

Summary

THE  
PARKINSON'S  
PLAN

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A NEW PATH TO  
PREVENTION AND TREATMENT

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An independent summary of the book \*

# The Parkinson's Plan

written by

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\* Created for the lay reader by Lynn Austin|

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<sup>1</sup> The authors have published over 1,000 research papers and cared for 10,000 individuals with the disease.

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### *Foreword*<sup>1</sup>

- Every six minutes, an American is diagnosed with Parkinson's.
- Every day, one hundred Americans die from Parkinson's.
- Every year, Parkinson's costs America \$50 billion.

....yet America had no plan

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### Chronology

1817 The first major description of Parkinson's disease

1964 PSP described \*

1976 Dementia with Lewy bodies \*

2024 *National Plan to End Parkinson's Act* \* passed

2024 *Healthy Brains Act* \* under consideration

2040 The Parkinson's population projected to double

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<sup>1</sup> Written by Congress members Gus Bilirakis (R) and Jennifer Wexton (D)

\* See the Glossary for a complete description

## INTRODUCTION<sup>3</sup>

In 1817, Doctor James Parkinson saw some old men with a tremor, stooped posture, and a shuffling gait. He wrote an article: *An essay on the shaking palsy*. Parkinson's Disease was officially born.

The disease has three forms. The first two are most common:

- One begins in the gut (“body first”)
- One starts in the nose (“brain-first”).
- One is genetic, but only about 15% of individuals with Parkinson's have a family history of the disease (“heritability”).

⇒ Parkinson's is *not* a natural consequence of aging.

In the end, Parkinson's is a whole body disease involving the skin, gut, brain, peripheral nerves and other organs.

**Chemicals** in our food, water, and air have created this largely man-made disease. They affect the **substantia nigra**, nerve cells in the brain that produce a chemical called **dopamine**.

In the **early stages**, people can function at remarkably high levels. Over time, however, Parkinson's takes a heavy toll. Parkinson's has a wide range of **symptoms** including

- constipation
- urinary urgency
- loss of smell
- sleep disturbances
- decreased facial expression
- depression
- anxiety
- fatigue
- drooling
- pain, and
- impaired thinking.

There are two **main therapies**: medications (levodopa) and surgery (DBS).

There are an estimated 90,000 **new cases** in the U.S. annually. [This would work out to about 50 new cases annually in DAC.] Parkinson's is increasing fastest in industrialized countries.

The book details four steps (the PLAN) to prevent and control Parkinson's: **P**revent, **L**earn, **A**mplify, and **N**avigate.

The **goals** are **0-10-100**: by 2035, a **0%** rise in new cases, a **10**-fold increase in research funding, and **100%** access to levodopa.

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<sup>3</sup> For definitions of special terms, see the **Glossary**.

## Chapter 1. Pesticides in our food, farms, and fields

Chemicals in the environment can be responsible for brain diseases. But, there is a lag time between the time of exposure and the development of the disease. The lag can be years or decades, and the relevant exposure can happen at an early age.

For example, **paraquat**, a herbicide manufactured by *Syngenta*, is sprayed on fields of corn, soybeans, and crops throughout the US. It is associated with a high risk of Parkinson's. In 2024, the EPA reauthorized the continued use of paraquat. Most countries in the world banned paraquat before 2022.

Pesticides are found in places one would not suspect. For example, of 300 French wines tested, remnants of pesticides were found in 90% of them.

A California study found that living within three blocks of where paraquat and other pesticides were used greatly increased the risk of developing Parkinson's. The risk was especially high among children, teenagers, and young adults when they were exposed.

*Consumer Reports* found that pesticide residue posed a significant risk in roughly 20% of the 59 common foods they examined, even some organic fruits and vegetables.

## Chapter 2. Toxic water

**TCE** was first created in a lab in 1864. It was used in dry cleaning and later in degreasing metal parts. In the 1950s, TCE was replaced by a look-alike PCE (often called "perc") in dry cleaning. The first case report linking TCE to Parkinson's occurred in 1969. Today, most dry cleaners still use PCE. When it evaporates, it can contaminate soil and water and invade the indoor air of homes, schools, and offices. Most exposure to TCE is from inhalation. Up to 30% of the groundwater in the U.S. has been contaminated with TCE. The link between TCE exposure and Parkinson's is supported by research.

In the U.S. TCE and PCE may be the most important causes of Parkinson's disease in suburban and urban areas. Certain pesticides are the likely dominant factors in rural areas.

**The landmark case.** From 1953 to 1987 at the Marine Corps training base, Camp Lejeune, NC largest human exposure from drinking water in U.S. history was registered. And worse, for twenty years the U.S. Marine Corps prevented full disclosure regarding the true extent of the contamination. The camp was not only home to marines but to their families as well. Hundreds of mothers suffered miscarriages. Some babies were born without brains.

Individuals do not get exposed to a toxic chemical one day and develop the disease the next. It takes time. Parkinson's in some individuals was diagnosed ten to forty years after exposure. This gap makes studies hard to conduct, risks difficult to identify, and findings especially concerning when they are observed.

An example. From 1984 to 1988, a Navy officer, Amy Lindberg, served as the Camp Lejeune hospital's food service director. She *thought* that she was overseeing the provision of healthy meals for the physicians, nurses, staff, and patients. But, all of it was contaminated with TCE. She got Parkinson's disease along with more than one hundred Marines. Today, she has digestive and urinary issues, pain, and mood changes. Inevitably, the medications she takes will become less

effective. Her coordinated movements will become jerky and unpredictable. She fears that she will become physically and mentally disabled. She is surprised that these chemicals are still being used today.

### Chapter 3. An invisible cause inside our homes

In 1984 in Pottstown, PA near Philadelphia, a construction engineer set off an alarm at the nuclear power plant where he worked. When they assessed the level of radon in his *home*, seven miles away, they found levels that were six hundred times the safe level established by the EPA. That was equivalent to smoking 135 packs of cigarettes a day. Radon does *not* cause Parkinson's, but it sounded the alarm to the possibility of pollutants entering homes. Today, many homes in the eastern US require a radon test before they can be sold.

After Love Canal (NY), the federal government created a "Superfund" program (1980) to clean up the country's most toxic sites and to hold responsible parties accountable for the costs. There are about 1300 Superfund sites in the United States. More than 70 million Americans and over 20% of all children live within three miles of one. For example, PCE's were used to clean silicon chips; now fifteen Superfund sites are located along a seven-mile stretch of US 101 in Silicon Valley.

{**Superfund site in Las Cruces.** The *Griggs & Walnut Ground Water Plume* is centered near the intersection of Griggs Avenue and Walnut Street in the city of Las Cruces in Dona Ana County, New Mexico. The area of the plume is about 2,500 feet wide by 4,000 feet long. In 1993, the New Mexico Environment Department (NMED) discovered tetrachloroethylene (PCE) contamination in the City of Las Cruces (CLC) municipal supply wells. Dissolved PCE was detected upgradient and downgradient of four affected municipal supply wells. This Superfund site is still analyzed annually for toxins.}<sup>4</sup>

Suggestions to lower the risk of getting Parkinson's:

1. Ban TCE and PCE.
2. Inform those who live near contaminated sites of the risks.
3. Test the water.
4. Take steps to reduce (mitigate) risks, for example, require protective equipment for workers.
5. Clean up contaminated sites.

### Chapter 4. The brain's front door

Parkinson's is very rare before age forty, after which the number of new cases begins to *triple* with every passing decade. But, the initial pathology (indication) of the disease is present long before symptoms appear. For example, loss of smell precedes Parkinson's symptoms in up to 90% of young individuals.

- It is very likely that without any chemical exposure there would be no Parkinson's. Those living in areas with typical air pollution levels had a 56% greater risk of developing Parkinson's. For example, Los Angeles is among the country's most polluted cities, and the incidence of Parkinson's in the county is among the highest in the country. But cars and coal are not the only sources of

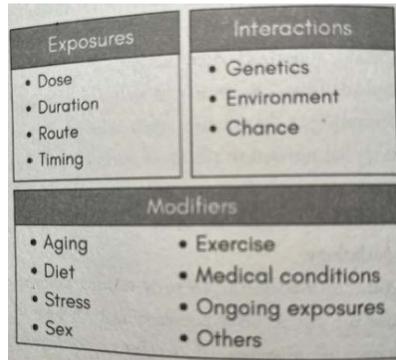
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<sup>4</sup> <https://cumulis.epa.gov/supercpad/SiteProfiles/index.cfm?fuseaction=second.cleanup&id=0605116>

Information provided by summarizer LAustin is given in brackets { }.

outdoor air pollution. There are power plants, golf courses, household fuel, shipping, aviation, agriculture, landfills, and mining.

Alzheimer's has more than doubled in the past generation but, after controlling for aging populations, its prevalence has changed little. Essentially, the increase in Alzheimer's coincides with the increase in the number of older people.



*Factors determining who develops Parkinson's disease*

The nose and the gut are the two sites where the disease enters the body. As the disease proceeds, different symptoms emerge, usually beginning with early loss of smell, then slowness of movement, then tremor (usually on one side), then sleep disturbances (like acting out one's dreams), then constipation, and then much later, dementia.

Influencers of the onset and progression

- Diet
- Exercise
- Sex
- Sleep
- Other medical conditions (e.g., diabetes)
- Stress
- Continued exposure to toxicants

## Chapter 5. Learn why

As in the successes of polio, we need to answer the 'why' questions for Parkinson's: *why* it starts, *why* it spreads, and *why* it progresses.

For Parkinson's disease, our efforts to learn why are hampered by limited funding, inadequate tools to study exposures, and in the case of makers of paraquat {and perhaps other toxins}, concealment of evidence.

87% of Americans with Parkinson's disease do not carry mutations in either of the two most common Parkinson's related genes (LRRK 2 or GBA). And, not everyone carrying a Parkinson's gene mutation actually gets Parkinson's. But, those with Parkinson's genetic mutations may actually be more susceptible to pesticides and to chemical exposures.

Many experiments have been carried out, but *failure* has been the norm for Parkinson's clinical trials.

## Chapter 6. The Parkinson's 25 - Actions to take to reduce the risk of Parkinson's

### FOOD

1. **Wash your produce**, even if it's organic.
2. **Change your diet.** The Mediterranean diet--high in fruits and vegetables and low in animal products--yields a lower risk of Parkinson's.
3. **Make sure your grocery store is safe.** PCEs, the dry-cleaning chemical, can readily spread beyond the walls of a dry cleaner<sup>5</sup>.
4. **Enjoy wine without pesticides.**
5. **Avoid, or manage, diabetes.**
6. **Have a cup of caffeinated coffee.** Caffeine consumption is associated with a decreased risk of Parkinson's.
7. **Farm {and garden} safely.** Avoid risky pesticides (for example, *pyrethroids*) and wear personal protective equipment.
8. **Check your well.** Test your well water *regularly* for pesticides, PCEs, and other toxins.
9. **Use a water filter.**

### INDOOR AIR

10. **Consider air purifiers.** High levels of air pollution have been associated with an increased risk of hospitalization for individuals who already have Parkinson's.
11. **Don't poison yourself.** Household and pet pests call for control. Select your remedy carefully. For example, pyrethroids in laboratory animals show signs that are similar to Parkinson's.
12. **Choose your home carefully.** Seventy million Americans live within three miles of a SuperFund site. If you live close to a SuperFund site, check your indoor air to determine if TCE or PCE is present. {See Chapter 3 above.}
13. **Dry clean cautiously.** Newly dry-cleaned clothes release dangerous gasses like TCE and PCE. Driving home from the cleaners, be sure your windows are down for ventilation.
14. **Check the ground floor.** If you live in a high-rise apartment, be aware of what businesses (dry cleaners?) are on the ground floor.
15. **Note what is near your child's day care center.**

### OUTDOOR AIR POLLUTION

16. **Roll up your windows in traffic.**
17. **Garden with care.** {see 7 above}

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<sup>5</sup> {When I moved to Las Cruces in 2020, I remember a dry cleaner located a few doors away from the *Albertson's* on North Main. In 2025, I notice that it has moved across the parking lot from *Albertson's*.}

18. **Be mindful of the greens.** Ask your golf club what kind of pesticides they use and when they spray.
  19. **Note what is near your child's school.** How near is the school to agriculture fields? What weed killer do they use on the sports field (2,4-D???)?
  20. **Use personal protective equipment.** While gardening or landscaping where pesticides are present, use long sleeves, pants, goggles, and respirators.
- MORE
21. **Exercise.** It is the best tool we have in the neuro-degeneration prevention tool kit. Also, it is beneficial for those who already have the disease.
  22. **Sleep well.** Sleep has been shown to clear toxins from the brain.
  23. **Avoid head trauma.** Those who have had a concussion have been shown to have a 57% higher risk of Parkinson's. Wear a helmet while biking, skiing, or skating.
  24. **Act locally.** Make your community healthier, especially with regard to pesticides.
  25. **Support our veterans.** Veterans make up 6% of the U.S. population but 10% of individuals with Parkinson's. Remember agent orange and Camp Lejeune.

Many individuals with Parkinson's remain undiagnosed.

**Ten “must-does” if you are diagnosed with Parkinson's disease.**

1. Take one multivitamin a day since dopamine replacement therapy depletes important factors and may lead to neuropathy and other nutritional deficiencies.
2. Apply sunscreen, wear hats and arrange to see a dermatologist once a year as Parkinson's is associated with twice the risk of skin cancer.
3. Exercise every day and ideally complete 7,500 steps or step equivalents, about 1 ½ hours of exercise per day as this has been shown to improve symptoms. Ride a recumbent bike or do alternative exercise if you can't walk.
4. Make stretching part of your daily routine as rigidity can gradually impinge on your flexibility.
5. Fight frailty by staying above your ideal body weight.
6. Keep your bones strong by having a bone scan for osteoarthritis every two years. (Individuals with Parkinson's commonly have soft bones.)
7. If you are coughing when eating, see a speech language pathologist and consider using an expiratory muscle strength trainer to reduce the risk of aspiration pneumonia.
8. Get evaluated at least once a year by physical, occupational, speech, and swallow therapists.
9. Have neuropsychological testing once every two years and stay engaged exercising your brain muscle, doing crosswords, cognitive puzzles, etc.
10. Monitor your sleep with a wearable device and work to get 6 to 8 hours of sleep every night as this will improve your symptoms the next day and improve stamina.

## Chapter 7. Amplify the voices

**Coordinated care** should be an essential priority for people with Parkinson's: the continuous process of practical, proactive, preventive assessment of needs, coupled with timely provision of services.

The modern American healthcare system has been built on a primary care gatekeeper model. You are required to select a primary care doctor who effectively controls your care. We need a care process that focuses on the *person*. It is as if the patient is the sun and all services orbit around them and not the doctor. The highest level of health care one can hope for is when a skilled team is talking and exchanging thoughts openly.

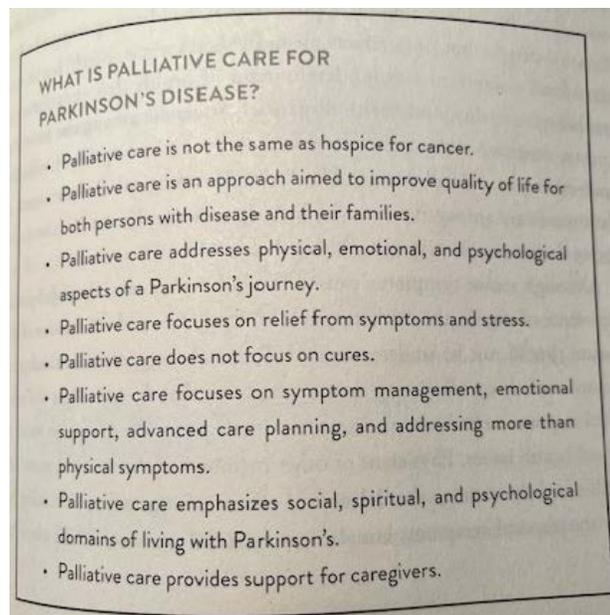
The four core principles of an ideal hub-based model of care are:

1. All interdisciplinary specialists are located under one roof.
2. Each specialist develops and communicates a patient-specific care plan.
3. Every patient is a potential research participant.
4. The relationship between the patient and each of the care providers is bidirectional.  
(patient → care provider & care provider → patient)

The doctor ought to be seen, not as a god, but as a guide—a guide for the other care providers.

A care manager (a spouse, care partner, family member, or friend) could be trained to help in the four elements of care coordination:

- patient navigation
- provision of information
- early detection of emerging symptoms
- continuous monitoring



Factors that reduce caregiver burden include.

- Timely diagnosis
- Effective communication and education about caregiver roles, medications, and adverse effects
- Rehabilitation and palliative care strategies
- Government entitlements and discussions of decision making capacity.

Some key organizations are:

- Michael J Fox Foundation.
- Parkinson's Foundation.
- The PD Avengers.
- Parkinson's Africa.
- Parkinson's UK.
- Parkinson's Australia.
- ParkinsonNet is a model Parkinson's health care system in the Netherlands.<sup>6</sup>

There are 54 medical centers around the world holding the 'Parkinson's Foundation' designation.

Examples are:

- The Veterans Administration's Parkinson's Disease Research, Education and Clinical Centers.
- The American Parkinson's Disease Association Centers of Excellence.
- The European Parkinson's Disease Association Centers of Excellence.

The stigma of a Parkinson's diagnosis is huge. Stigma comes from the negative perceptions and stereotypes that those diagnosed encounter in society. Stigma impacts emotional, psychological, and social well-being. Support groups<sup>7</sup> are valuable in helping those living with Parkinson's disease to improve their self-esteem and coping skills and lessen social isolation.

**Telemedicine** offers four C's: care, convenience, comfort and confidentiality. Telemedicine visits save money, save patients many miles of difficult travel, and reduce the risk of falls and

### **How can stigma affect a person with Parkinson's disease?**

- Physical symptoms can be mistaken for intoxication or other conditions and this has been shown to lead to social isolation and other challenges. People may also get impatient with the person for slowness to complete a task.
- Internalized stigma may lead to shame or embarrassment and reduced social interaction. Some cases can even progress to depression.
- Mental health may be worsened by stigma, leading to anxiety, depression and a lower quality of life.
- Fear of being judged or misunderstood can lead to serious consequences, such as lack of medical attention or compliance. (For example, an assistive device for walking is not used, putting the person in danger of falling.)
- Workplace stigma may lead to feeling misjudged and mistreated.
- Avoidance of social situations may lead to increasing isolation.

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<sup>6</sup> <https://www.parkinsonnet.com/>

<sup>7</sup> Such as the *Parkinson's Support Group of New Mexico* in Las Cruces.

accidents. And it is a more patient centered experience. It does have limitations however, for example, assessing eye movements, evaluating rigidity, and testing reflexes are difficult with telemedicine.

Many critical services are not covered by insurance. It would be better to have benefits cover:

- The expense of a licensed clinical social worker once a month
- A personal trainer
- A dietitian.

On a *worldwide* basis it is recommended to address global disparities in Parkinson's disease. For instance, being sure to provide dopamine replacement therapy pills for all who have been diagnosed with Parkinson's. Only 37 of the 110 countries reviewed by the *World Health Organization* had dopamine replacement pills consistently available in primary care settings.

Overall, we must

- Listen to the voice of the caregiver.
- Set up systems with care based operations centers.
- Combat stigma.
- Utilize technology to monitor and enhance care.
- Make dopamine available to everyone on the planet.
- Make the system comprehensive, coordinated, and proactive.

## **Chapter 8. New Treatments: navigate the first two frontiers**

The perfect treatment will have five characteristics.

- Inclusive of everyone at risk and those with the disease.
- Non-invasive and practical. For example, a pill.
- Low risk in the short and long term.
- Accessible to everyone on the planet.
- Cheap, especially if chronic therapy is necessary.

FRONTIER 1: THE NEXT FIVE YEARS - to alleviate symptoms

**Biomarkers.** It is possible to have one or more biomarkers without ever developing the disease. The best biomarker would give us diagnosis, prognosis, and treatment response. The current leading contenders include blood and spinal fluid levels of alpha-synuclein, skin biopsies, and a variety of brain-imaging scans. There are digital biomarkers that can detect subtle changes and possibly even early warning signs of disease progression. People with Parkinson's should ask their doctors whether any biomarkers can be used to enhance their care.

**Repurposing old drugs.** Two examples of drugs that might be repurposed for Parkinson's are semaglutide (a diabetes drug) and GLP-1 compounds (anti-obesity drugs). Many more are being investigated.

Other near-term possibilities include:

- Optogenetics-inspired DBS
- Telemedicine
- AI-robot-assisted programming

FRONTIER 2: SIX – TEN YEARS INTO THE FUTURE - to address symptoms and to slow disease progression.

Possibilities include--

- new drugs
- diets
- stem cells
- vaccines and
- immunotherapies

## Chapter 9. New Treatments: navigate the final frontier

Long-term possibilities include

- gene editing (CRISPR)
- combination therapies (learning from HIV/AIDS experience)
- nanomedicine
  - For example: *drug uncaging*. Load up an inactive or caged form of a drug and send it into the body where it can be activated or uncaged; drugs reach the target more efficiently.

There is a great need for Parkinson's specialists. Only about 50 specialists are trained per year in the United States.

## Chapter 10. The Plan

### GLOBAL ACTION

1. **Measure the disease.** No one knows how many Americans were newly diagnosed with Parkinson's in 2024.
2. **Ban dangerous chemicals.** In 2024, the EPA banned TCE and PCE, but *in January 2025 a freeze was put on the ban.*
3. **Adopt the Precautionary Principle.** When an activity raises threats of harm to human health or the environment precautionary measures should be taken even if some cause and effect relationships are not fully established scientifically.
4. **Stop subsidizing the use of pesticides.** The U.S. government spends about \$15 billion a year on farm subsidies, most of that goes to conventional farming which includes the use of paraquat on many fields.
5. **Give citizens the right to know.** {Remember Camp Lejeune.} People who live, work, or study near a contaminated site should be notified regularly (such as annually) of their

proximity to a Superfund<sup>8</sup> or other toxic site and the sites should be marked so the public knows.

6. **Create pesticide-free schools.**
7. **Build homes and schools away from freeways and interstates.** One-fifth of Americans live near roads with high air pollution.
8. **Develop organic golf courses.**

#### LEARN

9. **Pass the Healthy Brains Act.**
10. **Recognize that there are multiple causes of Parkinson's.**
11. **Assess the roles of nature and nurture.**
12. **Measure the toxic chemicals within us.**

#### AMPLIFY

13. **Enable all to receive levodopa.**
14. **Make insurance coverage of telemedicine standard**
15. **Double the number of centers of excellence.** Some 40% of Americans do not see a neurologist within four years of diagnosis.
16. **Reduce the stigma of Parkinson's.**

#### NAVIGATE

17. **Dramatically increase funding for Parkinson's research.** Current NIH funding is \$251 million a year.
18. **Lean into success.** Maximize the avenues of current successes.
19. **Go nano.** Nanomedicine Holds immense promise for both diagnosis and treatment.
20. **Rethink regeneration.** The new target may be an area of the brain that does not use the chemical dopamine to improve memory thinking and learning.

### **Parkinson's Goals for 2035**

- 0% rise in new cases of Parkinson's
- 10% increase in research funding and percentage devoted to prevention
- 100% access to levodopa

### **COMMON CAUSE**

- ❖ Pesticides, TCE, PCE, and air pollution don't just contribute to Parkinson's. They can lead to miscarriages, congenital abnormalities, asthma, cancer, Alzheimer's and countless other medical conditions.

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<sup>8</sup> Such as the *Griggs Walnut Plume Superfund Site* in Las Cruces.

## GLOSSARY

**Agnotology.** The deliberate production of ignorance, often for commercial gain.

**Aspiration pneumonia** is the leading cause of death in Parkinson's. It is a lung infection from inhaling substances like food, liquids, vomit, or saliva into the lungs.

**DAC.** Doña Ana County

**DBS** (deep brain stimulation). A surgery that alleviates symptoms and reduces the side effects of medications.

**Dementia with Lewy bodies** was first described in 1976, affecting actor Robin Williams. It is now known to affect an estimated one million Americans. Lewy Body Dementia (LBD) is directly related to Parkinson's disease; they are two forms of the same underlying condition, both caused by abnormal protein clumps called Lewy bodies, differing mainly by when cognitive vs. motor symptoms appear. In LBD, dementia starts early with thinking/hallucination issues, while in Parkinson's Disease Dementia (PDD), motor symptoms (tremors, stiffness) come first, with dementia developing years later, but both involve the same brain pathology.<sup>9</sup> These diseases have emerged only in the industrial age.

*Healthy Brains Act.* A bill drafted (July 2024) that instructs the director of the National Institutes of Health to establish research, training, and education programs to identify the underlying environmental causes of neurodegenerative diseases. It currently has 20 House co-sponsors.

**Levodopa.** It is a medicine that is converted to dopamine which can produce a dramatic response in most individuals.

*National Plan to End Parkinson's Act* Public Law 118-66. A bipartisan bill passed in the House (December 2023) and the Senate (May 2024) and signed by President Biden (July 2024). It requires the federal government to develop a plan to prevent and end Parkinson's disease.

**PSP** (progressive supranuclear palsy). A kind of Parkinson's on steroids first described in 1964.

**PD Avengers** is a global grassroots organization aimed at ending the disease.

[www.PDavengers.com](http://www.PDavengers.com)

**Radon** is a decay product of uranium, which is used in nuclear facilities. It is a gas that moves through the ground into cracks in buildings. It is a carcinogen.

**Scientific evidence** comes from unbiased, randomized, controlled trials.

**Substantia nigra** is a structure in the brain that produces dopamine.

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<sup>9</sup> AI. 20 December 2025

**TCE / PCE.** Trichloroethylene and its close relative perchloroethylene. It impairs the function of mitochondria (an organelle inside each cell that generates most of the cell's energy). It can be found in water, soil, and both indoor and outdoor air. It has been particularly concentrated in and near dry cleaners<sup>10</sup> and places where metal parts are degreased. In the US, some 250 million pounds are used annually.

**Vapor intrusion.** The migration of gaseous chemicals from underground sources into buildings.

**Vagus nerve.** The nerve that goes to the intestines.

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<sup>10</sup> In Denmark, a study showed that women who worked in laundry and dry cleaning had a *fifteen times higher risk* of Parkinson's compared to other workers.