. And the more you talk about uncomfortable topics, the more comfortable they may become.

As early as possible, acknowledge your loved one's experience and talk straightforwardly about it. Anna Greenfield, a writer and Hilarity for Charity grant board committee member whose mother Donna lives with early-onset dementia, suggests "clear and open talks" that include discussion of "the kind of care your loved one would want in the future."

As a person's ability to communicate changes, find new and different ways to connect. You may need to adjust how you ask questions (yes-no instead of open-ended, for example), or look to music or another shared interest to bond. Ava Butler adds, "No matter what's happening, don't talk down to your loved one like a child or about them in the third person."



ASK FOR AND ACCEPT HELP

As symptoms evolve, you may need more help managing symptoms, putting a care plan in place, or thinking about the best 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. An adult child may be able to schedule appointments or call the insurance company; a family friend might spend the afternoon with your loved one so you can run errands or take an exercise class; and a neighbor could pick up your groceries or bring dinner.

Also, be vulnerable enough to let people help in ways you would never ask or think of. Kindness can come from those you know as well as complete strangers who jump into action. (On the other hand, if someone is not helping — or even hurting — you with their attitude or advice, ask them to give you space.)



DO THE BEST YOU CAN

That's all you can ask of yourself. There will be days when your best may not feel very impressive and that's okay. Measure "success" and "good" by your own standards, not those of people without disease or how you imagine things should be.

Cherish the joyful days and moments, such as your loved one's face lighting up when looking at an old photograph, hearing the birds sing or watching children play. These "ups" might help balance the "downs."

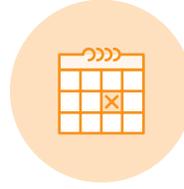


PARTICIPATE IN RESEARCH

Many people say they gain control of their disease by lending their voice to research. But there can be challenges: a person 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 risk for Parkinson’s or cognitive changes, for example).

People both with and without Parkinson’s or Lewy body dementia can find recruiting studies through Fox Trial Finder (foxtrialfinder.org), MJFF’s clinical trial matching tool. And MJFF’s Parkinson’s Progression Markers Initiative study (michaeljfox.org/ppmi), which follows people both with and without PD over time to understand disease onset and progression, is expanding to learn more. People with Parkinson’s, loved ones and family members can join.

There are many ways to get involved in research. Studies are available online or in person, one time or over many visits. Some involve testing a new therapy, getting a brain scan, or donating tissue to find ways to diagnose, track and treat disease. Others involve answering questions so that researchers can learn about the patient or care partner experience and needs.



PLAN AHEAD

Of course, you want the best for yourself and your loved one. Be optimistic! But at the same time, think about the future possibilities and take steps to prepare. (A good idea for everyone, no matter your age or health status.)

Although the time may never come when you need to stop driving or move out of your home to get the safest care, think about how you’d like to approach these situations. For example, you may want to agree you’ll stop driving (or get a driving assessment) if you have a “close call” or others notice changes in your driving. Or, you may want to outline the type of place you’d like to live if home is no longer ideal. Your doctor or social worker can help with these discussions and plans.

As you think ahead, consider financial planning. And complete advance directives, which are legal documents that list who can speak for you and your care if you become unable, and what treatments (CPR or a breathing tube, for example) you would or wouldn’t want if that happens.



“Ask your doctor for credible, trusted resources to learn more about dementia and your loved one’s condition.”

— Yael Wyte, MSW
ALZHEIMER’S ASSOCIATION, CA SOUTHLAND
CHAPTER | LOS ANGELES, CA



FOR CARE PARTNERS, TAKE CARE OF YOURSELF

As they say on airplanes, “put your own oxygen mask on before helping others.” Caring for another person can be a full-time job with overtime. But you can’t take care of someone else unless you first care for yourself.

See your own physician regularly and speak up about challenges during your loved one’s doctor visits. Make an effort to go out with friends, take a walk, or do whatever makes you happy or gives you a break.

Watch for care partner burnout, which may show up as irritability, depression or sleep problems. And know your limit. There may come a time when you need a break or can no longer safely care for your loved one on your own or in your home. Learn about “respite care,” which offers temporary relief for care partners.

And think ahead about other options, such as in-home

caregivers, assisted living or a memory care facility, even though you may never need them. These offer different levels of assistance and care, with varying costs. (Your doctor and social worker can help you navigate this information.) If you anticipate a move in the not-too-distant future, visit potential locations a few times (during a meal and group activity, for example) and discuss symptoms, such as hallucinations or decreased mobility, to ensure they are a good match.

If somewhere other than home becomes the safest place for your loved one, try to free yourself from any guilt. Matthew Patterson, a television writer and Hilarity for Charity grant board committee member shares his family’s experience: “My mom cared for my dad at home into advancing Alzheimer’s, but the decision to move him in his last two years helped preserve her well-being.”



Parkinson's Progression Markers Initiative

Through MJFF’s Parkinson’s Progression Markers Initiative (PPMI) study, researchers are learning about the Parkinson’s experience to develop better tests and treatments. PPMI gathers data and samples over time from volunteers around the world — both with and without Parkinson’s — to increase understanding of symptoms and progression; find measurements in the earliest stages (even before motor symptoms); and advance treatments to slow, stop or prevent disease.

Whether you have Parkinson’s or care about someone who does, you can help. Find out how and join PPMI, the study that could change everything, at michaeljfox.org/ppmi.



Managing Hallucinations and Delusions

For many people and families, these symptoms are among the most bothersome. Ava Butler, whose husband Richard lived with Lewy body dementia, shares her tips:

+ **Respect and reassure**

It's nearly impossible to convince someone that what they see or believe isn't real. And arguing can lead to frustration and loss of trust.

If your loved one experiences hallucinations, ask them 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.

If they have delusions, don't dismiss the belief but don't completely buy into it either. Ask non-intense, probing questions to learn more about what they believe and why.

These actions may help 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've seen that guy, 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 has 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, find creative ways around the hallucination or delusion. 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 and common feelings when living with a loved one who experiences psychosis. 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, to help process your feelings.

Sharing Your Experience with Others

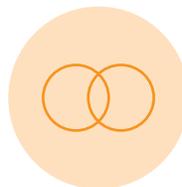
Talking about thinking and memory changes isn't easy. But the people who are closest to you will want to offer support. You're in charge of these conversations. You decide what to share with whom and when. Make a plan for whom you want to speak with, considering your:



LOVED ONES

Many people keep their symptoms or diagnosis secret because they feel ashamed or worry about being “discovered.” No one wants to be seen or treated differently. But keeping secret can increase symptoms, including feelings of loneliness and isolation. And when others sense something's wrong, they often create their own explanations.

Sharing your story also can give you freedom and ease to attend social gatherings and connect with others, which is important for brain health.



PARTNER

Some people worry that after opening up to their significant other they may be criticized or watched more carefully, and that any minor 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 — may worry about hurting their partner's feelings or, “pointing out progressions in Parkinson's.” Acknowledging the situation can bring you both relief and the opportunity to work through it together.



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 action 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 assistive technology. Others, 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 ahead of time your rights, the possible implications of your disclosure, and what accommodations you may be able to request.



TALKING ABOUT THINKING AND MEMORY CHANGES

Some tips for your conversations, if helpful, from MJFF's Patient Council:

+ 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.

+ 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.

+ Acknowledge fear

Future unknowns — especially around 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.

+ Build your own vocabulary

Words such as "dementia" and "psychosis" may not only be hard to define, they also may be associated with stigma and strong emotions. 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 progressed, he "unlearned" how to do things, such as use a computer and cellphone. When talking about her mom's changes, 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."

Research on Thinking and Memory Changes

Researchers are working to understand how and why cognitive changes happen and who is most at risk. And because Parkinson's disease, Lewy body dementia and Alzheimer's disease share some symptoms, brain changes and genetic risks, breakthroughs in one disease may lead to insights and benefits in another. Ongoing studies aim to:

+ Build understanding

Exactly how and why cognitive changes happen and who is most at risk are big unanswered questions. Clues may lie in abnormal proteins and genetic links.

In dementia, normal proteins misfold and clump in brain cells, and researchers believe these proteins contribute to 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 brains of people with Parkinson's.) In Alzheimer's disease, the misfolded proteins are tau and beta-amyloid. But researchers also find misfolded beta-amyloid in some people with Lewy body dementia as well as some older people who don't have thinking or memory problems. And the brains of some people with Alzheimer's have Lewy bodies, too. Learning more about these proteins not only will deepen disease understanding, it also may lead to better treatments and cures.

Genetics 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 mutations in several genes (such as GBA in Lewy body dementia and APOE4 in Alzheimer's) that increase risk. Studying these gene changes and their cellular pathways helps scientists learn how disease happens. Following people with gene changes to see who develops disease can show what factors protect from and lead toward disease.

+ Develop diagnostic tests

At this time, no test can, on its own, definitively diagnose dementia. But researchers are looking at different ways to diagnose, measure and track changes. These include questionnaires; rating scales; blood, spinal fluid or brain wave tests; and many others. They're also developing specialized brain scans to see misfolded proteins in the living brain, since some of these proteins currently can only be seen in the brain at autopsy.

Better tests would allow earlier and more accurate diagnoses. They also would speed research by getting the right people into the right research trials and determining more quickly and clearly whether an investigational therapy works.

Several programs are looking for measures of disease, or biomarkers:

— Parkinson's Progression Markers Initiative (PPMI):

The Michael J. Fox Foundation's landmark study, launched in 2010, collects data and samples over time from volunteers with and without Parkinson's to understand how the disease begins and progresses.

To increase disease understanding, develop better tests and treatments, and ultimately prevent Parkinson's, PPMI is expanding. Family members of people with Parkinson's, people with gene changes and other PD risks, and those newly diagnosed can help. Learn more at michaeljfox.org/ppmi.



- **Biomarkers Across Neurodegenerative Diseases (BAND):** A collaboration between MJFF, the Alzheimer’s Association, Alzheimer’s Research UK and the Weston Brain Institute, this study encourages researchers to compare different types of dementia in order to better diagnose and treat each of them. Read more about BAND-funded studies at michaeljfox.org/BAND.
- **Cure One, Cure Many Award:** A partnership between MJFF, the Alzheimer’s Association, the American Brain Foundation, and the American Academy of Neurology, this program aims to find ways to measure and monitor Lewy body dementia for earlier and more accurate diagnosis and treatment.
- + **Improve treatments**
Clinical trials are testing a variety of therapies to treat thinking and memory changes. These work on different pathways, including:
 - Brain chemicals (neurotransmitters), such as acetylcholine, dopamine, glutamate and serotonin, which play a role in memory and thinking;
 - Inflammation, which is associated with disease;
 - Genetic mutations, such as GBA, which increases risk of Parkinson’s and Lewy body dementia;
 - Misfolded proteins, including alpha-synuclein, amyloid and tau, which are linked to different dementias;
 - Others.

Finding ways to prevent or clear misfolded proteins is an area of significant effort toward slowing or stopping disease progression. At the time of this writing, trials are evaluating more than a dozen different anti-alpha-synuclein therapies in Parkinson’s. And because this protein also is involved in Lewy body dementia, there is reason to believe success in Parkinson’s could translate to Lewy body dementia.

Several anti-amyloid and anti-tau therapies also are in development for Alzheimer’s and related dementias. In 2021, the FDA approved Aduhelm (aducanumab), the first drug to clear amyloid brain clumps (and hopefully also slow progression) in people with early, mild Alzheimer’s. (Read more on **page 17**). More drugs targeting amyloid in Alzheimer’s also are already making their way through clinical trials and toward FDA approval. As researchers develop new therapies, they build more knowledge of the disease as well as how and when to test treatments. Some work now, for example, aims to identify and treat disease even before symptoms appear.

Many studies also are evaluating treatments for symptoms commonly associated with thinking and memory changes, such as mood or sleep difficulties, or hallucinations and delusions. These include new medications, repurposed drugs (already FDA-approved for another condition), brain stimulation, exercise (for the brain and body) and light therapy.

For the most up-to-date research information, visit Fox Trial Finder (foxtrialfinder.org) or clinicaltrials.gov.

Resources

The resources below offer information and tips for navigating Parkinson's disease, Lewy body dementia and Alzheimer's disease.

WEBSITES

The Michael J. Fox Foundation for Parkinson's Research

michaeljfox.org

Alzheimer's Association

alz.org

Alzheimer's Disease International

Information about dementia in 49 languages.

alzint.org/resource/other-languages

The Balm in Gilead National Brain Health Center
for African Americans

balmingilead.org/resources

Centers for Disease Control and Prevention

cdc.gov/aging/aginginfo/alzheimers.htm

ClinicalTrials.gov

A searchable database of clinical trials across the world and across all diseases.

clinicaltrials.gov

Diverse Elders Coalition

diverseelders.org

Forget Me Not Project

fmnproject.org

Fox Trial Finder

MJFF's online tool that matches volunteers with recruiting clinical trials.

foxtrialfinder.org

Hilarity for Charity

hilarityforcharity.org

Lewy Body Dementia Association

lbda.org

More than Memory Loss

morethanmemoryloss.com

National Institute on Aging

nia.nih.gov/health/alzheimers

Us Against Alzheimer's

Information and networks for African Americans, Latinos, women, veterans and others.

usagainstalzheimers.org



FREE TELEPHONE HELPLINES

Alzheimer's Association
Information and assistance available 24/7 in over 200 languages.
1-800-272-3900

National Asian Pacific Center on Aging Community Resource Helpline
Information and guided meditation available in eight languages. Visit the website for language-specific phone number: napca.org/helpline.

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
michaeljfox.org/your-role-research

Parkinson's 360
The Michael J. Fox Foundation for Parkinson's Research
michaeljfox.org/parkinsons-360

Parkinson's: A Love Story with Dementia for Dessert
Ava S. Butler

Information in this guide was accurate at the time of publication in August 2021. For the latest on Parkinson's and thinking and memory changes, visit michaeljfox.org.

The medical information contained in this publication 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.

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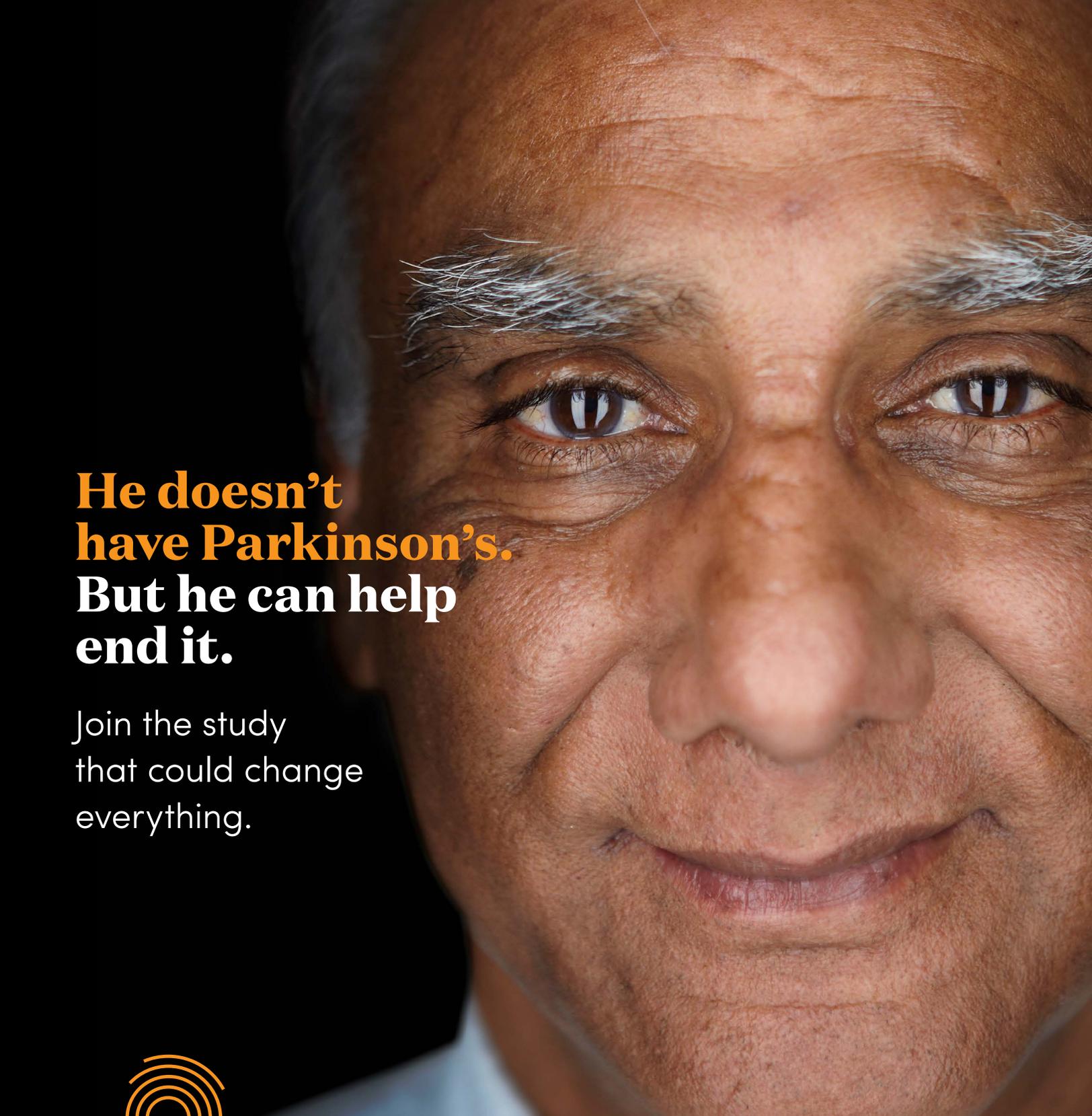
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**He doesn't
have Parkinson's.
But he can help
end it.**

Join the study
that could change
everything.



**Parkinson's
Progression
Markers
Initiative**

Through MJFF's Parkinson's Progression Markers Initiative (PPMI) study, researchers are learning about the Parkinson's experience to develop better tests and treatments. Whether you have Parkinson's or care about someone who does, you can help.

Participate today at michaeljfox.org/ppmi.

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