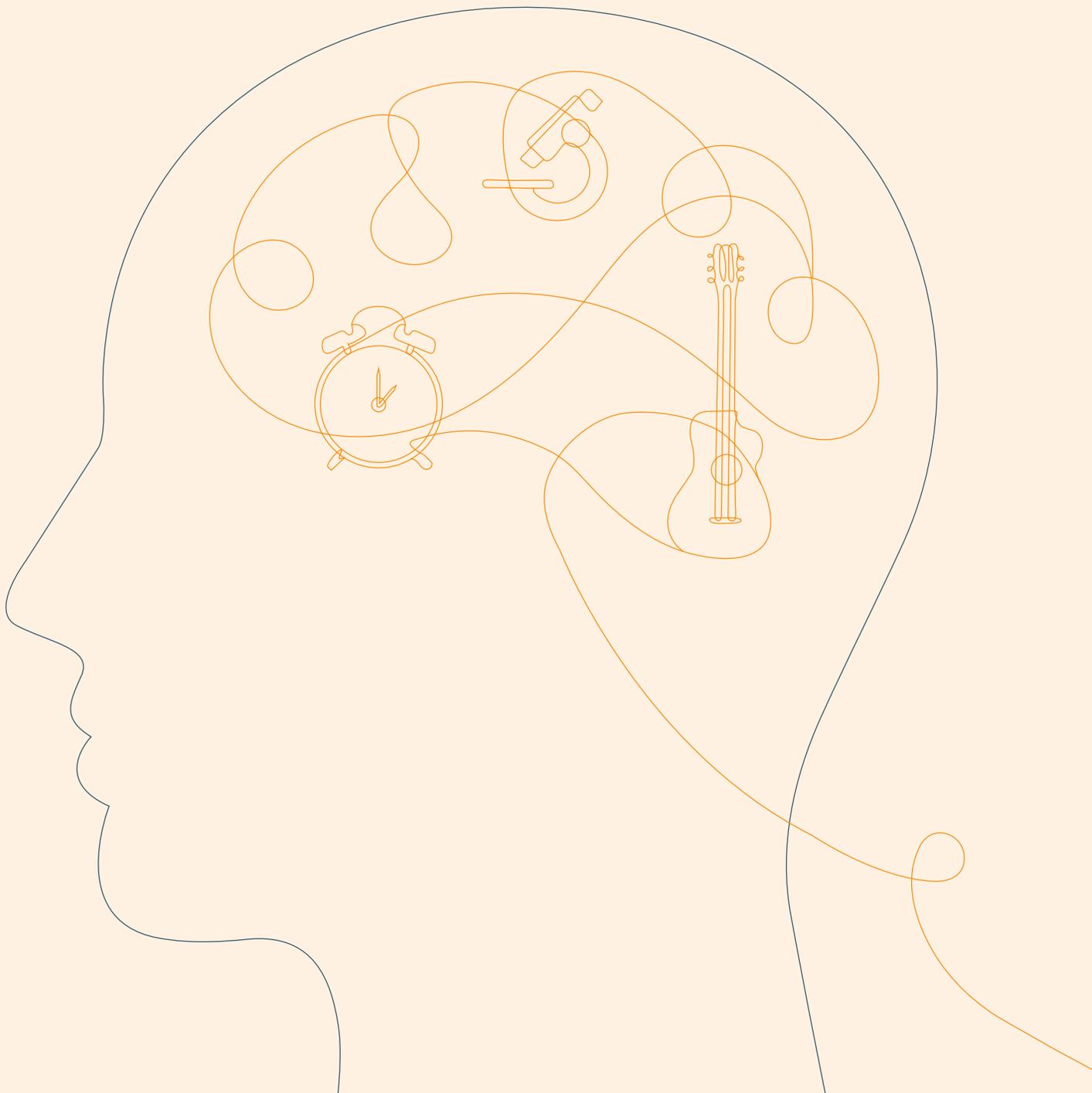




THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

Better Brain Health

A Guide to Caring for Your Magnificent Brain at Every Age





By Rachel Dolhun, MD

How this book was created

Family members of people living with brain disease, such as Parkinson's or Alzheimer's, often wonder: Am I at risk? Others, who are simply getting older or are interested in general well-being, also want to know their chance of disease and what they can do to protect and preserve brain health. Today, research is brimming with groundbreaking insights into how each of us can best care for our brain and limit risk for disease. And scientists are learning from people who live with risks to develop better treatments and, ultimately, prevent disease. Steered by your questions, this guide offers practical tips for boosting brain health and limiting risk and highlights the latest advances in brain research and the critical role we all play in moving research forward. Content development was led by Rachel Dolhun, MD, a movement disorder specialist, board-certified neurologist and senior vice president of medical communications at The Michael J. Fox Foundation. We are grateful to the community members who lent their voices and experiences to this resource.

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PPMI: The Study that Could Change Everything

Boosting Brain Health: There Is So Much You Can Do

Our brains are magnificent machines, directing every function, response and sensation in our body 24 hours a day. And there has never been a more promising time in brain research and understanding.

Regardless of what has brought you here, welcome! This guide offers clear information and tips for people of all ages, whether just getting older, at increased risk for a brain disease or already diagnosed.

Scientists are making unprecedented advances in unraveling the complex biology of the brain both in individuals who are simply aging and in those living with neurological disease. And these insights are flowing quickly into the drug development space to benefit all of us with better brain health that we can hang onto longer.

What it means for everyday people like you and me: Researchers now understand that there is so much we can do in our daily lives to boost brain health. From diet and exercise to social connection, research is piecing together the puzzle of how best to care for our precious brain, how to prevent disease and, if disease does arise, how to best treat it. Dozens of treatments are in clinical trials to slow or stop Parkinson's, Alzheimer's and other brain diseases. And research to predict and even prevent these conditions is expanding in a way we could only dream about a few short years ago.

As a reader of this guide, you might be focused on keeping your brain as healthy as possible throughout life. Or you may have reason to worry about the potential for brain disease, such as Parkinson's or Alzheimer's — perhaps because a family member lives with one of these conditions, you've learned you have a genetic or environmental influence linked to the disease, or you want to be prepared for whatever might come.

Regardless of what has brought you here, welcome! This guide offers clear information and tips for people of all ages, whether just getting older, at increased risk for a brain disease, or already diagnosed. It offers simple and effective steps you can take to care for your brain, learn how to limit and live with your personal risk for disease, and get involved in brain health research.

At The Michael J. Fox Foundation, we've been identifying and partnering with research groups worldwide to enable cutting-edge neurological research for more than two decades. We've funded more than \$1.5 billion in research to understand the incredible human brain and what gives rise to Parkinson's and other diseases. And it's part of our Foundation's mission to share everything we're learning with you. In fact, as a board-certified neurologist and movement disorder specialist, it's my entire job.

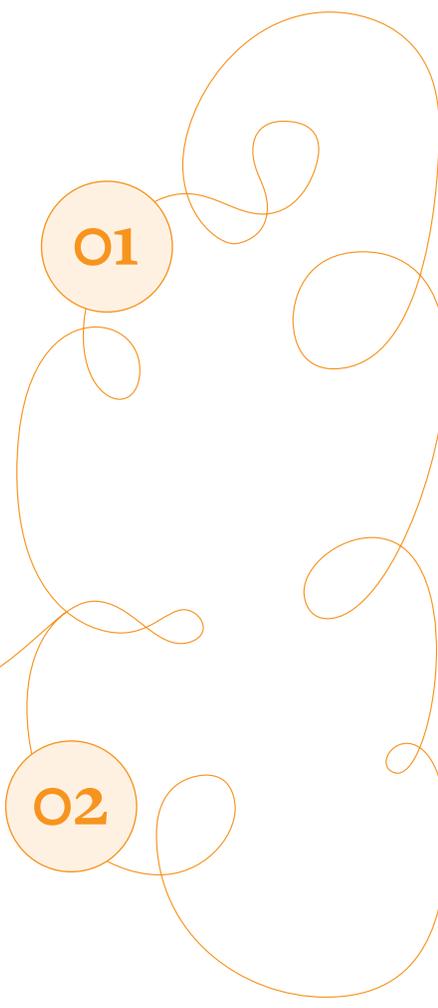
I hope this guide inspires and empowers you to care for your brain the same way you care for your heart, lungs and every other part of your phenomenal human body.

Four Tenets for a Healthy Brain

Whether you are actively managing known risk for disease, or simply want to take control of healthy aging, these four universal truths can help you navigate everyday behaviors to keep your brain's health in focus. If they are all you take away from this guide, they will still help you make healthy choices for yourself and your loved ones!

What's good for your body is good for your brain.

You already know that exercising regularly and eating a balanced diet can keep your heart, muscles and bones healthy. These activities also can boost your brain health. Your brain will thank you for practicing healthy habits as a routine part of your daily life. You don't have to run a marathon or join a gym; a short walk around the neighborhood is a great place to start. Similarly, no one eats healthy all the time, but swapping highly processed or high-fat/high-calorie foods for lean proteins, leafy greens, fruits and vegetables, and other minimally processed foods even a few times a week can make a difference to brain health.



01

02

Change is a normal part of getting older; disease is not.

Our bodies and brains naturally change with age. But disease, such as Parkinson's or Alzheimer's, is not a "normal" or expected part of getting older. Learn what to watch for and how to talk to your loved ones and doctor about any changes you notice. It's better to gather evidence-based information from trusted sources, like your doctor, than to live with toxic worry and stress — these are not good for your brain or any other part of your health.



Connection keeps your brain healthy.

Over recent decades the scientific evidence has mounted to demonstrate that positive, nurturing relationships and regular social interaction are as important for brain health as regular exercise and healthful eating. Loneliness and isolation can be as harmful as smoking or not exercising enough. Make it a priority to maintain existing relationships and build new ones. Connect regularly with others in-person, over the telephone or online. (But limit time spent in anonymous online interactions, such as scrolling through social media; studies show that this can ultimately stress us out or even increase our feelings of isolation over time.)

03

04

The answers to better brain health and care are in you.

Researchers are learning more about how the brain changes over time and how to treat and even prevent disease. No matter your age or health, you can help build understanding of the spectacular human brain. Sharing your experiences and participating in research studies is one way to take control of your health journey and to advance research progress.



Section 01



Caring for Your Brain at Any Age

As we get older, we change. Hair turns gray or thins, skin wrinkles and hearing decreases. Over time, the brain — its cells, blood vessels and chemicals — naturally changes, too. We may not learn or process information as quickly or easily as we once did.

KEY TAKEAWAYS

- + Age brings brain changes, such as minor memory lapses, which are normal.
- + Getting older also increases risk for certain brain diseases, such as Parkinson's.
- + There are many steps you can take to boost brain health throughout life.
- + You can help researchers learn more about brain health and disease.





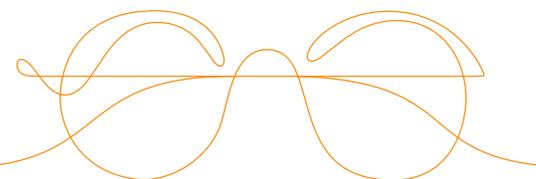
Memory might not be as sharp. It's common to forget new names or why you walked into a room, or to misplace your keys or glasses. These are normal experiences of aging.

Generally speaking, advancing age is also the biggest risk factor for brain disease, such as Parkinson's disease (PD) or Alzheimer's. These diseases don't happen in everyone; they are not an expected part of getting older. But if they happen to you or someone you love, they can change every aspect of your life. Even before they ever arise, it can be a source of stress just to live with the worry that they might. And one of the most difficult realities is that, unlike heart disease or diabetes, Parkinson's and Alzheimer's can't (yet) be predicted or prevented. There's not (yet) a medical test that can objectively determine your risk or track

disease-related cellular changes over time. By the time brain disease is diagnosed, cells already have been damaged and symptoms typically have begun.

But of course, none of us can keep from getting older. So why do some people get brain disease, and others not? Today we understand more about this than ever before. Researchers are hot on the trail of diagnosing disease much earlier. Imagine the difference it will make in all of our lives when diagnosis can occur well before any damage happens, in turn enabling treatment that could prevent symptoms from ever coming on. And though we aren't there yet, there is still much you can do today to boost your brain health throughout life.

Advancing age
is the biggest
risk factor for
brain disease.



Age-related Brain Conditions

Doctors and researchers believe that aging, along with genetics and environment, contributes to many diseases. The older you get, the more likely certain diseases may be. The most common brain diseases with aging include:

Alzheimer's disease

One in nine people aged 65 or older has Alzheimer's. This disease inspires fear in many because of the insidious ways it affects short-term memory and thinking and gets worse over time, seeming to steal what makes us "us."

Alzheimer's is a type of dementia. Dementia is an umbrella term for significant memory and thinking problems that interfere with or completely impede daily activities, such as getting dressed, making meals or doing household chores.

Researchers believe that in Alzheimer's the proteins beta-amyloid and tau misfold and clump in brain cells. There isn't yet a proven cure, but research is extremely active. In 2021, the United States Food and Drug Administration (FDA) approved the first medication targeting beta-amyloid to, potentially, slow disease-related change over time. And several currently available medications and treatments can ease symptoms.

Parkinson's disease

One in 10 people aged 60 or older has Parkinson's. This condition causes tremor, slowness, stiffness, and walking and balance changes. It also can cause mood and sleep changes, constipation, smell loss and other symptoms. The most common age at diagnosis is the late 50s or early 60s, but it can happen earlier, too. There currently is no blood test or brain scan for PD. Doctors rely on physical examination and medical history to determine whether a person has the disease.

Over time, symptoms gradually worsen. But many medications, surgeries and other treatments can lessen them. There is not yet a cure, but several therapies with the potential to slow disease are now in clinical trial testing. Many of these target alpha-synuclein, a protein that clumps in the brain cells of people with Parkinson's, or genetic changes linked to PD.

→ For more on Parkinson's, see page 48.

Stroke

A stroke is when the blood supply to part of the brain stops or decreases. Strokes happen when a blood vessel is damaged or clogged or when it breaks open and bleeds. The symptoms of a stroke depend on where it's located in the brain. Trouble speaking, for example, occurs when a stroke affects brain cells that control language.

In addition to age, high blood pressure, high cholesterol, diabetes and cigarette smoking increase risk for stroke. Treatments aim to decrease symptoms and prevent future strokes.

1 in 10

people aged 60 or older
has Parkinson's disease.



Protect Your Brain

Good brain health doesn't happen at an annual physical. Taking action to protect and preserve the health of your brain is an everyday activity and a set of habits to incorporate for life. While there are unfortunately never any guarantees with health, research consistently demonstrates that what's good for your body is good for your brain. Here are some of the most important and valuable things you can do.



30mins

of exercise at least five times a week boosts brain and heart function.

01 Get moving

Any aerobic exercise — one that increases your heart rate — is good for well-being and for body and brain health. Research suggests that physical activity can increase the number and health of brain cells and limit age-related changes.

Popular aerobic exercises include walking, running and cycling. But many “cardio” activities are effective. As always, the best exercise for you is the one you enjoy, feel safe doing, and will stick with.

Experts recommend at least 30 minutes of exercise five times per week. You can do 30 minutes at once or divide it into three 10-minute blocks over the course of your day. You can exercise alone or in a group; at home, in a gym or outdoors; or through an online class or smartphone app. or on your own. Start and increase slowly and try different activities to see what you most enjoy. Don't forget to include muscle strengthening, stretching and balance exercises a few times a week, too.

02 Eat well

What you eat affects your energy, mood and activity. And because of connections between the gut and brain, your diet also impacts brain health. To support your brain, experts recommend eating a balanced, healthy diet full of vegetables, fruits, whole grains and lean protein. Focus on whole, unprocessed foods and limit or avoid processed, fried or sugary foods. Learn about the benefits of different foods and ingredients; read food labels, because “healthy” names and marketing can be misleading. Work with a dietitian if possible. And when adjusting your diet, make one small change at a time.



03

Train your brain

Your brain is like your muscles — a regular workout can help it function better. But it's important to know how to work out effectively. For your brain this means introducing new challenges that require different kinds of effort and use different parts of your brain.

Learn how to speak a new language or play an instrument; practice drawing or painting; or scrapbook, join a book club or take a writing class. The wider the range of activities, the more your brain will forge new connections that can help it stay “limber” — receptive to new information and better able to process tasks of varied complexity. Researchers call this “neuroplasticity” and it’s a trait our brains retain throughout life.

04

Connect with others

We’re social creatures and our brains thrive mentally, emotionally and physically in the presence of other people. Positive, supportive relationships and regular social interactions boost brain health and well-being. Make a point of maintaining relationships: Set up a regularly scheduled call with a friend once a week. (Better yet, meet in person or learn how to use computer software to have a video chat.) And put yourself in situations where you can make new friends, too. Sparking conversation is a good way to work your brain and make new connections. Try taking a cooking class, signing up for dance night in the park or joining a travel club.

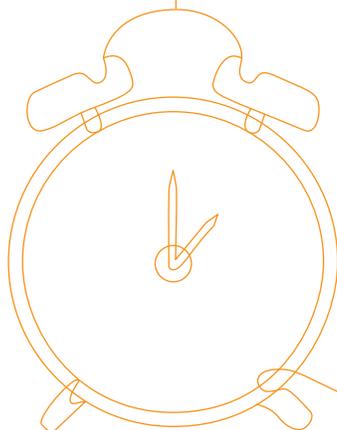
05

Get your Zs

Researchers believe sleep helps us store memories, boosts the immune system, and keeps our brain and body healthy. Make sure you get the recommended amount of sleep each night. For adults, that’s about seven hours on average, though only you know what makes you feel best; for some people it’s more and for others, less. You can maximize sleep quality by keeping a consistent bedtime and wake-up schedule, adopting habitual ways of winding down before bed, and regularly exercising earlier in the day.

If you have trouble sleeping, keep a diary for a few days to track your sleep. (Some wearables can help you track sleep and nighttime wakefulness digitally, if that’s your cup of tea.) The data you generate this way can help guide conversation with your doctor and suggest treatment approaches.

→ And if you or your bed partner has been diagnosed with a sleep disorder, see page 34.



7hrs

of sleep on average
per night keeps brain
and body healthy

Protect Your Brain *continued*

06

Reduce stress

Some level of stress is a normal human response to challenging and even positive life events. Stress can even be a good thing when it alerts us to situations we need to pay attention to or boundaries we need to set, for example. Other “good” stress includes exercise, which challenges our bodies in positive ways. But when prolonged, or severe enough to interrupt your daily life, stress can impact physical and brain health — leading to mood or thinking changes, headaches, sleep trouble and other difficulties.

Everyone’s stressors are different. Identify what triggers your stress and best ways to avoid or minimize those triggers. Also find ways to relieve your stress. These might include exercising, listening to music or journaling. For some, it’s practicing meditation or mindfulness, praying, or spending time in nature. For many, seeing a mental health counselor also is useful. If you have the resources, consider a wellness program that can help you learn and integrate healthy habits toward reducing stress.

Find ways to relieve your stress. These might include exercising, listening to music or journaling.

07

Monitor mood

Mood changes, such as depression and anxiety, are linked to memory and thinking changes. They may impact the brain directly or indirectly, by affecting outlook and activities. A person who feels down, for example, may not exercise as much or eat as healthfully.

Depression and anxiety are medical conditions. They are treatable with medication, talk therapy (counseling), exercise and other strategies.

08

Limit substance use

The United States Dietary Guidelines recommends moderate to no alcohol use. Moderate is defined as two drinks per day or less for men and one or less per day for women. Emerging evidence suggests that regular use of any amount or type of alcohol could contribute to disease.

While some alcohol may be okay, it’s best to avoid tobacco. Cigarette smoking is linked to Alzheimer’s, stroke, and other brain and heart diseases. If you smoke, ask your doctor about options to help you quit.

09

Manage medical conditions

Certain medical conditions can affect the brain. These include diabetes, high blood pressure and high cholesterol, as well as others. Medication also can have an effect. Some prescription and over-the-counter drugs, such as sleep aids and anti-itch pills, can cause confusion or cloud thinking.

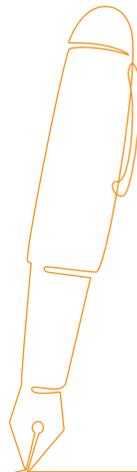
Talk with your doctor about how to best care for medical conditions and reduce potential brain impacts. Regularly review your medications together and always ask before starting over-the-counter medications or supplements.

10

Be aware of surroundings

Certain aspects of where we live and work, or environmental factors, can influence brain health. Pesticides, chemical solvents and air pollution, for example, are linked to PD and other brain diseases. Head injury or concussion also can increase Parkinson’s risk.

It may not be possible to avoid all these factors, but you can limit them. To protect your head, use a helmet when riding a bike or motorcycle, wear your seatbelt in the car, and avoid contact sports.



You Have a Role in Brain Health Research

You may be surprised to learn that you can play a role in brain research. Research participants without disease are known as “control volunteers.” They can help scientists learn more about how the brain works, how to keep it healthy, and how to treat and prevent disease.

66
The insights that we’re gaining through Parkinson’s research should be very translatable above and beyond Parkinson’s.⁹⁹

William Marks, MD, MS,
Head of Clinical Science and
Neurology at Verily Life Sciences

Volunteers often say that joining a study allows them to be in control of their health journey, give to others by fueling progress toward new treatments and cures, or support a loved one with disease.

Many ongoing studies are evaluating brain health and disease. Some test treatments to prevent disease, lessen symptoms or stop changes from happening over time. Others follow people for years to see how the brain and body change with both age and disease.

The Parkinson’s Progression Markers Initiative (PPMI) study, for example, gathers data and experiences of people with and without PD to learn how and why disease comes on from the earliest stages. It also promotes broader knowledge of brain health and other brain diseases.

→ Read more on page 51 and 54.

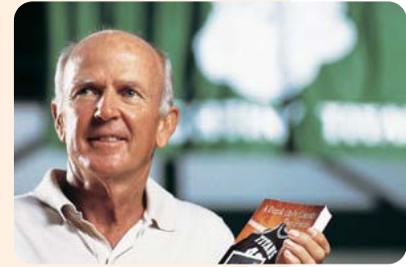
“The insights that we’re gaining through Parkinson’s research should be very translatable above and beyond Parkinson’s,” says William Marks, MD, MS, Head of Clinical Science and Neurology at Verily Life Sciences. He continues, “In many ways, participants in the Parkinson’s Progression Markers Initiative and in other Parkinson’s studies are contributing way beyond just the understanding of Parkinson’s disease itself.”

There are many opportunities to participate in research. You can share your experiences and health data by filling out online questionnaires or by visiting a research site in-person. Or you can test a new treatment. Some studies require only one questionnaire or visit; others ask you to come back every few months. There’s a study for every schedule and comfort level.

→ Learn more about research participation at michaeljfox.org/participate.



Giving My All to Parkinson's Research as I Get Older



Dennie Bridges,
age 82, retired basketball
coach and author,
Bloomington, Illinois

From coach to team member

I was a basketball coach for Illinois Wesleyan University for 32 years, and the athletic director for another 19 years. I retired when I was 76 years old, after 51 years. While I don't have Parkinson's disease myself, I have a number of high school and college classmates who have it.

One night, I happened to see an interview with Michael J. Fox on TV. I was really impressed with his passion and his story, how he tackled his situation head on. I decided to donate all the proceeds from a book I had published, about growing up in a small town, to The Michael J. Fox Foundation (MJFF).

66
While I don't have Parkinson's disease myself, I decided to join PPMI because I want to help research any way that I can.⁹⁹

Valuable information

Once I was connected to MJFF, I was inspired to get more involved. I read that they needed volunteers without Parkinson's for the Parkinson's Progression Markers Initiative (PPMI) study. I decided to join because, even though I don't have any connection to Parkinson's, I'm getting older and want to help research in any way that I can. I've been in PPMI now for the last nine years. At first, I went to Northwestern Hospital for testing every six months. But now I go once a year. I've had five or six spinal taps, had my blood taken and answered lots of questions.

All in

When it comes to research for Parkinson's, I'm all in. The longer researchers can track your symptoms or non-symptoms, the better, and that's why I'm sticking with my commitment. I gave my word.

Questions to Ask about Your Brain Health

Brain health is just as important as body health. Make it a priority to discuss brain care with your doctor at each visit, whether that's an annual physical, regular check-up or other type of appointment. Potential questions to open conversation:



What's one thing I can do to take care of my brain?

Your doctor knows your health, history and interests. They can help you tailor activities to promote brain health, such as exercising more minutes each day or watching less TV each week.

Could my medical conditions or medications affect my brain health?

Tell your doctor about all your medications, including over-the-counter drugs, supplements and herbal remedies. Don't lower or stop medication before speaking with your doctor, but ask if this may be an option for any medication that could impact thinking or memory.

What changes should I watch for?

Many people wonder what changes are normal with aging and what might be concerning. Ask what activities to monitor and what to look for.

Is this change something to worry about?

If you or your loved ones notice a change — no matter how subtle or mild — talk with your doctor. Many changes are part of age, but some can be from medication or new medical conditions.

Should I get memory testing?

Your doctor can do short memory tests during a standard office visit. But depending on your results and symptoms, you may want or need more detailed testing. Some people also may benefit from seeing a doctor who specializes in memory and thinking (a neurologist).

What's the latest research on brain health?

Researchers are studying how to keep your brain healthy and why disease happens. Ask your doctor for the latest research findings, credible sources to learn more, and opportunities to participate.



→ Visit foxtrialfinder.org for recruiting studies in your area.



Pay Attention to the Little Things

Change is part of getting older. But not all change is from age. Sometimes change can signal an emerging problem or new medical condition. It can be hard to know what's age and what might be something else.



WHAT TO LOOK OUT FOR

- 01 — Constipation
- 02 — Smell loss
- 03 — Slowing down
- 04 — Depression

Another difficulty is that some of the earliest possible signs of some medical conditions, such as Parkinson's, are mild or subtle. And they may not be ones you typically associate with the disease, such as shaking (tremor).

This doesn't mean that you should be overly concerned about tracking every change, no matter how minor. There are some common experiences that, surprisingly, especially in people over 60, can be associated with Parkinson's risk. If you experience these, first and foremost don't panic! For most people, these are not Parkinson's. But being aware of how you are changing can help you talk early and often with your loved ones and your doctor.

01 Constipation

Constipation is less frequent or more difficult bowel movements. "Normal" bowel movements vary significantly from person to person. Some people go once or more a day; others go a few times a week.

Many factors can cause constipation, including what you drink and eat and how much you exercise. Not drinking enough water, not eating enough fiber or not moving enough all can contribute to constipation. Make sure you drink at least six 8-ounce glasses of water per day,

more if you exercise or spend time outdoors. Gradually add high-fiber foods, such as apples with the skin on, bran and oatmeal, and beans and legumes. And make sure to exercise. Steady, moderate activity, such as walking, swimming or light weightlifting can help activate your digestive system.

Most of the time, constipation comes and goes with nothing more serious than a few days of discomfort. But rarely, particularly in people around 60 and up, constipation may be a sign of early changes associated with Parkinson's taking place in brain and body cells. It can show up years or even decades before the better-known movement symptoms (such as tremor, slowness and stiffness), and before diagnosis with the disease.

As a result, studying individuals over age 60 who are experiencing constipation may lead to increased understanding of Parkinson's risk. (For some people living with Parkinson's, though not all, constipation continues to be a symptom of the disease.)

If, over the course of a few weeks or months, you notice you go less often or have a harder time passing stool, especially if you are taking healthy steps but still experiencing constipation, talk to your doctor. Make sure to discuss the lifestyle changes you've tried and other medical conditions or medications that might

cause constipation. Many medications for pain and some for depression, blood pressure and other health problems, for example, can lead to constipation.

02 Smell loss

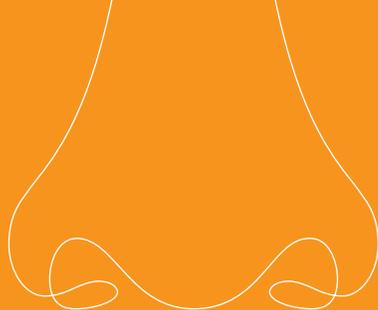
We may not fully appreciate our sense of smell until it decreases or goes away. The ability to smell helps us taste and enjoy our food. It also keeps us safe by letting us know if food is spoiled or something is burning, for example.

Sense of smell does naturally diminish as we get older. But loss of smell can also be part of other medical conditions. For some people with Parkinson's or other brain disease, smell loss is one of the first symptoms, happening years or decades before diagnosis.

But many other factors can cause smell loss: cigarette smoking; a cold, sinus infection, allergies or other nasal problems; or head injury. Some medications, such as nose sprays, could also impact sense of smell.

If you notice you can't smell as well as you used to, or that your sense of smell is gone, talk with your doctor. They can help you determine the potential cause and best treatment options.

Take
the



S

B

E

IL

Test
Challenge

The Nose Knows: Smell Loss and Your Brain

Our sense of smell plays an important role in monitoring brain health as we age. Unlike temporary smell loss associated with COVID-19, ongoing and progressive smell loss as we age can be a signal of early cell damage associated with brain disease. Now, preliminary results from the first 20,000 individuals to enroll in PPMI indicate that smell loss may be one of the most important signals of risk as we age.

Click on the link below to request a simple scratch-and-sniff test. We'll mail you a test, which takes about 15 minutes to complete, and share your results with the scientific experts leading The Michael J. Fox Foundation's PPMI study.

Sniffing Out Risk

The scratch-and-sniff test you'll receive is one of the most trusted and reliable used by doctors and scientists to assess the olfactory system. While it takes only a few minutes to complete, it is considered the "gold standard" to check on the health of your sense of smell.

[Request a Sniff Test](#)



I just don't move as quickly as I used to. It's one of the most common observations people who are getting older make.



Pay Attention to the Little Things *continued*

03

Slowing down

“I just don’t move as quickly as I used to.” It’s one of the most common observations people who are getting older make. You might find it takes longer to get ready in the morning or it takes more effort to get out of a chair or up the stairs. Some feel a little less steady on their feet. Loved ones might notice it’s harder for you to keep up on morning walks or weekly hikes.

Age does naturally cause slowing. That can make it especially hard to know what’s getting older and what might be something else. And that’s why it’s important for you to see your doctor. Many people chalk things up to age and miss the opportunity for an early and thorough evaluation.

In addition to age, conditions like arthritis, back pain and even vision changes can impact how quickly you move and how well you walk. But slowness also is one of the signs of Parkinson’s. In some people with PD, the first movement symptoms are very subtle: one arm not swinging as much while you walk; shuffling your feet or having trouble turning around. In others, it might be a golf swing that’s somewhat “off” or fingers that don’t type or text as easily as they used to.

If you’re a little slower or your golf game feels off, you needn’t automatically assume you have Parkinson’s. But you also don’t want to brush it off, either. Your best bet is to meet with your doctor, who can examine your movements, watch you walk, and help you determine next steps, which may include visiting a neurologist.

04

Depression

Feeling sad is a normal part of life. But when it lasts a long time and affects your daily life, it could be depression. Changes in brain chemicals play a role in depression. So do genetics and stressful life events. Depression also can be more common in older age, which could be because of changes in activity, health and other factors.

Depression is a medical condition, just like heart disease or diabetes. It’s treatable with medication, talk therapy (counseling) and other therapies. Connecting with others and exercising regularly also can help.

Depression can happen on its own or it can be part of other diseases. It can even be one of the earliest symptoms of Parkinson’s. After a PD diagnosis, some people comment that they’ve had depression for many years or much of their life. This does not mean that having depression always leads to Parkinson’s. But it does mean that it’s important to treat depression and to take steps to keep your brain as healthy as possible.

These changes are non-specific, meaning they can happen for many different reasons. One of the most common is getting older. But, as with any change, you don’t want to immediately attribute it only to age. Age very well may be the cause. But the only way to know for sure is to meet with your doctor. Ask them directly, “Is this age or might it be something else?” And work together to get to the bottom of it. Any of these changes, whether they are from age or something else, can impact your life. But there are ways to ease each of them and steps you can take to continue living as well as possible.

➔ For more on Parkinson’s, see pages 10 and 48.

Changes are non-specific, meaning they can happen for many different reasons. One of the most common is getting older.

Myths about Brain Health

There are many misconceptions about the brain and how to keep it healthy. Separating fact from fiction can help you understand and take care of your brain.

01

Myth

Alzheimer's is just part of getting older

Some memory and thinking changes are normal with age. But significant changes that interfere with daily activities (dementia) are not. Misplacing your keys may be normal, for example, but forgetting what they're for is not.

Different diseases can cause dementia. The most common is Alzheimer's. But there are others, too, such as Parkinson's and a related condition called Lewy Body Dementia. Age increases the risk of these diseases but does not guarantee them. Talk with your doctor and others your age to learn whether changes may be from age or something else.

02

Myth

Brain changes happen only in old age

Changes in brain cells or structure can start years or decades before a person has symptoms or is diagnosed with disease.

This means that healthy activities are important throughout life. It also means that people at risk for brain disease can make valuable research contributions toward understanding how and why disease comes on from the earliest stages and how to prevent it.



Healthy activities are important throughout life.

03

Myth

A pill can help you think better

No over-the-counter or herbal supplement has yet been proven to significantly improve memory and thinking.

Studies on ginkgo, ginseng, curcumin and other supplements have been small and/or shown conflicting results. Aim to get vitamins and nutrients through a well-rounded diet and then add supplements, as necessary, with your doctor's guidance.

04

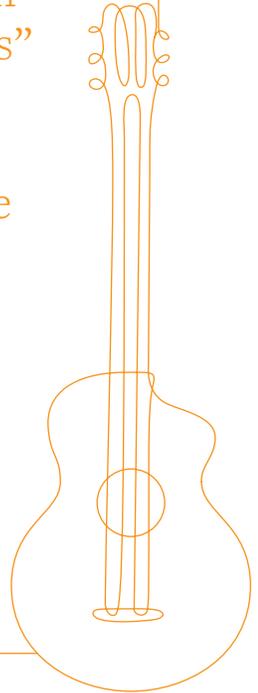
Myth

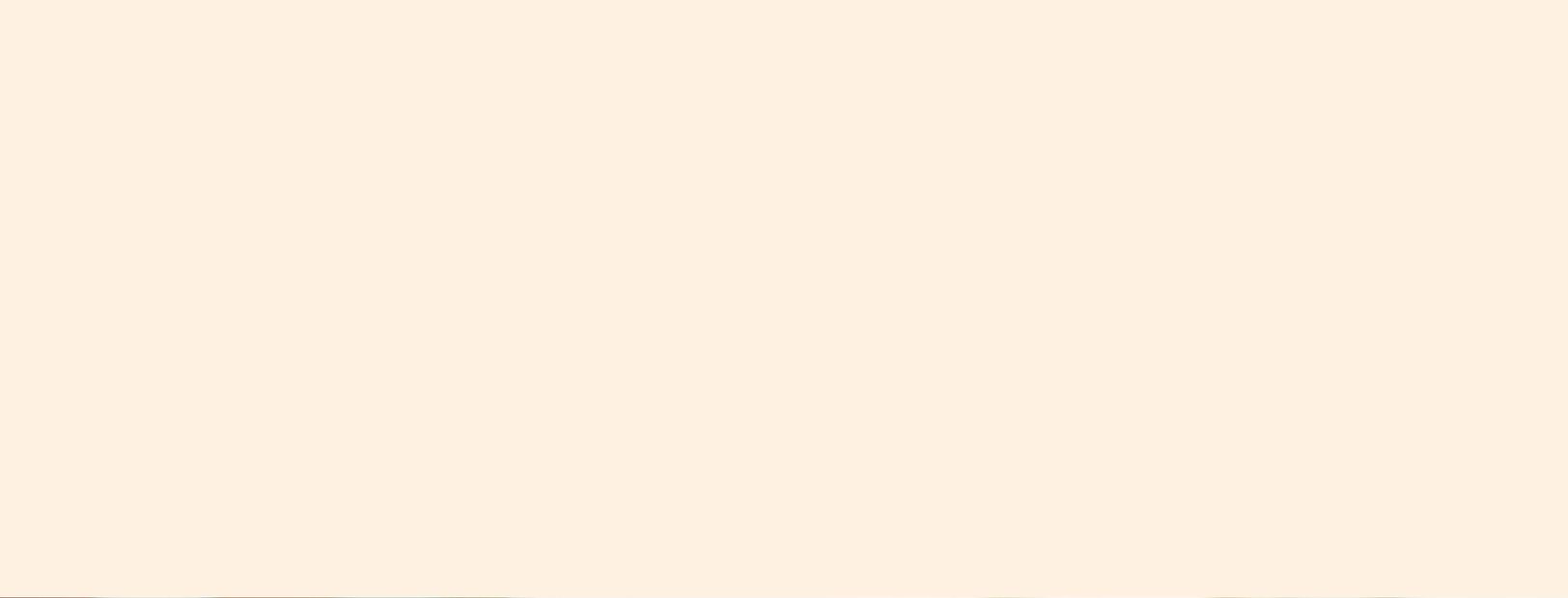
Brain games are the best exercise for memory

While any brain exercise is good, some may be better than others. Research in this area is a bit limited. But doing crossword puzzles or playing "brain games" may only make you better at those activities, rather than enhance overall memory or thinking.

More beneficial pursuits may include more complex activities, such as learning to speak another language or play an instrument, arranging flowers or woodworking, or doing math or word problems in your head while working out.

More beneficial pursuits than "brain games" may include complex activities like playing an instrument.





Section 02



Understanding and Living with Risk Factors

Take smart actions and stay positive in the face of increased risk. All of us, no matter how healthy we may be or what healthy lifestyle practices we may adopt, hold characteristics that increase the chance of getting certain diseases. These are called risk factors.

KEY TAKEAWAYS

- + Each of us, no matter our age or health, has factors that increase our chance of disease. These are called risk factors.
- + Risk factors are different for different people and for different diseases. But age is a common risk for brain disease, including Parkinson's.
- + Having a risk doesn't guarantee disease, and there is much you can do to limit risk.
- + People with risk factors can help researchers predict and prevent disease.



Risk factors are different for different diseases and for different people. They vary in the forms they take, whether they are avoidable, exactly how much they increase the chance of disease, and other aspects.

Risk factors can be conditions that we live with or ones that run in our family. A person with high blood pressure or elevated cholesterol levels, for example, is at increased risk of heart disease or stroke. Someone who has multiple family members with breast cancer or depression has a higher chance of each of these diseases.

Risk factors also can be changes in our genes or elements of the areas in which we work or live (our environment). Genetic mutations, pesticides and air pollution, for instance, can raise risk for Parkinson's disease (PD) or Alzheimer's. Lifestyle activities, such as smoking cigarettes, drinking excess alcohol or spending too much time in the sun, increase the chance of certain diseases, too.

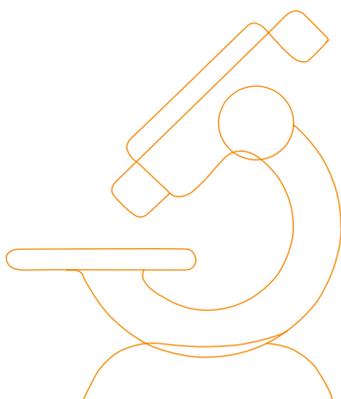
Just getting older is one of the biggest risk factors for brain disease, including PD. Researchers believe this is because, over time, age-related brain cell changes and harmful exposures can add up. These, in turn, affect how brain cells and genes work, potentially leading to disease.

But exactly how and why this happens, and how to stop it from happening, have been hard questions to answer. A main, perhaps obvious, reason: The brain is complex. And the brain with disease is even more complicated. But researchers are chipping away at that complexity. And now, we're moving closer to predicting and preventing brain disease like Parkinson's.

One of the critical steps on the path to prevention is learning why some people get disease and others don't. Not everyone gets disease as they age. Neither does everyone with a risk factor. Is that because of not-yet-identified gene changes that lessen risk? Or because of behaviors, such as practicing specific exercises or dietary habits, that protect from disease?

You can take comfort in knowing that, even with a risk, you are not destined to develop disease. But it's natural — and right! — to want to do everything you can to limit risk. Thanks to insights from a growing body of research, there are many science-backed steps you can take.

When it comes to risks for Parkinson's, for example, we now know more than ever. At The Michael J. Fox Foundation, we've been studying the brain and Parkinson's since 2000. We've made steady progress in better treatments and understanding. And we're on the path to predicting and preventing disease. As we make our way there, we want to share what we know about risks for Parkinson's, how to limit them, and how to join research toward a world without the disease.



Since
2000

The Michael J. Fox Foundation has funded more than \$1.5 billion in brain research around the globe.

PARKINSON'S RISKS

- + Physically acting out your dreams when you sleep
- + Carrying a genetic change linked to Parkinson's
- + Having a family member who lives or lived with the disease
- + Serving in the military
- + Being a man, especially over age 60



Parkinson's Risk Factors

66
I am hopeful that my participation in PPMI can, over time, lead to true scientifically proven cures and prevention strategies.⁹⁹

Brian Duggan

PPMI volunteer who lives with RBD, age 67, Mill Valley, California

01

Acting Out Your Dreams

While sleeping, you yell, punch, kick or move in other ways

What to know:

Good sleep is an important part of keeping your body and brain healthy. But, during times of stress or as you get older, good sleep may be harder to come by. Many have insomnia, or difficulty falling or staying asleep. Some wake up several times during the night to use the restroom. Others have sleep apnea, or temporary pauses in breathing. Still others act out their dreams.

When we dream, our brain prevents our muscles from moving. In some, these brain signals don't work properly, and a person moves while dreaming. This is called REM sleep behavior disorder (RBD). People with RBD often have very active dreams in which they're playing sports, running, or even being chased or attacked. They may yell, kick, thrash, punch, swing or make other movements. They might jump out of bed and run across the room or knock over lamps or other objects. You can easily wake a person with RBD, and they remember their dreams. Some with RBD have episodes once a month; others, a few times a week or more.

RBD is more common in men, people aged 50 or older, and those who live with Post-Traumatic Stress Disorder (PTSD). Certain medications, such as antidepressants, also can trigger RBD.

Loved ones may be the first to notice sleep changes. Spouses, sleeping partners or family members could be woken by noise or injured by accident. Not only can this be scary, it also can interfere with a good night's sleep. For some people with RBD and their loved ones, worry about what might happen during the night can also make it difficult to fall asleep.

→ Loved ones, read more on page 34.

A sleep specialist, a doctor with additional training in evaluating and treating sleep changes, can help. They can figure out what's causing sleep changes and recommend how to treat them. If you have RBD, medications may lessen acting out dreams and changes to your sleep habits and sleep area can keep you and your loved ones safe.

In many — but not all — people, RBD is one of the earliest symptoms of Parkinson's. It can come on years or decades before motor symptoms, such as shaking (tremor), slowness and stiffness, and a PD diagnosis. (In rare cases, acting out dreams is an early sign of a condition that is similar to, but separate from, Parkinson's).

→ Read more on page 30.

When learning about this connection, many people, understandably, are concerned about what the future may hold. But many also say it helps them take positive steps to care for themselves and their brains as best they can.

What you can do:

+ See a sleep doctor

If you act out your dreams, a sleep specialist can determine why. RBD is one cause for talking, yelling or moving during sleep, but there are others. Each condition has a different treatment and prognosis. Try to visit a brain doctor (neurologist) who specializes in sleep as these doctors know about both brain and sleep conditions. Ask your primary doctor for a recommendation or referral.

Testing often involves an overnight sleep study, which monitors your brain and muscle activity while you sleep. If you have RBD, your physician can prescribe medications, such as melatonin or clonazepam, and suggest strategies for safer sleeping. These may include sleeping on a low bed or mattress on the floor, in a sleeping bag, or separately from your partner, just until symptoms are controlled. You also may want to move potentially hazardous objects, such as lamps, away from your bed or outside your room.



Parkinson's
Progression
Markers
Initiative

→ Learn more and join at
michaeljfox.org/ppmi-study.

+ Meet with a doctor who specializes in movement disorders

Some people find it helpful to visit a doctor who has expertise and experience in diagnosing and treating Parkinson's and related conditions, called a movement disorder specialist. This type of physician can talk with you about the link between RBD, Parkinson's and other conditions; examine you for signs of brain disease; and connect you with the latest research. You can locate a specialist by searching online.

→ The International Parkinson and Movement Disorder Society maintains a directory at movementdisorders.org/MDS/Resources/Patient-Resources/Movement-Disorders-Specialist-Directory-Listing.htm

+ Contribute to research

People who act out their dreams can help researchers learn not only about sleep and brain health but also about disease. Studying why some people with RBD get Parkinson's and others do not is a critical step on the path toward preventing PD. People with RBD can point researchers to the earliest signs of disease in the body and brain. And knowing these signs could lead to tests to diagnose the disease earlier and more accurately and to treatments to stop disease from coming on at all.

The Parkinson's Progression Markers Initiative (PPMI) study, which aims to prevent Parkinson's, gathers data from people with and without PD. PPMI volunteer Brian Duggan, who lives with RBD, has said, "I am very grateful for the chance to contribute to important research. I am hopeful that my participation in PPMI can, over time, lead to true scientifically proven cures and prevention strategies." PPMI is now enrolling people with REM sleep behavior disorder.

IF YOUR LOVED ONE ACTS OUT DREAMS

When you share a bed with someone, how well they sleep can impact how well you sleep. If your loved one acts out their dreams, you may understand this all too well. In a survey, the majority of bed partners of people with REM sleep behavior disorder (RBD) said that their loved one's symptoms disturbed their sleep. More than half said they'd been physically injured by movements.

People typically aren't aware of acting out dreams when they are doing it, so bed partners often are the first to notice. And it can be genuinely frightening and risky to continue sharing a bed with your loved one under these circumstances. No one wants to be awakened in the middle of the night by their partner yelling or thrashing or, even worse, forcibly kicking or punching.

If your loved one acts out dreams, try not to panic. Avoid the urge to turn to the Internet, as general information about disordered sleep can be misleading, unhelpful or even alarming. Rather, seek out a doctor who specializes in sleep medicine (ask your primary doctor for a referral or search online for someone in your area) and attend the appointment together. Bed partners hold valuable information that can help doctors correctly diagnose and treat sleep troubles. The doctor will ask questions to gain a general idea of how often dream acting happens, what it looks like, and whether either of you has been hurt as a result. They'll also be interested in how easy it is to wake your loved one when they're dreaming and what they do upon awakening. Bring a list of your loved one's medications, including over-the-counter ones, and note any that are new or that recently changed.

(continued on next page)

RBD is treatable. Part of the treatment includes keeping you both safe and helping you both get the most restful sleep you can. Sometimes doctors recommend you sleep in separate beds or even separate rooms. This usually is temporary, until episodes become less frequent or less intense. But sleeping apart can be tough, especially when you've been sharing a bed for years or decades. Some couples find it helpful to spend time talking or relaxing together in bed right before going to sleep separately or after waking up in the morning. Others wind down together before bed by reading, drinking a cup of tea, or talking about the best part of their day.

While taking steps to optimize sleep, make sure you work on other aspects of health, too. Keeping healthy habits, such as exercising regularly and eating well, is easier when done together. Find something you both enjoy: a morning walk, an afternoon hike, or a weekly class at the gym or online. Download a few new recipes, take a cooking class or buy a new cookbook. These and other activities can make working out and eating well more fun and having a partner can keep you accountable.

Sleep is an active area of brain research — with efforts under way to understand normal and disordered sleep in its own right as well as its connection to other aspects of health and disease. Many people living with sleep issues and their bed partners report that joining research studies together is a powerful way to support each other and take charge of their health. In fact, people who act out dreams are in a position to make especially valuable contributions to Parkinson's research — as are their loved ones.

➔ Learn more at michaeljfox.org/ppmi-study.

Where might living with RBD lead?

After many years or decades of living with REM sleep behavior disorder (RBD), some people have no signs or symptoms of brain disease. Others develop Parkinson's. Still others (far fewer) develop a condition related to Parkinson's, such as Dementia with Lewy Bodies (DLB) or Multiple System Atrophy (MSA).

These conditions have much in common with Parkinson's. They share risk factors, including RBD and certain genetic links, and brain changes. They also have many of the same symptoms, such as tremor, slowness and stiffness. But they have other symptoms too, such as significant memory and thinking changes.

Early on, these diseases can be hard to separate. There are not yet tests, such as brain scans or blood tests, to tell them apart. Instead, doctors diagnose these conditions by talking with you and your loved ones and carefully examining how you move and walk and how you process and remember information. If you have RBD and experience trouble moving, changes in thinking or any other new symptoms, it's important to see a doctor who is expertly trained in diagnosing and treating these conditions, a movement disorder specialist. (Some people choose to see a movement disorder specialist shortly after diagnosis with RBD, even if they have no other symptoms, to learn more and build a relationship.)

Researchers are getting closer to tests to diagnose and distinguish Parkinson's from similar diseases. They're also working toward predicting who with RBD will get which, if any, brain disease. And because of overlaps in these conditions, research into one advances understanding and treatment of others.

Researchers are getting closer to tests to diagnose and distinguish Parkinson's from similar diseases.

For now, if you live with RBD, you can manage risk for both Parkinson's and related conditions the same way:

➔ Read *Protect Your Brain at Any Age* (page 12), work with sleep and movement disorder doctors and get involved with research. To learn more, visit michaeljfox.org/atypical-parkinsonism.

I Don't Have Parkinson's, but I'm Helping Researchers Get to the Bottom of It



Terry Goldin,
age 67, retired
architect, Wilmette,
Illinois

Things that go bump in the night

I don't have Parkinson's disease (PD), but I do have a condition known as REM sleep behavior disorder, or RBD. I never expected it. My wife, Holly, noticed that I was acting out my dreams. I used to play a lot of basketball, and I would dream about intercepting a pass, or stealing the ball — except the ball would actually be the glass lamp on the bedside table, and it didn't bounce when I tossed it across the room.

A desire to increase understanding

When the doctor confirmed I had RBD, it was reassuring to know that what I'd been experiencing had a name and treatment plan that seemed to work. The doctor also told us that RBD is linked to an increased risk of Parkinson's, however, and this was worrisome. But I'm focusing on the positive. I decided I would participate in research. Once I retired as an architect, I immediately jumped on the bandwagon and found the PPMI study. I'm motivated to help deepen

understanding about this disorder and its relationship to Parkinson's. And if I do start showing signs of Parkinson's, I'll find out sooner than later and I'll have relationships with doctors, researchers and others who know a lot about the disease. That will help me start managing it early on, which can contribute to things going better over time.

Leading the charge

I'm proud to participate in the PPMI study. In addition to answering questions about my health and lifestyle, I've gone through a battery of tests, including an MRI, but it hasn't been difficult. I would encourage anyone to do it, especially if they have RBD. It's important to me to do the right thing and be a leader in trying to get to the bottom of this thing.



KEEP IN MIND

- + Acting out dreams, or REM sleep behavior disorder (RBD), increases risk of Parkinson's.
- + A sleep or neurology doctor can diagnose and treat RBD.
- + A Parkinson's doctor, a movement disorder specialist, can help you learn more and watch for changes of Parkinson's and related conditions over time.
- + People with RBD can help researchers prevent Parkinson's.

I Want to Spread the Word about Parkinson's



Jaronda Little,
age 51, fine arts school
outreach officer,
Birmingham, Alabama

A difficult diagnosis

I'd never even heard of Parkinson's disease (PD) until my mother was diagnosed in 2006. It was a neighbor of ours who noticed that her gait was off. Initially, we attributed it to a fall she'd taken while carrying her groceries up the stairs. For the longest time, she got physical therapy, but her symptoms weren't getting better. And that's when her physical therapist suggested she see a neurologist, who gave her the diagnosis.

An active approach to treatment — and support

I made sure to read up on research, and when my mother was still living, we attended a Parkinson's support group together. When you meet someone who is also caring for someone with PD, you can share your experiences.

I know what PD can do to a person

I enrolled in a Parkinson's research study called BLAAC PD (Black and African American Connections to Parkinson's Disease) because there's still no treatment that can stop progression of the disease, and there's so much to learn.

Anything I can do to help researchers find out why it exists, how to treat it, or even how to prevent it, I'll do. The study requires people to give blood, and I went through all my contacts and emailed everyone — 30 people at a time — to get as many of my friends and family to participate as possible. I used to be a newspaper reporter, so I know how to scramble and find people.

Spreading the word

I know that it's not a guarantee that just because my mother had Parkinson's, I'll get it. But I am passionate about helping researchers find a cure, not just for myself but because I don't want anyone to experience Parkinson's the way my mom did. I saw her get weaker year after year. I hope treatments can be found to slow the progression of the disease so others will have a better quality of life and possibly live longer until a cure can be found. For too many people, the only time they learn about Parkinson's disease is when they're diagnosed with it. I want to help spread the word.

66
I wanted to provide more than emotional support and PPMI was a tangible way to do that.⁹⁹

Marc Jaffe
PPMI Participant, age 63,
Cleveland Heights, Ohio

02

Carrying a Genetic Change Linked to Parkinson's

When your DNA is implicated in Parkinson's risk

What to know:

People pursue genetic testing for different reasons. Many are curious what their genes might reveal about health and habits. Others want to know about their risk for a specific disease, especially if a family member is affected. No matter why you get genetic testing, learning you carry a gene change linked to Parkinson's can be worrisome, especially if no one in your family lives or lived with Parkinson's.

Having a PD genetic change is not the same as having a family history of the disease. Some people carry a genetic mutation but don't have any relatives with the disease. Others have multiple family members with Parkinson's but no known genetic connection.

No matter which describes you, you may be wondering, "What, exactly, does it mean to have a genetic mutation linked to Parkinson's?"

Let's review the basics. Genes are bits of biological information passed down from (biological) parent to child. They set aspects of our appearance, personality and constitution throughout our lives. We all have the same set of genes — scientists refer to this set as the human genome. But depending on the DNA of our particular family and heritage, we have

different changes in the structure of one or more genes. These are called genetic mutations or variants.

Some gene variants have no noticeable effect. Some lead to characteristic outward effects that make up the rich pageant of humanity in all its infinite variety. Still others — the ones that can cause us concern or even anxiety — play a role in our risk of getting a disease, such as Parkinson's.

Parkinson's is not a disease with a genetic "smoking gun." No known mutation leads to a 100-percent chance of causing PD. In other words: Having a genetic mutation linked to PD does not mean you will definitely get the disease. In fact, many people living with PD-linked genetic changes never go on to get it. (And research has much to learn from these individuals. They may have other protective factors in their DNA that, if harnessed for drug development, could be the key to preventing Parkinson's in everyone.)

It is likely that more genetic mutations linked to Parkinson's remain to be discovered. Of those research has uncovered to date, most raise Parkinson's risk only by a small amount. The most common occur in two genes called LRRK2 and GBA.

If you have undergone genetic testing and learned you have genetic changes linked to Parkinson's, there is plenty of reason for optimism. Even for people with the most common LRRK2 and GBA mutations, the chance of not getting Parkinson's is much higher than the chance of getting the disease. And there are steps you can take that may limit risk, such as exercising, eating well and staying connected to others.

→ See page 12 for more.

Your ethnicity and your genes

People of certain ethnic backgrounds, including those of Ashkenazi (Eastern European) Jewish and North African Berber descent, are more likely to carry Parkinson's genetic mutations. Researchers believe this is because many people in these populations share a (respective) common ancestor.

The most common Parkinson's gene changes — those that occur in the LRRK2 and GBA genes — are more frequent in these ethnic groups. The most common LRRK2 mutation, for example, occurs in approximately two percent of all people with PD. But this mutation is present in about 15 percent of people with PD who are Ashkenazi Jewish and in up to 40 percent of people with PD who are North African Berber. Similarly, GBA mutations happen in about 10 percent of people with PD overall, but in at least 15 percent of people with Parkinson's who are Ashkenazi Jewish.

Parkinson's Risk Factors *continued*

Still, not everyone with a LRRK2 or GBA mutation, even in these special populations, goes on to get PD. And for those who do, the symptoms of PD — when they come on and how they change — vary widely. Studying people with genetic links to Parkinson's helps researchers learn how and why disease starts, which helps them develop new, more personalized treatments and ways to prevent disease.

If you know that you are carrying a genetic mutation linked to PD, you can play a truly irreplaceable role in accelerating better treatments that will benefit everyone living with Parkinson's now and in the future. The key is to seek out ongoing research studies, which urgently need people like you and will highly value your participation. One such study is PPMI.

What you can do:

+ Know what genetic testing does and doesn't tell you

Genetic testing has come a long way in just the last few decades. It's incredible that you can send in a sample of saliva and receive detailed information about your genes. But it's important to realize what genetic testing can and can't tell you.

- A genetic test can tell if your DNA puts you at relatively increased risk for Parkinson's. It cannot tell if you have Parkinson's or predict whether you will get it.
- Most available direct-to-consumer genetic tests check for some, but not all, currently known Parkinson's mutations. They may look only for the most common mutations, such as those in the LRRK2 or GBA genes. While informative, these results are not a complete look at your genetics and Parkinson's. When considering testing or reviewing your results, make sure to find out what mutations are checked.

- Even if your test is negative for all currently known mutations, it doesn't guarantee that you don't have other risks for PD. These could include not-yet-identified mutations or environmental exposures.
- Genetic testing cannot replace personal advice and care from your health care provider (including a genetic counselor, if you choose to seek one out; read more below). They can provide much more context and information to help you understand what your genetic testing results mean for you and your loved ones.

+ Meet with a genetic counselor

A genetic counselor is a medical professional who is trained to help you understand your genetic profile. This includes genetic risks for diseases such as Parkinson's. They can help you understand your individual risk of disease as well as your specific chance of passing a gene change to your children.

Many direct-to-consumer tests and doctor's offices provide genetic counseling. If possible, it's best to meet with a genetic counselor both before and after testing. Before, they can walk you through benefits and risks and outline what to expect. After, they can guide you through your results and help define next steps. If you haven't yet met with a genetic counselor, ask your doctor to recommend one or search an online directory for someone in your area.

→ The National Society of Genetic Counselors maintains a database at findageneticcounselor.com.

Look for a genetic counselor who specializes in working with adults or neurological diseases. And check with your health care insurer about coverage and potential costs.

+ Join the genetic research revolution

People with a PD genetic link but without a Parkinson's diagnosis can help researchers understand how and why PD comes on and what factors lead toward disease or protect from it. This can lead to new treatments and ways to prevent disease.

Genetic research has, over the past few decades, enabled a much deeper knowledge of Parkinson's. And it's one of our best paths to continue moving forward. Genetic links give researchers a starting point to trace cellular pathways that lead to Parkinson's. These pathways may offer targets for new and better treatments as well as a cure. Clinical trials now are testing several genetic therapies with the potential to slow or stop Parkinson's progression. If proven effective, these treatments could benefit everyone with PD, regardless of whether they have a gene change.

Trials such as these are made possible by information from the Parkinson's Progression Markers Initiative (PPMI) study. PPMI is following people with PD genetic changes to learn more about the disease and to find better treatments and a cure.



Parkinson's
Progression
Markers
Initiative

→ Read more on page 54 or visit michaeljfox.org/ppmi-study.

With Parkinson's in My Genes, I Have to Take Action



Julie Hirsch,
age 54, loan officer,
Mercer Island,
Washington

Parkinson's in the family

For the last few years, Parkinson's disease (PD) has been a big part of my life. My father had PD and his sister — my aunt, who is now 86 — has it too. So did my grandfather on my mother's side. There's a strong family history.

By pure coincidence, I happened to learn I carry a GBA gene change when I had tests done to check out some health issues. Soon after, I learned my gene change is linked to Parkinson's. Knowing that, I had to take action.

A proactive approach

I went to see my dad's neurologist, a PD specialist, and he told me it's possible that I might develop Parkinson's at some point in my life. I tend to be an anxious person to begin with, so that was challenging to hear. But now that I know, I'm taking every step possible to plan and take care of myself. I work out a lot, walking at least three miles five or six times a week, biking at least 14 miles a few times a week, and skiing one day a week in the winter. Exercising helps me in relieving anxiety.

Staying up on the latest research

I'm part of MJFF's Parkinson's Progression Markers Initiative (PPMI) study and will continue it over my lifetime. Even if it doesn't help me, it might help someone else.

You don't know what is ahead of you

Everyone's journey with Parkinson's is different; there's no way to know what's ahead of you. I know there are going to be some great advances within the next five to seven years. I hold onto that thought and meanwhile, I just keep living.



KEEP IN MIND

- + Some changes in genes (mutations) increase the relative risk of getting Parkinson's.
- + Certain groups, such as Ashkenazi Jews, are more likely to carry certain Parkinson's mutations.
- + Genetic tests can tell you something about your risk, but not whether you have or will get Parkinson's. Knowing about your genes can help you take action in your health journey.
- + People with Parkinson's genetic links can help researchers develop new treatments and prevent the disease.

Parkinson's Risk Factors *continued*

03

Having a Family Member with Parkinson's

Your blood relative lives or lived with Parkinson's

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I'm living with Parkinson's and my family's living with it too.⁹⁹

Michael J. Fox

If you have a family member with PD, your risk of disease is generally about

3%

What to know:

If you have a family member with Parkinson's, you know that PD impacts not only the person living with it but also their loved ones. These effects vary from family to family and can change over time, as both Parkinson's and life change. Michael J. Fox has said, "I'm living with Parkinson's and my family's living with it too." How Parkinson's shows up in your life depends on many things, including your relationship to the person with PD, their symptoms, and their support systems. Some children grow up never knowing their parent without Parkinson's. Others are adults, with families of their own, when a parent or sibling is diagnosed. Immediate questions often center on how the disease might affect your loved one and their future and how you can best support them. But at some point, most family members also wonder if they could get the disease or pass it to their children.

Having a parent, sibling or child — a first-degree family member — with Parkinson's does raise your risk of disease. So does having multiple family members with the disease. But neither guarantees Parkinson's. Even with a family history, the overall chance of getting PD is still somewhat low. Estimates of risk vary based on where and how studies are done and whether you have a Parkinson's gene change.

→ See page 32 for more on genes and Parkinson's.

If you have a family member with PD, your risk of disease is generally about three percent, or 3 people out of 100. By comparison, the risk in the general population, for people without a family history of Parkinson's, is about one percent.

Most people with PD do not have a family history. But when Parkinson's does run in families, it could be because of shared environmental factors and/or genetics. Families typically share the same living and working spaces, which can include exposures that increase risk for PD, such as air pollution or pesticides.

They also share genes. Genes are inherited bits of information that direct what we look like, whether we're at risk for disease, and other aspects of health. Some families have gene changes that increase PD risk. Parents can — but don't always — pass these to their children.

→ Read more on page 33.

A single gene change explains Parkinson's in only about 10 percent of people. In most people, multiple gene changes, along with aging and environmental factors, bring on the disease.

What you can do:

+ Learn about Parkinson's

Knowing about the disease and its symptoms may help you understand your and your loved one's experiences. That may help you find ways to support your loved one and yourself. Ask your doctor and others in the community for credible resources. Consider joining a family support group or an online chat forum. In MJFF's online Buddy Network, for example, you can meet others like you and get tips and information.

→ Learn more at Parkinsonsbuddynetwork.org.

+ Consider genetic testing and counseling

Gene tests look for changes, or mutations, that cause disease or increase risk. Testing may be available through your doctor's office, a research study, or a direct-to-consumer kit, offered by 23andMe, Invitae and other companies. Some tests check for only the most common PD gene changes, others for all currently known links. Cost varies depending on how testing is performed and how detailed it is.

A genetic test cannot tell whether you'll get Parkinson's. This is because having a genetic mutation does not guarantee disease. Most people with gene changes never develop PD. In fact, even with a mutation, the chance of getting disease is still much lower than the chance of not getting it. On the other hand, not having a mutation does not ensure you'll always be Parkinson's-free. This is because there may be not-yet-identified genetic links or other factors that contribute to disease.

If possible, it's best to meet with a genetic counselor both before and after you get genetic testing. A genetic counselor can help you understand what genetic testing

can and can't tell you, what to consider before testing, and what results mean for you and your family. Research studies and direct-to-consumer products may include genetic counseling. If not, your doctor can recommend a genetic counselor, or you can search an online directory.

→ The National Society of Genetic Counselors maintains a database at findageneticcounselor.com.

Not every person who has a family member with PD needs or wants genetic testing. But many say knowing this information helps them make positive choices to support health, including participating in research.

+ Participate in research

Many family members are pleased to learn that they can join Parkinson's research. For many, research is a way to show support for a loved one and to take action in their own health journey. Marc Jaffe, for example, joined the Parkinson's Progression Markers Initiative (PPMI) for his wife Karen who lives with PD. PPMI gathers data from people with and without Parkinson's over time to learn about disease, find new tests and treatments, and, ultimately, prevent PD. Marc says, "I wanted to provide more than emotional support and PPMI was a tangible way to do that." He goes on, "When you're in research, you feel things moving and you see the finish line in the distance. It's great to be part of the process pushing us closer."

Family includes blood relatives as well as spouses and others who are considered family. The experiences and health data of loved ones can help researchers learn what genetic, environmental and lifestyle factors lead toward or away from Parkinson's. And this information can point to ways to treat and prevent disease.



KEEP IN MIND

- + Parkinson's can — but doesn't always — run in families.
- + Having a family member with Parkinson's increases risk but does not guarantee disease.
- + In most people, the cause of Parkinson's is a combination of genetics, environment and aging.
- + People with a family history of Parkinson's can help researchers prevent the disease.



→ PPMI now is enrolling family members of people who live or lived with Parkinson's. Learn more and join at michaeljfox.org/ppmi-study.

I Lost My Sense of Smell but Gained Perspective on Parkinson's



Joseph Capizzi,
age 74, retired
engineer, Philadelphia,
Pennsylvania

From volunteer to patient

My wife has had Parkinson's disease (PD) for about 15 years, and along the way, she started attending a support group. That's how I heard about the PPMI study. I decided to participate because I wanted to show my support.

My own Parkinson's journey

Many years ago, during a meeting of my wife's support group, they handed out little cards with different scent strips on them, and my wife brought one home for me to try. One of the signs of Parkinson's is a loss of sense of smell, and that's when I learned that my own sense of smell was diminished. But for a long time, I didn't exhibit any other signs of PD. Then, I noticed that I had some tremor, went to the neurologist and was diagnosed with Parkinson's myself. Emotionally, it didn't affect me that much. I've had a wonderful role model in my wife who leads a very busy life, and who doesn't worry about what tomorrow may bring. I've tried to adopt that outlook.

The power of data

I recently had my 14th study visit for PPMI at the University of Pennsylvania site in Philadelphia. I believe in the power of amassing a comprehensive database. For PPMI, year after year, they collect the same kind of data with the same people. That's going to be very powerful down the road. That's why I'll keep going as long as I can.

04

Serving in the Military

Veterans of the armed forces may be at increased risk for Parkinson's disease

110k

United States veterans are living with PD according to the U.S. Department of Veterans Affairs (VA).

What to know:

Military veterans, who give their time and risk their lives for others, are among the most selfless of volunteers. The type, length and location of service may vary, but the motivation to serve is often the same.

Veterans may be familiar and comfortable with certain types of risk. But many may not be aware that military service can put them at risk for Parkinson's and other conditions.

Not all veterans develop Parkinson's disease. But, according to the U.S. Department of Veterans Affairs (VA), at least 110,000 United States veterans are living with PD. In those who get Parkinson's, the disease could show up years or even decades after military service. In some people, the first signs — long before movement symptoms — are mood or sleep changes. Because these are common in veterans, they might not be recognized as an early part of the disease.

Most veterans, including those with mood or sleep changes, do not get Parkinson's. But knowing your risk, watching for new symptoms of any sort, and seeing your doctor regularly can help you stay on top of your health journey.

In veterans with Parkinson's, the cause of disease is likely a combination of aging, genetics and environment, as it is in civilians. But certain environmental factors linked to PD are also more common among veterans. These include Agent Orange, other toxins, and traumatic brain injury (TBI). Studies have shown associations between these environmental exposures and an increased risk of Parkinson's:

+ Agent Orange

Agent Orange is an herbicide, a chemical that kills plants or prevents them from growing. It was used to clear plants and leaves for military operations in Vietnam and the Korean demilitarized zone.

+ Chemicals and contaminants

In the 1980s, the water supply at Camp Lejeune was contaminated with trichloroethylene (TCE), a chemical that removes grease, as well as other potentially harmful compounds. TCE has been linked to Parkinson's.

Researchers also are investigating potential connections between disease and burn pits, areas on military installations where trash is burned because landfills aren't available.

+ Traumatic brain injury

Sudden impact to the head, with or without loss of consciousness, can cause traumatic brain injury. Veterans may experience TBI through an explosion in combat or a training exercise, for example. TBI symptoms can include headaches, mood changes, memory problems and more. A traumatic brain injury can be mild and temporary or more significant and longer lasting.

→ Learn more at research.va.gov/topics/tbi.cfm.

The VA recognizes Parkinson's as a "presumptive" illness linked to Agent Orange, Camp Lejeune contaminants, and moderate to severe TBI. This means that veterans with PD who were exposed to these environmental factors do not have to prove a connection between their service and Parkinson's to receive VA health care and disability benefits. They are automatically eligible and "service connected." Those who develop PD during service or within a year of discharge may also be entitled to these benefits.

→ Learn more at parkinsons.va.gov/patients.asp.

Researchers are studying military links to learn how and why Parkinson's comes on and to improve care for veterans and their families, and, ultimately, prevent the disease.

Parkinson's Risk Factors *continued*

What you can do:

+ Take charge of your health

Many veterans qualify for free or low-cost health care and services, including regular checkups and medication, at the VA. For those with a service-connected illness, such as Parkinson's due to Agent Orange or other exposures, the VA covers all care related to the illness. In some cases, family members also may be eligible for certain benefits.

→ Learn more at va.gov/health-care/eligibility.

If you experience PD symptoms, such as tremor, slowness, stiffness or acting out your dreams, see a Parkinson's doctor — a movement disorder specialist — at one of the six VA Parkinson's Disease Research, Education, and Clinical Centers (PADRECCs) or 51 Consortium Centers across the United States. Your primary doctor or neurologist can make a referral.

→ Learn more at parkinsons.va.gov.

+ Advocate for Parkinson's research and policies

The Parkinson's Research Program at the Department of Defense (DoD) is a government-funded research program dedicated to PD. It fills research gaps by, for example, studying links between military service and Parkinson's. The Michael J. Fox Foundation, along with the PD community, advocates to increase funding for this and other government-sponsored Parkinson's research. Advocates also push for support of Parkinson's care needs, such as access to medications; care partner assistance; and physical, occupational and mental health therapy coverage.

Examples of successful advocacy for Parkinson's include:

- Expanding the list of Agent Orange presumptive diseases to include parkinsonism, or Parkinson's-like symptoms, such as tremor, slowness or stiffness. Parkinsonism can be caused not only by Parkinson's but also by long-term use of certain medications, multiple small strokes, or conditions similar to PD, such as Dementia with Lewy Bodies (DLB), Multiple System Atrophy (MSA) or Progressive Supranuclear Palsy (PSP).
- Allowing Navy Vietnam veterans with Parkinson's or parkinsonism who served in offshore waters to file a disability claim with the VA to receive benefits. (Agent Orange-related benefits previously were limited to "boots on the ground" veterans.)
- Maintaining funding for the Department of Defense Parkinson's Research Program.

Ongoing policy efforts include advocating for further research and education on the effects of environmental factors, an increase in funding for the DoD Parkinson's Research Program, and enhanced care for veterans with TBI, as well as others.

→ To get involved, visit michaeljfox.org/advocacy.

+ Contribute to research

Veterans — regardless of health status or location of military service — have valuable experiences to contribute to research. Many veterans say that volunteering for research is a way they can continue to serve, well beyond military duty. Research studies are exploring military and environmental links to Parkinson's and other brain diseases to better understand, treat and ultimately prevent them.

One of these studies, the Parkinson's Progression Markers Initiative (PPMI), welcomes veterans both with and without Parkinson's. PPMI follows participants over time to learn how and why disease comes on and to develop ways to diagnose and treat it earlier.



→ Learn more and join at michaeljfox.org/ppmi-study.

In Service of Getting Answers about Parkinson's



Brad Lindberg,
age 63, U.S. veteran,
Wilmington,
North Carolina

A life of service

I retired as a Colonel in the Marine Corps after 27 years of service. I was designated as an attack helicopter pilot, but I also served in many other staff, school and ground assignments. I met some incredible people, including my wife, Amy, at Camp Lejeune in Jacksonville, North Carolina. She served on active duty in the Navy. Amy was 26 and I was 28.

Marching to a different drummer

One day, about five years ago, Amy and I were walking down the street and I happened to notice that she wasn't swinging her right arm. I began to call a "marching cadence" to get her to swing her arm, which we laughed about. But after some time, Amy began to feel anxious and a bit off her game mentally. After having some tests done, we decided to see a neurologist. The doctor was very straightforward. When she said, "You have Parkinson's," we were shocked, but at the same time relieved to confirm our suspicions.

Project PD

Right away, Amy took Parkinson's on as her own project. She helped expand a local Parkinson's group in our senior center and is involved with Rock Steady Boxing and with The Michael J. Fox Foundation. She is always linking people together who should be talking. Amy is committed to daily, rigorous exercise, keeping our family in line and assisting me with our honeybees. I also enjoy working out and spending time in the bee yard — both get me going and help me feel clear-minded.

Tag team

I've learned all about Parkinson's from my wife. Right now, she's part of multiple research projects and veterans' working groups. One working group is comprised of veterans who were stationed at Camp Lejeune and are diagnosed with Parkinson's. They are providing feedback to help the Department of Veterans Affairs better understand Parkinson's disease. There are so many veterans who have health issues related to their service. Participating in research might be a way to help others and to get more answers.

KEEP IN MIND

- + Agent Orange, other toxins and traumatic brain injury are linked to Parkinson's.
- + These environmental exposures and other risks, such as acting out dreams, are more common among military veterans.
- + Not every veteran and not every veteran who had an environmental exposure develops Parkinson's.
- + Veterans can help researchers understand military links to Parkinson's and prevent disease.



Parkinson's Risk Factors *continued*

05

Being a Man, Especially over Age 60

How your sex plays a role
in your risk

What to know:

Compared to women, men have a higher risk of many diseases, including Parkinson's. Among people living with PD, about 60 percent are men and 40 percent are women. There are many possible reasons for these differences in disease rates, which include differences in biology, lifestyle and environmental exposures. In general, men:

- Have lower levels of certain hormones, such as estrogen; these hormones may protect the brain from Parkinson's, Alzheimer's and other diseases.
- Tend not to visit the doctor as often for regular checkups or preventative health care screenings. And if new symptoms come on, men may wait longer to see a physician, meaning disease may progress further before diagnosis.
- Are less likely to practice healthy behaviors, such as avoiding tobacco, limiting alcohol, eating well and exercising regularly.

- Are more likely to be exposed to environmental experiences linked to disease risk. This could include holding jobs that involve pesticides, solvents or other substances linked to brain disease, or being more likely to experience head or brain injuries — through contact sports or military service, for instance — which raise risk.

Inequities and bias in health care also could be a factor. It's possible that women get Parkinson's at a rate similar to men but are under-diagnosed. Doctors might, for example, be more likely to diagnose Parkinson's (or other) disease in men while dismissing or seeking alternate explanations for symptoms in women.

Men and women also have different disease paths and medication responses. Women might experience more Parkinson's non-motor symptoms, such as mood, digestion and blood pressure changes. Such features may not be recognized as Parkinson's as readily as the cardinal movement symptoms of the disease (resting tremor, rigidity and slowness of movement).



KEEP IN MIND

- + Parkinson's is more common among men compared to women.
- + Men and women may, in general, have different Parkinson's symptoms, journeys to diagnosis, and medication responses.
- + Different biology, lifestyle factors, and environmental influences may explain PD differences between men and women.
- + Men can help researchers understand sex differences in brain health to enhance care and prevent disease.

60%

of those diagnosed with Parkinson's disease are men.



Parkinson's
Progression
Markers
Initiative

→ Learn more and join at
michaeljfox.org/ppmi-study.

What you can do:

+ Make your health a priority

It's never a good idea to bury your head in the sand where your health is concerned. See your doctor for yearly checkups. Medicare and many private insurers cover an annual wellness visit for free. An annual visit with your doctor is a good opportunity to stay on top of your health or catch any changes early. And if you or others notice changes in your physical appearance, mood or activity, don't put off talking to your doctor.

Start or continue healthy efforts and ask your partner or friends to join you. Hold each other accountable for making doctor visits, share what you're learning about brain health, or focus your social connections around healthy habits, such as going for a walk while you catch up.

+ Know your risks

Certain occupations or job worksites may involve substances that could increase risk for PD. Examples include pesticides used in agriculture work; solvents used by electricians, machinists or drycleaners; and chemicals used in welding. Ask your employer about potential risks and ways to protect yourself.

Also learn what diseases run in your family. Find out what conditions your parents, grandparents and siblings live or lived with. This helps you and your doctor know what to watch for and how to limit risk.

+ Volunteer for research

Sex can play a significant role in health and disease. It can impact biology, behavior and disease experience. By learning more about these differences, doctors can provide better care, and researchers can develop better treatments and, ultimately, prevent disease. But they need men to participate. Overall, men are less likely to join studies on health promotion or health-related behaviors. Without men, researchers won't find answers to better health for both men and women.

Participating in research is one way to contribute answers for yourself and others. Many say joining research allows them to take action in their health. It can give you more regular, direct contact with health care professionals and help you understand your own health journey.

The Parkinson's Progression Markers Initiative (PPMI) study, which follows people with and without PD in pursuit of better treatments, a cure and prevention of PD, needs men, especially those 60 and older.



Section 03



When Parkinson's Risk Becomes Parkinson's Diagnosis



As you learn about Parkinson's disease (PD), especially if you are living with one or more known risk factors for the disease, you may wonder how to know if you have it and what will happen if you do. First and foremost, it is important to maintain perspective. The majority of people living with risk factors for Parkinson's do not go on to get the disease. Because information is an antidote to toxic worry, this section describes some of the experiences and responses that are part of being diagnosed with PD.



How do I get tested for Parkinson's?

Many are surprised (and disheartened) to find that there is no test your doctor can order to determine if you have PD. No blood test, brain scan or other lab test can, by itself, tell if you do or don't have the disease. Similarly, no test can predict if you'll get PD. (The Parkinson's Progression Markers Initiative study, PPMI, is working to change that.)

→ Read more on page 54.

Currently, the only way to know that you have Parkinson's is to see a doctor who is an expert on the disease, a movement disorder specialist. To evaluate for PD, the physician talks with you and your loved ones about your symptoms, how long you've had them, if they're changing, and more. They also carefully watch how you move and walk.



What are the symptoms of Parkinson's?

The doctor will look for the three main movement, or motor, symptoms of Parkinson's: shaking (tremor), slowness and stiffness. To make a diagnosis, they need to see slowness plus tremor or stiffness. These symptoms look and feel different for different people.

- + Slowness may be taking longer to get ready in the morning or to do things around the house. Loved ones might notice you have trouble keeping up on usual walks, hikes or other activities. Some have difficulty typing or buttoning. Many realize one arm doesn't swing like it should while walking.
 - + Tremor is shaking that happens at rest, when you aren't using your hands or legs. This could be while watching television, riding in the car, or chatting with a friend.
- It goes away when you're using your arms and legs, such as while making dinner, writing a note or gardening. Tremor typically starts in one finger, hand, arm or leg. It comes and goes.
- + Stiffness is described by many as tightness or pain. It may be in the same location as tremor, and it can come and go, too. Doctors check for stiffness by moving your arms and legs while you relax.

How do doctors make a Parkinson's diagnosis?

Even though no test can diagnose Parkinson's, blood tests or brain scans may still be helpful. These can find or rule out other conditions that cause similar symptoms. And tests can support a doctor's diagnosis of PD, especially if your symptoms and examination are not fully consistent with the disease. Brain imaging could include a CT or MRI scan, which look at the brain's structure and are normal in PD.

Sometimes, when a person's examination does not clearly point to Parkinson's, doctors may recommend a DaTscan. This specialized image peers into the brain's dopamine system. It can separate diseases that affect dopamine, such as Parkinson's and related conditions, from those that don't, such as essential tremor. In this way, it can confirm a doctor's diagnosis. But it cannot, on its own, diagnose or predict Parkinson's, even among people who are at risk for the disease. Research studies, including PPMI, are looking at if and how DaTscan, along with other measures, might be able to predict who will get Parkinson's and how symptoms will change over time.

I'm still worried. What else can I do?

Knowing you have a risk for Parkinson's can, understandably, cause concern. But it also can inspire positive actions that help you feel better in many ways. Some people living with increased risk for Parkinson's choose to see a movement disorder specialist even if they don't have PD symptoms. (Ask your primary doctor for a referral or search online for someone in your area.) This can lessen worry by helping you learn more about your specific risk profile and what to watch for. You can go once and then check in again if you notice changes. Or, you can visit yearly so the doctor can monitor for signs of disease and share the latest research and opportunities to participate.

Others take a wait-and-see approach. In this case, you and your loved ones will want to be on the lookout for any changes in movement. If anything new or different comes up, even if it's subtle or not significantly bothersome, visit a movement disorder specialist.

Living in fear of what may lie ahead doesn't help. Michael J. Fox says: "If you spend all your time focusing on your worst-case scenario and then it actually happens, you've lived it twice." Is your worst-case scenario Parkinson's? Something else? Naming it won't make it happen. But it may help you find ways to work through worry. And it can shift your focus to living each day as well as possible, whatever that means for you.

Remember: You know yourself best. If you are feeling overwhelmed, or if anxiety or worry is interfering with your day-to-day activities, it can be helpful to talk with a therapist, counselor or spiritual advisor.

Parkinson's Fast Facts

Estimates suggest that more than 1 million people in the United States and 6 million worldwide are living with Parkinson's, making it the second most common major brain disease after Alzheimer's. Because age is the greatest risk factor and the populations of many Western countries are aging, some estimates predict that the number of people with Parkinson's could double by the year 2040.



Parkinson's disease:

01

Stems from a lack of dopamine

Dopamine is a brain chemical that fuels movement, mood, motivation and more. In Parkinson's, the specialized brain cells that manufacture dopamine are damaged or lost.

02

Is caused by age, genetics and environment

The precise causes of Parkinson's remain unknown (and the subject of intensive investigation by research groups around the world). But in most people, PD likely is caused by a mix of getting older, genetic risk and exposure to one or more environmental factors.



03

Leads to tremor, slowness and stiffness

The cardinal PD symptoms are movement changes. But how these come on and to what degree — as well as how they change over time — are different in each person.

04

Brings mood, sleep and other symptoms

The lesser-known PD symptoms involve other body systems. Not everyone has any or all of these symptoms. They can come on years or decades before movement changes.

05

Can run in families

PD can, but doesn't always, affect multiple family members. Even in families where several members have Parkinson's, known genetic risks are not always present; this tells us that PD also can arise as a result of shared environmental factors.

06

Does not have a test for diagnosis

Unlike other conditions (such as heart disease), there is no objective test that can, by itself, tell whether you have or will get PD. Currently, doctors diagnose the disease through physical examination. But researchers are nearing a test for PD.

07

Has treatments for symptoms, but no cure yet

Medications, surgeries and other therapies lessen symptoms to help people stay active and independent. And many therapies in clinical testing have the potential to slow or stop disease.



USA
Today: We
Can Help End
Parkinson's

By Michael J. Fox



Parkinson's
Progression
Markers
Initiative

In December 2021, The Michael J. Fox Foundation announced the relaunch and major expansion of its landmark clinical study, the Parkinson's Progression Markers Initiative (PPMI). The study, which began in a cohort of Parkinson's patients and control volunteers in 2010, already has made major contributions to the understanding of Parkinson's disease with the participation of more than 1,400 everyday people and a network of research groups worldwide.

More than

20k

people like you have partnered with researchers in the Parkinson's Progression Markers Initiative (PPMI)

Now the study is growing to include the full spectrum of Parkinson's — from people who have not been diagnosed with the disease, to those who are newly diagnosed, to those with advancing PD. To mark the relaunch of PPMI, Michael J. Fox penned a *USA Today* Op-Ed urging everyone — especially men over age 60 and those living with specific risk factors for PD — to take part and help the study deepen understanding of Parkinson's and accelerate the development of better treatments for the disease.

If I told you a simple action you take today could change everything about how Parkinson's disease is diagnosed, managed and treated — not decades from now, but in the near future — would you do it?

I don't mean giving money. (Though that helps, too. Research is unbelievably expensive.)

We're on a mission to solidify our early understanding of who's at risk for Parkinson's, who gets it, who doesn't and why. But this requires a new level of public participation.

250

scientific papers based on PPMI data have been published.



And I'm not talking just to the people who, like me, are living with Parkinson's disease.

In December 2021, The Michael J. Fox Foundation and a "who's-who" of Parkinson's researchers announced a clinical study that promises to rewrite the future of Parkinson's disease and to generate breakthroughs that could impact other major brain diseases such as Alzheimer's, too. I'm asking you (yes, you) to be part of it.

The Parkinson's Progression Markers Initiative (PPMI) was launched in 2010. Since then, PPMI has studied 1,400 people like you, with and without Parkinson's disease, in the United States, Europe, Asia and Australia.

These heroes are giving qualified scientists access to their anonymous clinical information, including test results and brain scans, to hunt down patterns and details that have already contributed significantly to a better understanding of Parkinson's. To date, more than 250 scientific papers based on PPMI data have been published, and researchers around

the world now access this data for independent studies on average 2,200 times a day.

Predicting Parkinson's early on

Now the study is entering a new stage — bringing us much, much closer to the ability to predict who might get Parkinson's before symptoms ever show up. When you can predict who's going to get a disease, you've already started down the path to preventing it.

And this is where you come in. We're on a mission to solidify our early understanding of who's at risk for Parkinson's, who gets it, who doesn't and why. But this requires a new level of public participation — 100,000 people — to help researchers build on what's already known about the early signs of Parkinson's, ones that we've observed but haven't yet pinpointed scientifically.

For example, did you know that people who act out their dreams while sleeping might be more likely to develop Parkinson's?

PPMI has helped scientists zero in on this discovery and now aims to take it to the next level. This kind of finding can give us a critical window into processes taking place in the brain and body cells of people who don't have Parkinson's today but might be at risk to get it in the coming years. And that could move us closer to new and better treatments for the disease — or even preventing it altogether.

How you can help

Participating in the study is simple. For most people, it's as easy as filling out questionnaires online every few months. The longer you keep doing it, the more your profile can offer to research. And because privacy is critical, we've taken every step to safeguard the personal data you share with researchers.

There was no PPMI when I was diagnosed in 1991. The doctor told me I had Parkinson's and 10 years left to work, all in the same sentence. (He was wrong about that second part.)

I'm sure he wished there were some treatment that would have stopped the disease process right then and there, so I could move on with my life and never think about Parkinson's again.

With your help, that's where PPMI is headed.

The Michael J. Fox Foundation has been at this work for 21 years. To patients, including me, that feels like a long time, but in scientific terms it's the blink of an eye. It's why we need to stay focused on the day we find a cure. With your help, we'll get there. Until then, we're persistent, we're problem-solvers and we're optimistic — and grateful to you for being part of it.



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Parkinson's
Progression
Markers
Initiative

→ Learn more and join PPMI at
michaeljfox.org/ppmi-study.

PPMI: The Study that Could Change Everything

The Parkinson's Progression Markers Initiative (PPMI) is changing how patients, families, doctors and scientists think about brain disease. Now it needs you.

The Michael J. Fox Foundation launched PPMI in 2010 to better understand Parkinson's and advance new treatments. Since then, the study has changed how research is done and what scientists know about the brain. It is a cornerstone of our understanding of disease and has heavily influenced clinical trials. In 2021, the study announced a major expansion to study the full spectrum of Parkinson's — from those who have never experienced a symptom to those living with later-stage disease. Now at more than three dozen clinical sites in 11 countries, the study has added an online platform with the ambitious goal of enrolling as many as 100,000 people.

PPMI follows people — with and without Parkinson's — over time to learn more about how disease starts and changes. That information may lead to insights and tools that can help better diagnose, treat and even prevent brain disease. The study shares its data set — the most robust in Parkinson's research — with scientists in real time to speed breakthroughs. On average, its data is downloaded by researchers around the world more than 2,200 times a day.

This landmark initiative is only possible through partnerships. Leaders across the field and nearly 40 funding partners have helped shape PPMI. Most importantly, more than 1,400 participants enrolled in PPMI over its first decade. Many of those people continue in the study.

The more people who volunteer and share their data, the closer and faster we'll get to better treatments for people living with Parkinson's today and to preventing Parkinson's for future generations. PPMI needs you.

→ Get started today at michaeljfox.org/ppmi-study.



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

Join the study
that could
change everything

Whether you have Parkinson's disease or not
join the study at michaeljfox.org/ppmi-study to
see if you could help change everything about how
Parkinson's is diagnosed, managed and treated.
Thank you.



Parkinson's
Progression
Markers
Initiative



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Profiles: As told to Paula Derrow

We are grateful to the individuals who shared their personal stories in this resource. We also thank Debbie Raymond, MS CGC, genetic counselor at Mount Sinai Beth Israel in New York, New York, for review of genetic and related information.

The material in this guide was accurate at the time of publication in May 2022. For the latest on brain health and Parkinson's, visit michaeljfox.org.

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