EVERYTHING YOU NEED TO KNOW ABOUT PARKINSON’S DISEASE

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THE TOP 101 QUESTIONS ABOUT PARKINSON’S DISEASE

By Lianna Marie

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Rather, you are urged to read all the available material, learn as much as possible about Parkinson's Disease and tailor the information to your individual needs.

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Why I Wrote this Book
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I wrote this book for my mom. Her name is Val and I think she’s the best (you probably think your mom is the best but that’s okay ‘cause you’re supposed to think that way).

She’s had Parkinson’s disease for over 16 years now and though she’s had her tough times, she’s remained a positive, hopeful person and this has been a real inspiration to me.

When she was first diagnosed, there really wasn’t a lot of information out there to teach her about what it meant for her to have the disease. If there was info out there, it was hard to find.

These days, it seems as though there’s so much information out there with the internet and everything. The problem is, (or at least what we think) there seems to be a lot of stuff written about Parkinson’s in what I call “doctor language” and it sometimes takes a doctor’s degree to understand what they are trying to say! Also, there aren’t a lot of resources out there that have all the information you want to know about Parkinson’s in one place.

This is why I decided to write this book. It took my mom 16 years to learn a lot of stuff on her own about having PD. She told me she wished that there had been more information out there to help her understand and deal with her disease as it was progressing.

Together we came up with this idea of asking people with Parkinson’s, as well as their families, friends and caregivers, the most important questions they had about PD. We got a lot of questions, both general and specific, and put them together as the “Everything You Need to Know About Parkinson’s: The Top 101 Questions About Parkinson’s Disease”.

Whether you have Parkinson’s, care for, or know someone who has PD, we hope this book will help you. That’s what it’s all about. Mom and I want everyone who is affected by this disease to be able to be as much informed as possible, so they can continue to lead happy, productive lives.
Some Words You Need to Know

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**Antioxidant:**
- a chemical that *prevents damage to cells* in your body

**Bradykinesia:**
- *slowness* of movement

**Dopamine:**
- a chemical substance (neurotransmitter) found in the brain that sends impulses from one nerve cell to another and *regulates movement, balance, and walking*
- the substance that is lost in PD

**Dopamine Agonist:**
- drugs that *imitate the effects* of dopamine

**Dyskinesia:**
- the most common and disruptive *side-effect of PD medications*
- an *involuntary movement* that can accompany peak doses of levodopa
- *dystonia* (abnormal muscle tone of one or more muscles), *athetosis* (slow, involuntary movements of the hands and feet), and *chorea* (involuntary, dance-like movement of the extremities and head) are specific types of dyskinesia

**Levodopa:**
- the *most effective anti-Parkinson drug* which is changed into dopamine in the brain and usually combined with carbidopa as Sinemet

**Neurologist:**
- a specialist in the diagnosis and treatment of *disorders of the nervous system*

(*In this book we often use the word *doctor* instead of neurologist*)

**Off Time:**
- when people with Parkinson's have a *decrease in their ability to move* and have other symptoms that make it hard to get up from a chair, to speak, walk, or perform their usual activities (*can also be called “down” time*)
- happen because the person's dose of levodopa has worn off too soon or has suddenly and unexpectedly stopped working.

**Parkinsonian:**

- a person with Parkinson’s disease

**PD:**

- short form for Parkinson’s disease
What is Parkinson’s?

To put it simply, Parkinson’s is a disease that affects the functioning of a small part of the brain.

Basically what happens is that certain nerve cells in that small part of the brain (the part called the “substantia nigra”) start to degenerate and when they do a chemical in the brain called dopamine is lost.

Dopamine is a chemical that helps transmit signals or messages from the brain to different parts of the body. Because the dopamine is reduced and the brain can’t send the signals as well, this causes problems with body movement in someone with Parkinson’s.

Unfortunately, the sad part about Parkinson’s disease is that it is a disease that is long lasting and gets worse over time.

However, the good news is that because the disease progresses slowly, it usually takes years before there is a serious impact on a person’s quality of life.
What is the History of Parkinson’s?

Parkinson’s disease is named after an English doctor and writer named James Parkinson who first described the disease.

He wrote a paper about the disease which was published in 1817. This was the first time in history that someone described the symptoms of this disease in depth.

His paper was called “Essay on the Shaking Palsy” and to this day Parkinson’s disease is still sometimes called the “shaking palsy”.
What Causes It?

In short, we don’t know yet. There are many theories about the possible causes of Parkinson’s, but none of them have been proven yet. Most people researching the disease agree that there are probably multiple factors that contribute to someone getting Parkinson’s.

A lot of people ask about things like heredity, pesticides, head trauma (as in Muhammed Ali’s case), and aging, and whether or not these could be possible causes for Parkinson’s.

First of all, let’s start with what the researchers do know. They do know that Parkinson’s does not result from something that a person has done, from his or her diet, or from stress.

Head trauma is also something that researchers know rarely causes Parkinson’s. Some studies have found though, that those who have experienced a head injury are four times more likely to develop PD than those who have never suffered a head injury.

The same studies showed that the risk of PD increases by 8 times for people who required hospitalization for head trauma and 11 times for those people who had a loss of consciousness, skull fracture, prolonged memory loss or more complications. Even though the association is strong, researchers warn that this doesn’t mean that head injuries cause PD. The same is true for tumours.

Researchers also know that heredity does not play a major role in causing the disease except in familial Parkinson’s disease (families with many members having the disease over several generations). Basically, if you have a family member who has Parkinson’s, it is most likely a coincidence if you happen to develop the disease as well (because the disease is so common).

Researchers have discovered that it is possible that some people have a genetic susceptibility to developing Parkinson’s disease. What that means is that for example, some people just don’t have the ability to deal with toxic materials, so when they are exposed to them, they may develop PD.

Speaking of toxic materials, this is an area in which researchers searching for possible causes of Parkinson’s are currently very interested in.

Researchers have suggested that Parkinson’s might result from a toxin that gradually builds up in the brain, causing the degeneration of certain nerve cells in that small part of the brain we talked about earlier called the substantia nigra.
This toxin could build up either through exposure to an environmental toxin or as a by-product of a process of the brain. It could also be possible that people get the disease from exposure to a toxin early in life, combined with factors related to aging.

Unfortunately, there still is no firm evidence that environmental toxic materials such as industrial pollutants, herbicides, and pesticides may cause Parkinson’s. Researchers will have to continue to work on this one….

Finally, in regards to aging, there is evidence that the number of nerve cells in the substantia nigra decreases as a natural part of aging. Maybe Parkinson’s is related to aging then? But what about all those people who are in their 50’s, 40’s or younger with Parkinson’s?

Researchers have considered that maybe there is some kind of accelerated aging process taking place in the brains of people with Parkinson’s, but what the process is or how it starts is still unclear.
Who Gets It?
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Here are some quick facts about who Parkinson’s affects:

- it is estimated that **6.3 million** people have the disease world wide
- about **1 to 1.5 million** Americans have the disease
- **1 in 1000** people develop the disease
- **1 in 100** people over the age of 65 develop the disease
- **1 in 50** people over the age of 80 develop the disease
- **60** is the average age of developing the disease
- about **1 in 7** people with Parkinson’s develop it before the age of 40 (“Early-Onset Parkinson’s Disease”)
- in Early-Onset Parkinson’s, the disease develops between the ages of **21 and 40**
- men and women are **equally likely** to develop Parkinson’s (although some studies say men may be slightly more likely)
- all ethnic groups and occupations are about equally affected by the disease
- studies show that smokers are **less likely** to develop the disease (though the reasons are still unclear)
How Do I Know if I Have Parkinson’s?

In order to really know if you have Parkinson’s you need to be diagnosed. The process of diagnosis usually begins with you contacting your family doctor who will usually refer you to a neurologist or geriatrician.

The neurologist will take the history of the development of the symptoms from you and conduct a neurological exam. You might also be recommended to take some lab tests that will help determine if you have a different condition that may be similar to Parkinson’s, but really is not. For example, there are tremors that are not related to Parkinson’s.

There is still no one specific test that helps in the diagnosis of Parkinson’s. Diagnosis comes from being examined by your neurologist and by ruling out other possible causes for your symptoms.

What made my mom decide to go to the doctor originally was the tremor she was experiencing in her right hand. Obviously, she knew this was not “normal” so she went to get it checked out.

Unfortunately at the time (about 16 years ago), the doctor dismissed it because he said she was too young to have Parkinson’s (she was 48). Nowadays though, Early-Onset Parkinson’s is well known to doctors so she probably would have been diagnosed much sooner (it took 3 years for her to finally be diagnosed).

Though she did not realize it at the time, there were other additional symptoms that she was experiencing before her diagnosis that were the first signs of Parkinson’s. She did not know that these were linked to her having the disease until after she started learning about the signs and symptoms, after her diagnosis.

Other than her obvious hand tremor, she said she knew there was something different in her walk. She noticed that her feet seemed to hit the floor differently and that there was more wear and tear on the heel of her right shoe.

She also noticed dryness in her eyes which she later found out was due to the fact that people with Parkinson’s don’t blink as often. Another thing that happened was that her sense of smell was not as good as it normally was.

My mom always had a keen sense of smell so this was more obvious to her. She later read an article in Reader’s Digest that said that the loss of sense of smell is one of the first signs that appears in people with Parkinson’s.

Finally, the last things she noticed were while she was at work. One was
the fact that her handwriting was not round and fluid anymore, but rather “tight” or tense looking. The other thing she noticed at work was as she calls it, her “scatter brain”. She would often find herself starting a project then putting it down and moving on to another before it was finished.

These symptoms experienced by my mom are all common to someone who is being diagnosed with Parkinson’s, but there are others as well (check out the answer to question #28- “What are the most common symptoms?”) Remember that every person is different and so are the number and types of signs and symptoms that one would expect to see before diagnosis.

What convinced my mom’s neurologist that she had the disease was when he asked her to walk and he noticed that her one arm didn’t swing like the other (it actually stopped swinging). This is also a sign that many people with Parkinson’s have.

It is important to keep in mind that there are several Parkinson’s “look-alikes” (see question #16- “Are there different types of Parkinson’s?”) and in the end, it is the neurologist who will ultimately need to tell you or your loved one if you have Parkinson’s disease.
Is it Hereditary?

As mentioned earlier, researchers say that heredity does not play a major role in causing the disease except in familial Parkinson’s disease (families with many members having the disease over several generations).

Even with familial Parkinson’s disease though, studies show that in most of the cases, the inheritance factor is not of major importance.

It’s been found that about 5 to 7 percent of people with Parkinson’s have a relative with the disease. This percentage is no higher than we’d expect from chance alone. Basically, if you have a sister, brother, mother, father, uncle, or aunt, etc., who has Parkinson’s it would only be a coincidence if you also got the disease.

A recent study of twins showed that Parkinson’s disease before age 50 is strongly genetic. The same study did not find genetics to be a factor in Parkinson’s disease after age 50, but this finding is not ironclad.
Where Does it Start?
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Parkinson’s disease starts in the small part of the brain called the **substantia nigra**. The symptoms of the disease develop when the levels of the chemical messenger dopamine are reduced by about **80 percent**.
How Fast Does it Progress?

This is a hard question to answer. It really varies from one person to another. The time between when the symptoms first appear to severe disability can vary between 3 and 30 or more years.

Sometimes the disease will remain static (doesn’t change) for the first ten years (happens in about 5 to 10 percent of cases) and sometimes severe disability can occur within a few years (happens in about 6 to 15 percent of cases). Most people with the disease will have a progression that falls somewhere in between these two extremes.

Some studies have shown that people with Parkinson’s whose first symptom was a tremor and whose main symptom has remained a tremor have experienced a slow progression in the disease (this probably accounts for about 5 to 10 percent of all cases).

I know this was a question my mom asked her neurologist almost immediately after diagnosis. It took a while for him to give her what she calls a “straight answer” but when he finally did he said that she could expect to have a major disability within 10 years.

She was diagnosed at 51 and had to take a disability pension from her work at the age of 62 so I guess the doc was pretty accurate in my mom’s case.
Is There any Way to **Slow the Progression** of the Disease?

First of all, the diagnosis part of Parkinson’s is **very important**. New research says that if you can catch the disease very early on, often something can be done to delay the progression.

The sooner you can start treating the disease with proper medication, the better. Starting on the drug **Deprenyl (selegiline)** early in the disease can **possibly slow the progression down**.

There is some controversy about the use of Deprenyl though. Although it is possible that Deprenyl may help slow the progression of the disease early on, not all researchers agree.

I know Mom sometimes feels a bit sad about the fact that it took so long (3 years) for her to get diagnosed and started on treatment. She wonders how much she might have delayed the progression of her PD had she known she had the disease sooner.

There have been many studies on various new drugs, nutrients, vitamins, etc., which have all been trying to figure out if this disease can be slowed down.

There was a study at Emory University and nine other centres nationwide a couple of years ago. In it, researchers found that the naturally occurring compound **coenzyme Q10** could slow the progression of PD in its early stages by up to **44 percent**. Research is still ongoing into this.

**Vitamins C, E, and selenium** have also been linked to possibly helping slow the progression of the disease.

Finally, a more recent study has suggested that a drug called **Rasagiline** may also slow the progression of Parkinson’s disease, but it is still too early to tell.

Mom’s doctor has always encouraged her to try **vitamins and herbs** to see if they help. He says they can’t hurt, so why not? Why not ask your doctor if you think some of these things might help you?

You might also want to check out **question #74 “What alternative treatments are available for PD?”** to see if there might be any other alternative treatments you may want to talk to your doctor about.
Are Some Cases Worse Than Others?

Yes! Everybody’s different, but in general people with Parkinson’s who have a tremor tend to have a milder type of Parkinson’s.

Some people (especially those who have a tremor in one arm) may have a very mild form of the disease and require no treatment for several years.

Mom had a tremor in one hand for at least three years without any other major symptoms. Also, her doctor has been very surprised at how slow the progression has been to the left side of her body. She has only recently noticed slight tremors in her left hand and this is 16 years after her diagnosis.
What Are the Stages of Parkinson’s?

Two doctors named Dr. Hoehn and Dr. Yahr developed a scale that puts Parkinson’s disease into five stages. The first stage is the mildest stage of the disease and stage five is the worst stage.

The symptoms may be mild or severe or happen a lot, or not as much. Also, the time spent at each stage of the disease varies, and the skipping of stages, from Stage 1 to Stage 3, for example, is not uncommon.

Stage 1 The main symptoms- tremor, muscle stiffness, slowness of movement and problems with posture- are only on one side of the body. Problems with balance might also appear.

Stage 2 The disease will be on both sides of the body now and minor symptoms like problems with swallowing, talking and something called “facial masking” (loss of facial expression) may be noticed.

Stage 3 The same symptoms of Stage 2 are still there but may be worse now. Problems with balance will now be noticed for the first time. At this stage, the person with PD is still independent.

Stage 4 The person with PD will now be getting more and more disabled and will need help with some or all activities of daily living.

Stage 5 At this stage the person is confined to a wheelchair or bed and needs total assistance.
Do People Die from Parkinson’s?

No, people do not die from Parkinson’s. People with the disease die of the same causes as do other people of the same age.

You may have heard someone say “so and so died of Parkinson’s...”, but this is not true. They may have died of complications related to the disease, but the disease itself is not the official cause of death.

One interesting fact is that people with Parkinson’s are less likely to die of cancer, maybe because they are less likely to smoke.
What is the Life Expectancy of Someone with PD?

With proper treatment, the life expectancy of people with Parkinson’s is about the same as the general population (currently about 77 years but varies depending on what country you live in).

Some studies suggest that life expectancy is somewhat affected, but more recent estimates say that it remains within six months of normal life expectancy. (That’s good news!)
**How Long Can a Person with Parkinson’s Expect to Keep Their Independence?**

Again, **everyone is different**, and the best person to ask this question to is your neurologist. Most people (including my mom who was diagnosed at 51) live **many years** after diagnosis without experiencing **any major disabilities**.

It’s a good idea to talk to your doctor/neurologist regularly in an open and honest way about your symptoms and how you are feeling. This will help him or her to help you best achieve the **maximum out of your medications** and hopefully **extend the length of time** in which you can remain **independent**.

When my mom was first diagnosed, a family member suggested she go to a meeting for people with Parkinson’s. When she got there, she encountered a room full of people in wheel chairs. This was very discouraging for her (and probably not the best idea for a newly-diagnosed person to do!).

She decided at that moment that she was going to **do all that she could to keep her independence for as long as possible**. She explained to me that though today she often likes the **choice** of say using a scooter to get around a shopping mall, she doesn’t want to feel that she **has** to be in that scooter.

“Don’t let anyone take away your independence”, my mom says. In other words, don’t give up and say, “Oh well, I have Parkinson’s. I guess I’m doomed to being in that wheelchair.”

Her advice is to **keep doing as much as you can for as long as you can** without causing you and yours too much **stress**. Obviously, if something can be done in a few minutes that is taking you an hour, don’t be so stubborn as to not ask for help.
Can Parkinson’s Be Prevented?

To date, there is no known prevention or cure for Parkinson's disease. There are, however, several treatment options, including drug therapy and/or surgery that can reduce the symptoms, and make living with the disease easier.
Are There Different Types of Parkinson’s?

Yes, there are two main types of Parkinson’s disease. The main type, idiopathic or primary Parkinson’s disease is what about 76 percent of all people with PD have. In this type, the cause of the disease is unknown.

People with this type of Parkinson's are diagnosed when they have 3 of the 5 main symptoms (resting tremor, rigidity, bradykinesia, problems with posture, and walking problems) and there is no history of injury or illness or any other known cause of the symptoms, and when there is a good response to levodopa therapy.

The second type, called secondary Parkinsonism, is what the remaining 24 percent of people with PD have. In this type, there are other causes for the disease and they are therefore considered to have Parkinsonism secondary to another illness or known cause.

Here are the two types of Parkinson’s and some descriptions of the different forms of Secondary Parkinsonism:

1. IDIOPATHIC OR PRIMARY PARKINSON'S DISEASE

2. SECONDARY PARKINSONISM:

   - Postencephalitic Parkinsonism

     Back around the time of World War 1, there was a viral disease called encephalitis lethargica that attacked almost 5 million people throughout the world, and then suddenly disappeared in the 1920s.

     The disease was known as sleeping sickness in the United States and it killed one third of the people who got it and in many others it led to post-encephalitic Parkinsonism.

     This postencephalitic Parkinsonism was a pretty severe form of movement disorder in which some patients developed disabling neurological disorders.

     (In 1973, neurologist Oliver Sacks published “Awakenings”, which was an account of his work in the late 1960's with surviving post-encephalitic patients in a New York hospital. Using the then-experimental drug levodopa, Dr. Sacks was able to temporarily "awaken" these patients from their statue-like state. There's also a movie by the same name that was released in 1990)
• **Drug-induced Parkinsonism**

  This form of Parkinson’s is **reversible** and sometimes results from use of certain drugs (ex. chlorpromazine and haloperidol) that are used for psychiatric patients.

  Some drugs used for *stomach disorders* (metoclopramide) and *high blood pressure* (reserpine) may also produce parkinsonian symptoms. **Stopping** the medication or **lowering the dosage** causes the symptoms to go away.

• **Striatonigral Degeneration**

  In this form of Parkinsonism, the substantia nigra is only **mildly affected**, while other brain areas show more severe damage than occurs in patients with primary Parkinson’s disease.

  People with this type of Parkinsonism tend to show **more rigidity** and the **disease progresses more rapidly**.

• **Arteriosclerotic Parkinsonism/Vascular Parkinsonism**

  This type of Parkinson's is sometimes known as **pseudoparkinsonism**. It involves **damage to brain vessels** due to multiple **small strokes**.

  You probably **won’t see tremor** in this type of Parkinsonism, but you most likely will see **dementia** (loss of mental skills and abilities).

  Drugs used to treat Parkinson's **don’t really help** people with this type of Parkinson’s.

• **Toxin-induced Parkinsonism**

  Some **toxins** like manganese dust, carbon disulfide, and carbon monoxide can also cause Parkinsonism. A chemical known as **MPTP** (methyl-phenyl-tetrahydropyridine) causes a **permanent** form of Parkinsonism that closely resembles Parkinson’s disease.

  Researchers discovered this reaction in the 1980s when heroin addicts in California who had taken an illicit street drug contaminated with MPTP started to develop severe Parkinsonism.

  MPTP-induced Parkinsonism is **very rapid** in its onset (as quick as a few days to full symptoms), whereas **idiopathic PD** has a **slow progression** and may take **years** to become evident.
• Parkinsonism-Dementia Complex of Guam

This form occurs among the Chamorro populations of Guam and the Mariana Islands and may be accompanied by a disease resembling amyotrophic lateral sclerosis (Lou Gehrig's disease).

The progression of this disease is fast, with people usually dying within 5 years. Some researchers wonder if there might be an environmental cause, like the use of flour from the highly toxic seed of the cycad plant.

This flour was a dietary staple for many years when rice and other food supplies were unavailable in this region, especially during World War II. Other studies, however, disagree with this link.

• Parkinsonism Accompanying Other Conditions

Parkinsonian symptoms may also appear in patients with other, neurological disorders such as Shy-Drager syndrome (sometimes called multiple system atrophy), progressive supranuclear palsy, Wilson's disease, Huntington's disease, Hallervorden-Spatz syndrome, Alzheimer's disease, diffuse Lewy body disease, Creutzfeldt-Jakob disease, olivopontocerebellar atrophy, and post-traumatic encephalopathy.

• Parkinsonism Due to Other Causes

Parkinsonism symptoms may also appear as a result of boxing, other head trauma, and hydrocephalus (an abnormal accumulation of cerebrospinal fluid (CSF) within cavities called ventricles inside the brain).
Idiopathic Parkinson’s disease is the most common form of Parkinson’s, also called primary or classic Parkinson’s.

Parkinson’s disease is called idiopathic Parkinson’s because the cause is unknown. In the other forms of Parkinson’s, a cause is known or suspected.
What is Parkinson’s Plus?

Parkinson's Plus disorders are like cousins of Parkinson's disease. They’re called Parkinson’s Plus because they are disorders that have similar symptoms to Parkinson’s.

Many people get these Parkinson Plus disorders and think they have Parkinson’s but actually do not. These disorders are different from idiopathic PD.

Some examples of Parkinson Plus disorders are:

- Multiple-system atrophy (MSA)
- Progressive supranuclear palsy (PSP)
- Shy-Drager syndrome
- Striatonigral degeneration
- Parkinsonism-dementia-ALS complex
- Corticobasal degeneration
- Autosomal dominant Lewy body disease
- Alzheimer’s disease
- Wilson's disease
- Guam disease

Some of the major ways in which Parkinson's Plus is different from idiopathic Parkinson's are as follows:

1. **Levodopa** therapy rarely works with PD Plus syndromes

2. PD Plus syndromes **show additional symptoms** that people with PD don't have. For example, in Corticobasal degeneration, there is the alien limb phenomenon (not feeling in control of the activities of an arm or leg)

3. There **isn't a resting tremor** in PD Plus and people often experience falls early on in the disorder
What is **Lewy Body Disease**?

Lewy body disease is a kind of **dementia**. Dementia is a general decline in cognitive abilities (thinking, memory, language, etc.).

There are many kinds of dementia. The most common and best known kind is Alzheimer's disease. Lewy body disease is thought to be the **second most common kind of dementia**. It causes **cognitive problems** similar to those seen in Alzheimer's disease and **motor problems** like those in Parkinson's.

Lewy body disease is currently **incurable** and it gets worse with time.

Lewy body disease is also referred to as dementia with Lewy bodies, Lewy body dementia, diffuse Lewy body disease, senile dementia of Lewy body type, and Lewy body variant of Alzheimer's disease.

The following are some of the symptoms of **Lewy Body Disease**:

- **cognitive problems** (problems with thinking, memory, language, etc.).
- **motor problems** like Parkinson's disease (but not as severe), difficulties in **walking** are the most common problem
- **muscle stiffness** and a tendency to fall are common
- tremor **less** common
- periods of being alert and coherent alternate with periods of being confused and unresponsive to questions
- visual **hallucinations** (usually occurring early on) and **delusions**
What is Essential Tremor and How is it Different from PD?

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**Essential tremor (ET)** is the most common cause of tremor (involuntary shaking). It is a condition that affects the muscles of the **hands, arms, head and** sometimes the **voice**.

Essential tremor **does not affect life expectancy**, but things like **writing** and **eating** can become very difficult.

ET does not increase the risk for Parkinson's disease but the condition is **often mistaken for Parkinson's**. Although ET is 10-20 times more common than PD, people with essential tremor can go on to develop Parkinson's disease (but how many do so isn't known).

Both essential tremor (ET) and Parkinson's disease (PD) are movement disorders and are sometimes associated because they have similar features. A movement disorder can be defined as any disease or injury that interferes with an individual's movement.

**Symptoms of Essential Tremor (black) vs. symptoms of Parkinson's (red):**

- tremors that get worse with purposeful movement (action tremor) / have resting tremor (tremor gets worse at rest)
- nodding head (head tremor) / tremor may involve the chin, but rarely the head
- **fast** tremor (4 to 12Hz)/ tremor **not as fast**
- tremor is usually bilateral (on both sides of the body) / tremor starts on one side only then eventually progresses to the other side
- tremors are the only symptom/ tremors are only one of many symptoms of PD
- difficulty with balance is **rare**/ loss of balance and increased falls is **common** in people with Parkinson's
- tremor can **usually** be relieved **temporarily** with ingestion of small amounts of **alcohol**/ tremor is **not** usually relieved by alcohol
- tremor **does not** respond to antiparkinsonian medication/ tremor **does** respond to antiparkinsonian medication
- a pill-rolling quality is usually **not present** in tremor/ pill rolling quality **is present**
• doesn’t cause other health problems/ is associated with a stooped posture, reduced rigid limbs, slow movement, a shuffling gait, speech problems other than tremor and sometimes memory loss

• minor loss of sense of smell/ loss of sense of smell is more significant

• family history of ET usually exists/ family history of PD doesn’t usually exist
What Percentage of People With PD Do Not Have a Tremor?

If PD starts without signs of tremor, it is likely to be more severe than if tremor had been present. Up to 25 percent of people with Parkinson's disease do not have tremor.
Does Age Play a Role in Getting Parkinson’s?

Age is one of the main risk factors for Parkinson’s disease. Although the disease can affect adults in their 20’s, it usually starts in middle or late life. The risk continues to increase with age.

Some researchers think that people with Parkinson’s disease may have damage within their brains from genetic or environmental factors that becomes worse over time.
Are There Look-Alike Conditions that Have Similar Symptoms to Parkinson’s?

Yes, there are several “Look-Alikes” to Parkinson’s. A number of people first diagnosed with Parkinson’s may have these instead.

Here are some of the conditions that can sometimes be confused for Parkinson’s:

- **Benign Essential Tremor:**
  
  This is a common condition that may appear in older people and slowly progress over the years. The tremor is usually equal in both hands and increases when the patient stretches their hands out in front of them or when their hands are moving.

  The tremor may involve the head but not the legs. People with Benign Tremor have no other Parkinson’s symptoms, and there is usually a family history of tremor.

  Parkinsonian Tremor and Benign Tremor generally respond to different drugs. A small number of people with Benign Essential Tremor (less than five percent) develop PD.

- **Shy Drager Syndrome (Multiple System Atrophy):**
  
  This is a condition in which the earliest and most severe symptoms are dizziness on standing, bladder difficulty, and impotence.

  These autonomic symptoms are followed by PD symptoms such as rigidity, tremor, bradykinesia, problems with posture, and gait difficulty.

- **Normal Pressure Hydrocephalus:**
  
  This is a pretty uncommon condition where the person has difficulty walking, has mental changes (like forgetfulness), and bladder problems.

  The condition is caused by an enlargement of the fluid cavities (called ventricles) in the brain which compress the parts of the brain that help you think and walk.

  There is no known cause of Normal Pressure Hydrocephalus. The condition may be helped by a shunt (a tube placed in the ventricle which drains off the excessive fluid and carries it away).
• **Striato-Nigral Degenereation:**

  This is also an uncommon disorder in which people become **stiff and slow** and develop **difficulties with balance and walking**.

  Usually people **do not have tremor** and it’s hard to tell if they have this condition or PD just by giving them a neurological exam. One thing that will be different between the two conditions is that people with Striato-Nigral Degenaration will **not respond to Levadopa**.

  Only after the person dies can you tell if the person had this disorder or PD because in Striato-Nigral Degeneration most of the damage is in the Striatum part of the brain and **not the Substantia Nigra** (like in PD).

• **Pseudobulbar Palsy:**

  This is a common disorder that happens in people with disease of the blood vesels of the brain (Arteriosclerosis). Arteriosclerosis is especially likely to happen in people with **high blood pressure or diabetes**.

  People develop Pseudobulbar Palsy as a result of having **many small strokes** (ministrokes), most of which are so mild that they are **unaware** of them.

  The ministrokes usually damage the part of the brain that controls **balance and walking**, the same area involved in PD.

  You may not be able to tell the difference between these two disorders by a neurological exam alone, but people with Pseudobulbar Palsy **do not respond to antiparkinsonian drugs**.

• **Progressive Supernuclear Palsy:**

  This is an uncommon disorder where people develop **paralysis of their eye movements, difficulty in speaking, rigidity, and senility**.

  People with this disorder experience changes in the brain that are similar to those of PD, but are greater. **Antiparkinson drugs don't work** as treatment for this disorder.

• **Wilson's Disease:**

  This is a **rare inherited** disorder that happens to people **below the age of 40**, and involves damage to the **brain and the liver**. Early diagnosis is important in this disease because treatment prevents further damage to the brain and liver.
• **Hallervorden Spatz Disease:**

This is also a rare, **inherited** progressive disease that begins in **late childhood**. Hallervorden Spatz Disease happens when too much **iron** collects in certain parts of the brain. There is **no treatment** for this disease.

• **Olivopontocerebellar Degeneration:**

This is an uncommon disorder where people have a hard time with **balance and walking**, often called Ataxia. People may have an action or sustention tremor, but do **not have rigidity or bradykinesia**.

The disorder results from a deterioration of the nervous system and **does not respond to antiparkinson drugs**.

• **Huntington's Disease:**

This is an inherited disease which usually begins **early in middle life**. People with this disease have **involuntary movements** (dyskinesias, chorea) that are associated with changes in behavior, personality, and mood.

The chorea (which resembles the involuntary movements caused by Levodopa) may happen before, during, or after the mental changes.

Once the disease is fully developed, it is easily distinguished from PD. However, the symptoms of a childhood form of **Huntington's disease** may resemble PD. Levadopa usually worsens the symptoms of Huntington's disease.

• **Dystonia:**

This is an inherited disease that begins in **childhood** and is progressive. People with this disease develop **unusual postures of the head and neck, arms and legs**.

This is called Generalized Dystonia. Another type of this disease is **Segmental Dystonia**. It develops in adulthood and involves only one part of the body, e.g. the head and neck.

• **Brain Tumors:**

Tumors of the brain that are close to the substantia nigra or the striatum may put **local pressure** on these parts of the brain. This local pressure may then result in the **appearance of symptoms** that look like PD.
A CT (CAT scan) or NMR (nuclear magnetic resonance scan) of the brain will exclude the possibility of a brain tumor as the cause of the Parkinsonian symptoms.
What is Early-Onset Parkinson’s?
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Early-Onset Parkinson’s (also called Young-Onset Parkinson’s or YOPD) is when symptoms of the disease appear before the age of 40. This happens to about 1 in 7 people with the disease.

Studies have shown that early-onset PD is not a lot different from the late-onset form. There are few differences though, that are listed below.

- levodopa therapy works but it is associated with on-off fluctuations and diskinesias relatively early on in the disease
- the disease may progress more slowly than classic PD
- most people with early-onset PD have mostly rigid, akinetic (without movement) forms of the disease
- tremor is often a more prominent early symptom in early-onset PD than later-onset PD
- dystonia (abnormal PD muscle spasms) may show up earlier in early-onset PD than in later-onset
- dementia is rare in people with early-onset PD
- depression may occur more often and earlier on in the disease compared to people with later-onset PD
Do People With Early-Onset Parkinson’s Have a Different Life Expectancy Than Those Who Are Diagnosed Later in Life?

The life expectancy of someone with early-onset PD is not affected by the disease, just like it is not affected by classic idiopathic PD.

There is evidence that the progression of the disease is slower in early-onset PD. This is because in younger people, tremor is usually predominant and its presence often means a slower progression of the disease.
Is the Chance of a Normal Life Less Likely for Someone Who has Been Diagnosed With Parkinson’s Later in Life?

No, the chance of having a normal life does not have to be reduced if you are diagnosed later in life. Again, everybody’s different and your symptoms may progress faster or slower than the average person with PD.

I had a great uncle who was diagnosed with Parkinson’s in his late 70’s and he lived for many years before his symptoms became debilitating.
Can Parkinson’s Be Cured?

Well, we would certainly like to think so! Researchers are still working hard to find a cure and though they have not found one yet, they have made a lot of progress.

There is very real hope that the causes, whether genetic or environmental, will be figured out and the exact effects of these causes on how the brain works will be understood.

Even though there is currently no cure for Parkinson’s disease, by identifying individual symptoms and determining the right kind of treatment, most people with the disease can live enjoyable, fulfilling lives.
SIGNS AND SYMPTOMS

What are the Most Common Symptoms?

Symptoms of PD vary from person to person and not everyone is affected by all of them. In some people, the disease progresses quickly; in others it does not.

Here are the most common primary symptoms of Parkinson's disease:

Tremor:

In the early stages of the disease, about 70% of people experience a slight tremor in the hand or foot on one side of the body, or sometimes in the jaw or face. It looks like a 'beating' movement and is regular (4-6 beats per second).

Because tremor usually appears when the muscles are relaxed, it's called "resting tremor". This means that the affected body part trembles when it is at rest and not doing work and often stops when you start using (or working) that part of the body.

The tremor often spreads to the other side of the body as the disease progresses, but will remain most obvious on the side of the body where it first started.

A few more points on tremors include:

• usually occur at rest, may occur at any time
• may become severe enough to interfere with activities
• may be worse when tired, excited, or stressed
• finger-thumb rubbing ("pill-rolling tremor") may be present

("pill-rolling" is seen especially in the hands; this is fairly unique to Parkinson's disease. The term refers to the motion that a pharmacist uses to align a handful of pills before placing them in a bottle or, possibly, the motion used to roll a marble between the thumb and forefinger. Eventually the tremor becomes more generalized.)
Rigidity:

Basically this means **stiffness or inflexibility of the muscles**. Normally muscles contract when they move, and then relax when they are at rest. In rigidity, the muscle tone of an affected body part is stiff.

Rigidity can result in a **decreased range of motion**. For example a person **may not swing his or her arms** when walking. Rigidity can also cause pain and cramps at the muscle site.

Bradykinesia:

Bradykinesia is a **slowing of voluntary movement**. In addition to slow movements, a person with bradykinesia will likely also have incompleteness of movement, difficulty in initiating movements, and arrests of ongoing movement.

The person may begin to walk with **short, shuffling steps** (festination), which, combined with other symptoms such as **loss of balance**, increases the incidence of **falls**.

They may also experience **difficulty making turns or abrupt movements**. They may go through periods of **"freezing"**, which is when the person is stuck and finds it difficult to stop or start walking.

Bradykinesia and rigidity can occur in the facial muscles, causing a "**mask-like**" expression with little or no movement of the face. The slowness and incompleteness of movement can also affect speaking and swallowing.

Here is a list of some **secondary symptoms** of Parkinson's disease:

- **Speech/Voice Changes:**
  - slow speech
  - low-volume voice
  - monotone
  - difficulty speaking

- **Changes in Facial Expression:**
  - reduced ability to show facial expressions
• "mask" appearance to face
• staring
• may be unable to close mouth
• reduced rate of blinking

• **Loss of Fine Motor Skills:**

  • difficulty writing, may be small and illegible (called micrographia)
  • difficulty eating
  • difficulty with any activity that requires small movements
  • movement is slow and uncontrolled

• **Difficulty swallowing**

• **Drooling**

• **Pain**

• **Dementia or confusion**

• **Sleep disturbances**

• **A variety of gastrointestinal symptoms, mainly constipation**

• **Skin problems**

• **Depression**

• **Fear, stress or anxiety**

• **Memory difficulties and slowed thinking**

• **Sexual difficulties**

• **Urinary problems**

• **Fatigue**
• Muscle aches and pains (myalgia)
• Loss of energy
• Unstable, stooped, or slumped-over posture
What Are the Most Significant Signs to Look For to Determine if Someone Has Parkinson’s?

In 50 to 80 percent of people with Parkinson’s, the condition starts with the subtle so-called "pill-rolling" tremor of one hand. This is very typical (and was the first sign my mom had).

The uncontrollable tremor looks like the fingers are rolling a pill or a marble continually. This is severe at rest and decreases during movement, and isn’t there when the person is asleep.

Emotional stress, tension, and being tired make the tremor worse. Your hands, arms and legs are often affected, in that order.

In some people, there is no tremor, and rigidity of the muscles is present. The face becomes mask-like, expressionless, with less blinking and with mouth open.
Are There People Who Have Had All Their Symptoms Disappear?

We are not aware of anybody who has had all of their symptoms disappear without medications. With medications however, the main symptoms can disappear. Everybody experiences different success with medications but initially, you should experience the disappearance of the main symptoms of PD.

Mom has found her symptoms to disappear completely while at big parties like her wedding and her retirement party. These nights you could have sworn by looking at her that she didn't even have Parkinson's. Of course this is temporary but it does say something about how much your mood can affect your symptoms.

Why not throw yourself a party? Celebrate! Surely you can find a reason to have people over to the house for a get-together? You might be amazed at how much hanging out with people you love and who love you can help your symptoms disappear....
What Parts of the Body are Affected?

The simplest answer is all the parts of the body. Well, that’s what it may feel like sometimes, Mom says.

The brain is the first part of the body that is affected in a person with Parkinson’s. As mentioned before, certain nerve cells in the small part of the brain called the “substantia nigra” start to degenerate and when they do a chemical messenger in the brain called dopamine is lost.

The substantia nigra has important connections with motor centers (brain centers that control movement) and so it plays a very important role in how we move. The chemical messenger dopamine is used by the substantia nigra so when dopamine is lost, messages to motor centers in the body can’t go through. This results in mobility problems for people with Parkinson’s.

Because dopamine is so important in the control of muscles, when it is lost the muscles act differently. Sometimes they tighten up, becoming stiff and rigid. In addition, movement becomes slow, problems develop with one’s walking and posture and balance is also affected.

Parkinson’s also affects the body temperature control system, digestive system, sexual function, and bladder control. Not all people with Parkinson’s would necessarily experience difficulties with all of these however.
How Does Parkinson’s Affect Behaviour?

Although everyone is different, Parkinson’s can and probably will affect your personality which will then affect your behaviour.

As in my mom’s case, though she was a pretty positive person to begin with, she isn't always able to be that way as much anymore (though I must admit she does a pretty good job at being positive most of the time). Obviously then, if a person with Parkinson’s was not very positive to begin with, he or she would probably have an even harder time with the disease.

Another change in her behaviour is her lack of confidence. This has probably come gradually as she has lost to her ability to do some of the things she used to be able to.

Self-esteem can also be greatly affected by Parkinson’s especially if you were lacking in this department before you got the disease. If you are at all self-conscious you may have a hard time being in public as you experience side effects of the disease like excessive shaking or moving of arms or legs.
How Does Parkinson’s Affect One Psychologically?

Psychologically speaking, only a small amount of people with Parkinson’s (about 15 to 20 percent) develop dementia which is an intellectual decline and loss of memory.

Many people with Parkinson’s complain of problems like absent-mindedness, slowness of thinking and difficulty with mentally challenging tasks. However, not everyone with Parkinson’s notice changes in their cognitive abilities (ie. your ability to think).

My mom said she really noticed her inability to stay focussed on the task at hand very early on. She said she often felt like a “scatterbrain”. This can be a result of Parkinson’s medication, which controls production of dopamine, and may affect a person’s ability to concentrate.

Now, sixteen years later, she notices from time to time she will say a word in a sentence that has absolutely nothing to do with what she is talking about. She’s not sure why this happens, but figures it must have something to do with the disease.

Hallucinations, paranoia, and delusions are all possible side effects of Parkinson’s disease medications. Switching to different Parkinson’s disease medication can sometimes control these.

A hallucination occurs when you think something is present when it isn’t. For example, you may hear a voice but no one is there. The hallucinations are not frightening and the Parkinsonian is well aware they are not real. If the drugs are working well, you may choose to live with this side effect.

An example of paranoia is when you think someone is following you when they are not. Delusion is when you are convinced something is true, despite clear evidence proving that it is not.

Parkinsonians may also suffer from nightmares and vivid dreams that are not a result of the Parkinson’s but instead, the side effects of medications.

In order to deal with any previous psychological “challenges”, the first step is to address any other medical conditions that could produce hallucinations, delusions, or paranoia.

Your doctor will check for things like imbalance of chemicals, possibly kidney, liver or lung function, as well as check for certain infections since these problems could cause mental disturbances.
Other medications that you may be using, including over-the-counter medicines, could also be responsible for these problems. Make sure you tell your doctor about **all medications, including herbal therapies, that you are taking.**

Some people may not be able to tolerate changes in their Parkinson’s disease medications without increasing their symptoms. In these cases, it may be necessary to treat the mental disturbances with **anti-psychotic medicines.**

Unfortunately, some anti-psychotic medicines can **worsen** Parkinson’s disease. There are alternatives though, and your doctor will be able to help you find them if you need to.

If you are experiencing any of the previously mentioned mental disturbances, **talk to your doctor right away.** There is likely a treatment that will make you feel better.
How Does Parkinson’s Affect One Emotionally?

Parkinson's is a neurological, not a mental, disorder. In most cases, it slows the body, not the mind. However, when brain cells are affected by medication, you should expect some emotional changes.

Depression is a huge part of Parkinson's. Many people with the disease are affected by this. Paranoia, fear, and anxiety are also things that can be experienced by people who have the disease. My mom wonders if maybe these things come from losing your sense of confidence in things like walking and everyday activities.

Both anxiety and depression are very common among people with Parkinson's and may occur due to seratonin imbalance, a side effect of certain medications.

This may eventually lead to loss of memory. Anxiety and depression are difficult to diagnose in patients with Parkinson's because the symptoms are similar to those of the disease.
How Does Parkinson’s Affect One Socially?

Socially speaking, it can be difficult for a person with Parkinson's because others may look at them as though they are as my mom says, some sort of “freak” with all the involuntary moving (like the dyskinesia) that they're doing.

In reality, most people probably don't look at people with Parkinson's as freaks but it's easy to feel that way when you have the disease.

As the disease progresses, it can be hard to be in public sometimes. For instance, when my mom experiences a sudden shutdown of her body she'll often have troubles walking through doorways. This can attract a lot of attention from others and can be very emotionally disturbing to any person with Parkinson's.

Also, when eating out, it can be hard at times for the person with Parkinson's because it's often hard to hold onto cutlery. Several times, my mom has been embarrassed and upset because she can't stop dropping things at the dinner table. Even amongst friends, she at times finds it very hard emotionally to do things like this.

Finally, it can sometimes be hard on your social life if you have a partner (for example, a husband or wife) and if you can no longer do the things the way you used to (like going dancing).
Can Parkinson’s turn into Alzheimer’s Disease?

At this point, researchers are still trying to figure this out. Some believe that Parkinson’s and Alzheimer’s disease cannot exist at the same time but others believe they can.

In the early stages of Parkinson’s, dementia is somewhat different from the dementia seen in Alzheimer’s disease. In Parkinson’s the dementia can be seen as being forgetful, having a hard time making decisions, planning, reasoning, having slow thought processes, etc. In Alzheimer’s there is a great loss of memory and intellectual abilities.

In the later stages, the dementia in Parkinson’s can be as severe as that seen in Alzheimer’s disease.

About 20 to 25% of people in the later stages of Parkinson’s develop dementia severe enough to interfere with day-to-day functioning. This is about 10-15% higher than the general population at the same age.

Unfortunately though, it’s impossible to predict which people with Parkinson’s will develop this problem.
Does Parkinson’s Lead to Early Dementia?

As mentioned in the previous question, it is thought that about 20 to 25% of people in the later stages of Parkinson’s develop dementia severe enough to interfere with day-to-day functioning. This is about 10-15% higher than the general population at the same age.

Unfortunately though, it's impossible to predict which people with Parkinson’s will develop this problem.

Although people with Parkinson's are at a slightly increased risk for developing dementia, most people won't have problems with this.

When a person with PD begins to show signs of dementia, it is important that a careful search is made for treatable conditions. Two possible causes of dementia in PD that can be treated include medications and depression.

Many anti-parkinsonian medications interfere with thinking and memory, especially drugs in the class known as anticholinergics including Artane and Cogentin. All anti-parkinsonian medications have the potential to cause confusion.

Depression is a common problem in PD and may seem like dementia with its symptoms of poor concentration, thinking and memory. These symptoms do go away though, as soon as the depression is treated.
Do Long Term PD patients **Develop Memory and Reasoning Problems** or Could Meds for PD Cause This?

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Yes, long term Parkinson’s patients do develop memory and reasoning problems related to dementia about **15 to 20 percent** of the time. Sometimes this can happen at middle-age but generally speaking these problems happen when you get **older**.

About **20% of people taking levodopa** may experience side effects of confusion, delusions, and hallucinations but these symptoms occur more frequently in older people with a later onset of the disease.
Does Parkinson’s Cause Depression or Is It a Side Effect of the Drugs?

Well, it can be both. Depression is common in people with Parkinson’s and can happen as a result of the disease and/or because of the side effects of the drugs taken for the disease.

For most people with Parkinson’s disease, depression can be controlled.

Depression can actually increase the physical effects of Parkinson’s disease and possibly cause a progression of the disease. If you experience five or more of the following symptoms for longer than two weeks at a time, you should contact your doctor.

• Depressed mood
• An inability to find pleasure in things that were once pleasurable
• Sleep disturbances (inability to sleep or sleeping excessively)
• Change in appetite
• Fatigue
• Altered level of activity
• Difficulty with concentration
• Low self-esteem
• Thoughts of death

Depression may be treated with psychological therapy, as well as with medications. People seem to do better when they receive both psychological and drug treatments.

*NOTE: Make sure you check with your pharmacist about taking any new medications (like antidepressants) as there may be some that may not be compatible with your PD medications.

There are many anti-depressant medications available, each with their own advantages and disadvantages. Your doctor will know which ones are best for you.

Most people with Parkinson’s disease should not take Ascendin
(amoxipine) because this medication could temporarily worsen the Parkinson’s disease symptoms.

Psychological therapy can help a person with Parkinson’s disease regain their sense of **self-worth** even though they may not be able to do as much anymore.

It also can help the person maintain good relationships with **caregivers** and **family members**, despite the fact that they may be depending on them more.
Is it Normal for Someone with Parkinson’s to Experience Anxiety?

Yes! It is absolutely normal for someone with Parkinson's to experience anxiety. There are so many reasons why you could feel anxious. The minute you get diagnosed with this disease, there are things to be anxious about.

This is like any other disease though, and oftentimes being proactive and finding out more about it can help (ex. the different progression rates, support systems available, etc.).
Is Stress a Factor in Making Symptoms Worse?

YES! Stress can have a very negative impact on the symptoms of Parkinson's disease, so it's important to focus on managing the stress in your daily life and finding some relaxation.

Stress and chronic illness go hand in hand. Stress comes from a variety of different sources that can be physical, as well as emotional.

Stress can come from daily life tasks, events, problems, fatigue, as well as anxiety and frustration with having to deal with the limitations and life adjustments that Parkinson's disease often creates.

The important thing to be aware of, however, is that stress can worsen Parkinson's disease symptoms, especially tremor and mobility. Therefore, it is important to focus on stress management and relaxation in your daily life.

The following are some stress management techniques you may want to incorporate into your life. Not all techniques work for everyone. You have to experiment a little to find something that works for you. Try more than one technique, and then use it often. Remember that the key to successful stress management is practice.

Deep Breathing:

Take slow, deep breaths from your diaphragm. Breathe in through your nose and out through your mouth. Count to five as you breathe in and five as you breathe out. Do this several times until you begin to feel more relaxed.

Progressive Relaxation:

Get in a comfortable position, close your eyes and slowly focus on relaxing different parts of your body, one at a time. Start from your head and work down to your feet. There are many different relaxation tapes out there that can guide you.

Relaxation Tapes/CDs/Books:

There are many different relaxation materials available in bookstores and over the internet. Music stores usually have a section on relaxation. You may have to experiment a little to find something that works for you.
Meditation:

There are many good books and tapes on this topic. You may also be able to find classes that are offered in your community.

Massage:

Massage can be very helpful in relieving muscle tightness, but it is also extremely relaxing to body and mind. Mom loves this and gets a good half hour to an hour massage as often as she can.
What is a PET Scan and What is it Used For?

A positron emission topography (PET) scan is a test used to give doctors and their patients more information about how the cells in your body are functioning.

There are no lab tests that can diagnose Parkinson’s, but sometimes a PET scan is used to detect low levels of dopamine in the brain. It also looks at the activity and function of brain regions involved in movement.

The test is done by injecting a small amount of radioactive material known as a tracer into a person’s vein in the arm. The tracer sends out small, positively charged particles (positrons) that interact with negatively charged particles called electrons in your body.

The PET scanner is able to detect the product of this interaction and uses it to make an image. This process allows a doctor to look at a body organ from every angle and detect potential problems.

This test is not commonly used to diagnose Parkinson’s disease because it is expensive and not widely available.
Is Difficulty Sleeping a Symptom or Side Effect of the Drugs?

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Having difficulties sleeping are common in people with PD and can be both a symptom of the disease and a side effect of the drugs.

The drugs Sinemet and sometimes Eldepryl can interfere with sleep.

Taking your medications at different times may help your difficulties with sleep, but there is no magic formula that works for everyone.

It may take some time to figure out when the best times to take your medications are, and whether or not you need to change the dosage before bedtime. Your doctor can help you with this.
Does Parkinson’s Have an Affect on Blood Pressure?

People with Parkinson’s may experience low blood pressure due to the medications that are taken for the disease.

Some people with PD also have a history of high blood pressure (hypertension) and are already taking medication to lower it. Adding an antiparkinson drug can lower the blood pressure even further, resulting in dizziness or fainting. In this case, the medication for high blood pressure can often be reduced or stopped.

There a few things that you can do if your blood pressure is low because of your PD medications:

- **Avoid standing**, especially after exercise, since blood will pool in your legs. If standing at the sink or a workbench, keep your feet moving a little.
- **Avoid very hot baths or showers**, and always sit down to towel off.
- **Get up slowly from the lying position**, and avoid getting up from a meal too quickly.
- Make sure that you **drink plenty of fluids** and use extra salt.
Does Parkinson’s Disease Affect the Heart Valves?

No, not exactly. It's not the disease which affects the heart valves, but possibly a medication used in treating the disease.

There's a drug named Pergolide which is used to treat tremors in Parkinson's disease that may be responsible for heart damage.

Researchers say that there is enough evidence to recommend that anyone with heart problems not take Pergolide, which is sold as Permax and has been used since 1989 to treat the tremors and restless leg syndrome of people with Parkinson's disease.

More research needs to be done about this condition but, in the meantime, researchers have stated that "Pergolide should be discontinued if valvular disease is detected and no other cause identified."
How Does Parkinson’s Affect Gait?

Some people with Parkinson's have difficulty starting to walk. They have problems lifting their foot in order to start walking and may take a few small and uneasy steps before walking at a steady pace.

While they are walking, they stop swinging their arms. They will also shuffle (a bunch of small, short steps) their feet and walk with their body weight on the front part of their feet.

Festinant gait is when a person starts taking small short shuffling steps that become faster and faster. What sometimes happens is that the shuffling becomes so fast that he/she falls forward or runs into something.

Sometimes the same happens only backwards. There was a time when my mom had problems with this. For what seemed like no reason at all, she would just start shuffling backwards. We laughed at it to help her be less anxious, and would say “Hey Mom, you need to switch gears, you're in reverse!”

You need to be careful as the caregiver if and when you see someone with Parkinson's shuffling because this can often lead to falls. About one-third of people with Parkinson’s disease fall relatively frequently. People with Parkinson’s lose their ability to regain their balance when they start to fall so it is important to stay near them if they’re having walking difficulties.

Something called freezing can also happen when a person with Parkinson’s is walking. This often happens in doorways, and basically makes it impossible for the person to move. It is like their feet are glued to the ground.
What is Dyskinesia and What Can be Done to Help Stop It?

Dyskinesia is basically abnormal, involuntary movements. It is caused by too much dopamine in your system. Once the effects of your medication start to wear off, you take higher doses and this causes the excess of dopamine.

Some studies say that the drug amantadine may be useful for the management of levodopa-induced dyskinesia, but it is not a long term solution for it.

One simple way that my mom has found to help stop her dyskinesia is to go for a brisk walk. She says that doing any kind of, as she says “purposeful activity” helps make the dyskinesia go away.
Does Parkinson’s Cause Pain in the Limbs and Back Areas?

Yes, Parkinson’s can cause pain in the limbs and back areas. First you should figure out whether there may be other causes for your pain though, such as arthritis. Talk to your doctor.

You often get back pain because of the strain placed on your back from the stooped posture which is common in people with Parkinson’s.

If you do experience pain in your limbs or back area, it will probably appear along with other more typical symptoms of PD, like tremor and slowness.

If your pain does accompany your other PD symptoms, and improves when these are improved by PD medications, then you should talk to your doctor about adjusting the dosage or frequency of your PD medications. The treatment for pain caused by PD is most often the same as the treatment for motor symptoms of PD.

Another reason you might experience pain is because of leg cramping. Pain caused by cramping can be a sign of a recent increase in activity, (and in this case the pain usually goes away after the exercise becomes more routine).

Pain can also occur as your medications are wearing off.

If the typical anti-cramping suggestions like exercise, massage, the application of heat, etc., don’t relieve the cramping well enough, you might need to try anti-cramping medications. Talk to your doctor about it and he or she can help you figure out what might work for you the best.
Does Parkinson’s Affect Vision?

Yes, Parkinson’s can affect your vision. Problems with vision can occur as a symptom of the disease and/or as a side effect of medications.

You might find that your "upgaze", or ability to look up at things like signs that are above you, is not very good. Some people also have difficulties in adjusting their eyes to changing light levels and find it hard to see at night.

Blurry vision can be a side effect of anticholinergics (drugs used to control tremor). It can also be caused by the lack of blinking that occurs as a side effect of the disease.
What is Myerson’s Sign?

If you were to tap on the glabella (the area between your eyebrows, just above your nose) of someone who does not have Parkinson’s, at first they would start blinking, but then they would stop even if you kept tapping.

Sometimes in Parkinson’s patients, if you were to tap on this same spot, they would just keep on blinking, and not be able to stop. This is what’s called “Myerson’s Sign”.
Dysarthria means difficulty speaking. About half of all people with Parkinson's have problems with speech which can include difficulties with volume, phrasing, rhythm, and clarity.

Here are some of the typical problems that people with PD may have with speech:

- **slurring words** often
- **a soft and quiet voice** (so quiet you sometimes can't even hear it)
- **sudden pauses or long breaks** in the middle of a sentence while trying to remember a word or thought
- **a dull tone of voice**, with no energy or rhythm
- **a hurried way of speaking** that sometimes seems like a stutter
- **slow speech patterns**, with repeated sounds and stops

Ask your doctor to see what's best for you, but being that this can be a severely limiting symptom of Parkinson's disease, seeing a speech pathologist may be your best option.
Is There a Skin Condition Associated with Parkinson’s?

If you have Parkinson's disease, it is common for the skin on your face to become very oily, especially on the forehead and at the sides of the nose (this is known as Seborrhea). The scalp may become oily too, resulting in dandruff. In other cases, the skin can become very dry.

These problems are also the result of an autonomic nervous system that’s not working properly. Standard treatments for skin problems help. Sweating a lot is another common symptom, and is usually controllable with medications used for Parkinson's disease.

There is also an odd skin condition (called "livedo reticularis") that is a side effect of the drug Symmetrel (variety of amantadine used for treating dyskinesia).

The signs of this condition are purple blotches on your thighs and forearms, and swelling in your feet. These markings sometimes stay on your body even after you stop taking the medication that caused it.
Is Constipation Caused by Parkinson’s or the Medications You Take for Parkinson’s?

Constipation is a common complaint for people with PD. It is a symptom of the disease but can be worsened by medications.

Many factors other than medications can contribute to constipation. Stress, depression, poor eating habits, lack of exercise, and not drinking enough fluids can all take their toll on your body.

Instead of simply trying to manage this problem, you should also try to prevent it.

Here are a few things that might help:

- **Increase your daily fluid intake**, especially in hot weather. Try drinking at least six cups of liquid should be drunk daily.

- Older people may not be able to tolerate large amounts of raw fruit and vegetables, but can usually manage dried fruits, hot prune juice, canned fruits, and soft cooked vegetables, all of which may help.

- Adding a **high-fiber cereal** to your diet is important, but it should be started slowly and in small amounts. Large amounts can cause stomach cramps and excess gas, particularly in people who cannot exercise.

- **Exercising regularly** is very important.

- **Stool softeners, bulk laxatives, and bowel stimulants** are the main kinds of laxatives available over-the-counter. If changing your diet doesn’t work, you can try any one of these.
TREATMENT AND MEDICATION

How do you Treat Parkinson’s?

In order to treat Parkinson's you will need access to most, if not all of the following people:

- **neurologist** (your doctor will refer you to one who will decide on your treatment plan)

- **occupational and/or physical therapist** (if you need to relearn how to dress, shower, eat and perform other everyday tasks smoothly)

- **massage therapist**

- **counsellor** (to help you adjust to your diagnosis and the changes it means for your lifestyle)

- **social worker**

- **speech therapist** (if you need help with communication)

- **registered dietician**

Generally speaking, the treatment for Parkinson's disease is designed to:

- Maintain overall quality of life
- Improve mobility and function
- Reduce rigidity
- Reduce tremor
- Reverse slowed movements
- Improve posture, gait, balance, speech, and writing skills
- Maintain mental sharpness

Most people with Parkinson’s disease can be treated using prescribed medications. Check out question #58 “What are the latest drug treatments for Parkinson’s?” to find out what kind of drugs your doctor might prescribe for you.

If you don’t react well to medications, or if the medications stop working, you might be advised to have surgery.
Depending upon your needs, medical history, health, and symptoms, one of the following procedures may be considered:

- Deep brain stimulation
- Pallidotomy
- Thalamotomy
- Gamma knife

These procedures are all explained in the answer to question #78 “Is there an operation for people with PD which can improve their quality of life?”

There are many other procedures being researched. Questions #80 “What is fetal cell transplantation?” and #81 “How can stem cells help someone with PD?” talk about some of the most recent developments in treating PD.

Alternative therapy may also be used, see answer to question #74 "What alternative treatments are available for Parkinson’s?".
What Medications Do You Start With?

Your doctor will decide which medications and proper dosages are best for you. He or she will probably monitor you closely for the first while to see if the medications and dosages are working right for you.

In my mom’s case, after she was diagnosed she started on the two main drugs used to treat Parkinson’s; Sinemet (levodopa-carbidopa) and Selegilene (also know as Deprenyl).

The Sinemet was prescribed to help keep the dopamine levels in her brain from falling too much and the Selegilene was prescribed to help slow the progression of the disease, and help the Sinemet work more effectively.

Now, sixteen years later, Mom is on a very similar treatment plan as the one she was on when she was diagnosed. She now takes the Controlled-Release (CR) version of Sinemet and takes the drug Mirapex.

She has also had to increase the dosages of these meds over the years, as her body over time has become used to them and requires more to do the same job.
How Can a Person With PD Get the Most Out of Their Medications?

Here are a few things you might like to try to increase the effectiveness of your medications:

• Take the medication as prescribed by your doctor. Make sure you understand the expected benefit and potential early side effects of a drug before you leave the doctor's office. Remember that he (or she) probably has more clinical experience in treating people with Parkinson's disease than anyone else who is likely to give you advice.

• All side effects of antiparkinson drugs are reversible by lowering or stopping the dosage.

• Do not increase or suddenly stop any of your drugs without checking it out with your doctor first.

• Take medications with food as taking them on an empty stomach often leads to increased side effects. Note: some meds need to be taken on an empty stomach to get the most benefits from them; check with your doctor first.

• Another tip Mom had was to avoid eating large amounts of protein at any time. She has found that eating too much protein really reduces the effectiveness of her meds.
How Do You Know If You Are Getting the Most Out of Your Medications? (How much “off” time is reasonable?)

Though you may not always be able to achieve it, you should be aiming for as little “off” or “down” time as possible (i.e. time when you are basically having stay put in one place for a period of time because your medications have worn off).

Some people with Parkinson’s will find that after they take their meds there is a period of time before they kick in. This is true for my mom. She usually expects to have to wait up to 45 minutes (usually less than this) after she takes her medications for them to start working and her to have “on” time (or in her words, for her to “have wheels”).

Her way of telling whether or not she is getting the most out of her meds is to see how much time each day she spends in “off” mode. For her, if she has to wait more than an hour for her meds to kick in, or has more than four hours in one day in this down time, she knows she needs to talk to her doctor about possibly changing the dosage and/or timing of her medications.

One thing that has helped the effectiveness of her meds is being able to take them on an empty stomach. This wasn’t possible for her in the beginning because she got nauseous all the time (a common side effect of the drugs) but after her body got used to it, she was able to switch the timing of taking her meds.

Mom says the good thing about having less food in your stomach is that the meds work better but sometimes it can seem they are working too well because you get more of the side effect dyskinesia. You might have to experiment a bit with the timing of your meals and meds in order to find what’s best for you.

One tip Mom had for helping your medications work better is to avoid sitting in one place for long lengths of time. If you have to sit anywhere for over an hour at a time, try to get up every hour and do some stretching or moving around to keep your muscles from stiffening up too much.

Mom says regardless of when she last took her medications, sitting in one spot for a long time can really make it hard to get moving again.
What Are the Latest Drug Treatments for Parkinson’s?

There have been some amazing changes over the past decade in treating Parkinson’s disease. Researchers have made new medications and are able to understand how to use them better than before. This has really helped to improve the quality of life in people with the disease.

There are two general ways to treat Parkinson’s disease with medication. The first is to try and slow the loss of dopamine in the brain and the second is to try and improve the symptoms of Parkinson’s disease by other means.

Most people with Parkinson’s disease can be treated well enough with medications that help get rid of their symptoms.

Remember that you have the right and responsibility to know what medications are being prescribed for you. The more you know about your medications and how they work, the easier it will be for you to control your symptoms.

The following is a list of drugs that may be prescribed to you by your doctor. Don’t be afraid to talk with him or her about your treatment plan. You are in this disease together.

Five classes of drugs used to treat symptoms of PD:

Dopaminergic Agents:

• Levodopa

Levodopa (also called L-dopa) is converted in the brain into dopamine, the same chemical created by substantia nigra cells and used to control movement.

Levodopa was introduced as a PD therapy in the 1960s, and remains the most effective therapy for motor symptoms. It lessens and helps to control all the major motor symptoms of PD, including bradykinesia, which is generally the most disabiling part of the disease.

• Sinemet (levodopa/carbidopa)

Sinemet is made up of levodopa and another drug called carbidopa. Levodopa enters the brain and is converted to dopamine while carbidopa prevents or lessens many of the side effects of levodopa, such as nausea, vomiting, and occasional heart rhythm disturbances.
There are two forms of Sinemet, controlled-release or immediate-release Sinemet. **Controlled-release (CR) Sinemet and immediate-release Sinemet are equally effective in treating the symptoms of Parkinson's disease, but some people prefer the controlled release version. Ask your doctor which approach is best for you.**

Even though Sinemet is the most effective medication and has the least short-term side effects, there is also a **high risk of long-term side effects**, such as involuntary movements (dyskinesia).

If you use levodopa on a long-term basis, you may experience **restlessness, confusion, or abnormal movements**.

Changes in the **amount or timing of the dose** will usually prevent these side effects, but most experts now recommend alternatives to Sinemet, like **dopamine agonists**, and use Sinemet only when the alternatives fail to work the way you’d like them to.

- **Dopamine Agonists**
  
  Dopamine Agonists are drugs that **imitate** what levodopa does in the brain.

  Even though they are not quite as effective as levodopa, they really help the symptoms and **delay the start of mobility problems**.

  **There are a variety of dopamine agonists that are available:**

  - Apomorphine (Apokyn)
  - Bromocriptine (Parlodel)
  - Pergolide (Permax)
  - Pramipexole (Mirapex)
  - Ropinirole (Requip)
  - Cabergoline (Not approved in the US as of late 2004)
  - Lisuride (Not approved in the US as of late 2004)

  **Requip** and **Mirapex** are newer medications, and are **safer and more effective** than the older drugs, Parlodel and Permax.

  Newer dopamine agonists like **Requip** are often the **first choice of treatment** for Parkinson’s disease because they don’t have the same risks of long-term problems as levodopa therapy does.
**COMT Inhibitors:**
- Entacapone (Comtan)
- Tolcapone (Tasmar)

COMT inhibitors help make a dose of levodopa work longer by preventing it from breaking down.

Both Entacapone (Comtan) and Tolcapone (Tasmar) have been shown to decrease the amount of "off" time (the period of time when PD symptoms are present).

Tolcapone is more effective than Entacapone, reducing off time in clinical trials by 2-3 hours, versus 1 to 2 hours for entacapone.

By taking these drugs, you are usually able to reduce your levodopa dose by 20%-25%.

**MAO-B Inhibitors:**
- Rasagiline (Not approved in the US as of late 2004)
- Selegiline (Eldepryl/Deprenyl)
- Rasagiline (still being tested)

Selegiline, Eldepryl and Deprenyl are all names for the same drug. They work by helping to conserve the amount of dopamine available by preventing the dopamine from being destroyed.

Though not all researchers have been able to agree on this one, there is some evidence that this drug may slow the progression of Parkinson's, especially early on in the disease.

This drug is well-tolerated by most people, so many experts recommend using it despite the controversies. Common side effects are nausea and vomiting.

**Anticholinergics:**
- Trihexyphenidyl (Artane)
- Benztropine
- Ethopropazine
Anticholinergics have a **limited role** in PD. They are mostly effective against **tremor and rigidity**, and their side effects may be greater, especially in older people.

**Amantadine (Symmetrel):**

Amantadine (Symmetrel) helps **reduce the motor symptoms** of PD (by increasing the amount of dopamine available for use in the brain) somewhat, but helps **reduce dyskinesia** even more.

Symmetrel may be helpful in treating people with mild Parkinson's disease, but it often causes significant side-effects including confusion and memory problems.
Is it Safe to Take Other Drugs While on PD Medication?

Most drugs are safe to take with antiparkinson drugs. There are a few drugs that need special attention though:

- One group of drugs known as dopamine antagonists (for example haloperidol (Haldol), rispiridone (Risperdal) and metoclopromide (Maxeran), prochlorperazine (Stemetil), chlorpromazine (Largacty and Zyprexa) should be avoided because they can worsen the symptoms of Parkinson’s by blocking the action of dopamine in the brain.

They are generally prescribed for nausea or psychiatric conditions. Check with your doctor or pharmacist if you are not sure whether you have been prescribed one of these.

- Demerol (often used to control postoperative pain) can cause confusion and hallucinations in people with PD and should be avoided.

- Always remember to talk to your doctor about any concerns you may have about drug interactions

Tips on Avoiding Interactions With Other Medications:

- Read all of your medication labels carefully.

- Make all health care providers aware of all the medications you are using.

- Know your drug and food allergies.

- Make a list of your medications and dosages. Eye drops, skin lotions and vitamins are considered medications and should be included on your list. Keep this with you and update when you need to.

- Review possible drug side effects. Most reactions will happen when a new drug is started, but not always. Some reactions may be delayed or might happen when a new medication is added.

- Use one pharmacy if possible. Try to fill all your prescriptions at the same pharmacy, so the pharmacist can monitor for interactions and provide proper dosing and refills.
What Are the Side Effects of Sinemet?

Sinemet is a Parkinson’s disease drug that is a combination of levodopa and carbidopa. This combination reduces the harmful side effects caused by using levodopa over a long period of time.

Most people taking Sinemet experience side effects, but these may go away during treatment as your body adjusts to the medicine.

Here are some possible side effects that may occur and usually do not need medical attention: (yes, this list is long but remember that you won't have all these side effects)

- **occasional involuntary movements** (may include chewing, gnawing, twisting, tongue or mouth movements, head bobbing, or movements of the feet, hands, or shoulder. These may respond to a reduction in the dose.)

- **loss of appetite**

- **darker colored urine, saliva and sweat** (urine may at first be reddish, then turn to nearly black after being exposed to air. Some bathroom cleaning products will produce a similar effect when in contact with urine containing this medicine. This is to be expected while taking this medicine)

- **dry mouth**

- **upset stomach** (other medications such as Permax can cause this as well)

- **headache**

- **dizziness** (you may get dizzy when you stand up due to the drop in blood pressure; get up slowly over several minutes from sitting or lying position and be careful climbing stairs)

- **abdominal pain**

- **change in taste** (may cause a bitter taste, or a burning sensation on your tongue)

- **increased sweating**

- **lightheaded** (avoid driving, doing other tasks or activities where you need to be alert until you see how this medicine affects you)
• passing gas
• trouble sleeping (including nightmares)
• constipation
• diarrhea
• hiccups

**NOTE:** If you find these side effects to continue or become too much trouble, **talk to your doctor.**

Other side effects not listed above may also occur in some people. If you notice any other effects, check with your doctor.

**Here are some reasons not to take this medicine:**

• If you have an **allergy to carbidopa, levodopa**, or any other part of the medicine.

• If you have any of the following conditions: **Narrow-angle glaucoma, history of melanoma, unexplained skin spots.**

• If you have taken a **monoamine oxidase inhibitor** (phenelzine, tranylcypromine, isocarboxazid) in the last 14 days.
If One **_Goes Off Sinemet_**, How Will One Be Affected?

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Do not stop taking Sinemet (a combination of **_carbidopa_** and **_levodopa_**) suddenly. It may take several weeks before you feel the full effects of this medicine. Stopping suddenly could make your condition **_much worse_**.

You should not suddenly stop taking this medicine unless your doctor tells you otherwise.
How Can Side Effects of PD Drugs be Managed?
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One of the major side effects of the antiparkinson medication Sinemet is nausea. Nausea is much less common with controlled-release Sinemet, which is absorbed more slowly than the regular Sinemet.

Dopamine agonists can cause nausea even in people who did not experience it with either kind of Sinemet. Building up your dose very slowly can help, even though you may be impatient to feel the improvement in your PD symptoms.

In Canada and other parts of the world there is a drug called domperidone (Motilium) which is used to prevent the nausea caused by antiparkinson drugs.

Some ways to control or relieve nausea are:

- **Drink clear or ice-cold drinks.** Drinks containing sugar may calm the stomach better than other liquids.

- **Avoid orange and grapefruit juices because these are too acidic and may worsen nausea.**

- **Drink your drinks slowly.**

- **Drink liquids between meals instead of during them.**

- **Eat light, bland foods** (such as saltine crackers or plain bread).

- **Avoid fried, greasy or sweet food.**

- **Eat slowly.**

- **Eat smaller, more frequent meals throughout the day.**

- **Don’t mix hot and cold foods.**

- **Eat foods that are cold or at room temperature to avoid getting nauseated from the smell of hot or warm foods.**

- **Rest after eating, keeping your head elevated. Activity may make your nausea worse and may lead to vomiting.**

- **Avoid brushing your teeth after eating.**
• If you feel nauseated when you wake up in the morning, eat some crackers before getting out of bed or eat a high protein snack before going to bed (lean meat or cheese).

• Try to eat when you feel less nauseated.

  *If these techniques don’t seem to help your queasy stomach, ask your doctor for more ideas.

Another major side effect of antiparkinson drugs is dizziness. Dizziness occurs due to the fact that the drugs can lower your blood pressure. It may occur in the early stages of treatment, but it usually resolves over time. If it doesn’t, talk to your doctor.
How Can You Prevent “Freezing”?  
---------------------------------------------

- **count your steps** as you walk (try marching or “left, right, left, right...

- one great thing Mom discovered was **music** - try putting on a cd with some fast-paced music on to keep you going - even better, carry an **MP3 player** around with your favourite tunes on it so you can “plug in” anytime you need a lift *(read more about this in the Bonus questions)*

Let’s face it, you may not always be able to prevent freezing. Here are some ways to help you out if you do:

- **rock in place from foot to foot to get moving again**

- **have someone place their foot in front of you, or visualize something you need to step over**

- **try covering your eyes- this can “trick” your brain and allow you to walk straight ahead with no problems**

- **you may choose to simply wait after all, the freezing will pass**

- **if you are in a hurry you can slowly sink to your knees and crawl but obviously this is only practical at home**

- **walk very carefully backwards or sideways (this works very well for my mom)**
What Can Be Done to Help Increase Mobility in People With PD?

The first step is to ask your doctor for an evaluation by a physical therapist. The therapist will make up a detailed evaluation with recommendations for your treatment.

Physical therapy cannot stop the disease, but it may help slow down the loss of mobility that comes with PD.

Physical therapists teach people with PD and their caregivers exercises to increase mobility and techniques to deal with specific trouble areas such as freezing, getting in and out of bed, getting up from a sitting position, etc.

Physical therapy can help people who are in various stages of Parkinson's - from the recently diagnosed to those who have had Parkinson's for many years.

My mom has found physical therapy to be very helpful. She goes once a week. She also tries to get outside everyday to do some form of exercise. This is to help her keep her mobility for as long as possible (remember the statement; "use it or lose it!").

Getting outside also helps prevent depression which can often make you lose your motivation to do any exercise.

Something else that Mom has found helpful in increasing her mobility is massage therapy. She loves this and goes once a week (she’d go more if she could afford it).
How Can You Get Rid of the Tremors?

Tremors can be a real pain in the butt and though there's no way to prevent them, you can take steps to reduce them.

Stay away from stimulants like caffeine and amphetamines. Although small amounts of alcohol may reduce tremor, try not to drink large amounts of alcohol because it can make the tremors worse.

People with Parkinson's disease have had success with levodopa or other antiparkinson drugs.

There is also a surgical procedure called Deep brain stimulation (DBS) that can be used to treat tremors in people with Parkinson’s (it also helps reduce rigidity, stiffness, slowed movement, and walking problems). You can read more about this procedure in the answer to question #78 “Is there an operation for people with PD which can improve their quality of life?”.

At this point, the procedure is used only for people who have symptoms that can’t be controlled well enough with medications.
What is the Patch and Will It Help With Tremors?

Researchers are developing a new way to deliver drugs for Parkinson’s to the brain. The “Parkinson’s Patch” gives a steady, uniform dosage of medication, which reduces the risk of side effects.

Rather than swallowing pills several times a day, people apply patches to their chest just once a day.

Doctors hope to learn whether this new delivery system can improve the motor symptoms of Parkinson’s disease in a consistent, smooth fashion.

They hope the continuous delivery of drugs made possible by the patch technology will more closely imitate the brain’s own actions.
Can Nicotine Help with Parkinson’s?

It is known that most people with Parkinson’s never (or only for a very short period) smoked cigarettes. This fact originally led researchers to the idea that something in nicotine helps to prevent PD. So far, however, no researcher has been able to figure out what in nicotine **MAY** have some **protective aspect**.

Researchers are now looking at ways of using nicotine to make some of the symptoms of PD not as bad.

In a few small studies, the people studied found **some benefit** to their PD symptoms while on a nicotine patch.

It is still **too soon to tell** whether or not nicotine is of any real benefit to people with PD. It will have to undergo many further studies before doctors can recommend this as a treatment for PD.

Researchers are also trying to make sure that these nicotine patches will not cause addiction to nicotine - similar to that seen in people who smoke.
How Can You Prevent Drooling?

People with PD don’t have more saliva than people without PD, they just swallow less often. As a result of this, there ends up being an excess amount of saliva which then often results in drooling.

There may not be a way to get rid of this problem entirely, but here are a few suggestions which may help prevent drooling and possibly some embarrassing moments:

- suck on hard candy, lozenges or gum to control excess saliva (if you are not at risk of choking)
- use a straw when drinking to strengthen the muscles of the lips, mouth and throat
- try to keep your head up and your posture straight because stooping encourages drooling
- swallow first before you talk
- when you’re not eating or talking, keep your mouth closed and your lips tight together (people with PD tend to let their jaw drop open which encourages drooling)
- breathe through your nose (this will help keep your mouth closed which will then help keep the saliva in your mouth)
- remind yourself to swallow to help prevent saliva build up
- you may try rubbing a strong smelling lip balm over your mouth to remind you to swallow
- try putting one or two drops of atropine eye drops (0.5%) under your tongue to reduce the amount of saliva- this works for some people but you should check with your doctor first
How Can You Help Dry Mouth?

- if you are not at risk of choking, suck on hard candies or chew gum to help keep your mouth wet/lubricated
- try not to eat too many dry foods like peanut butter, crackers and chips because they stick to the throat and dry out the mouth
- eat sour candy or fruit ice to help increase saliva and moisten your mouth
- add sauces to foods to make them softer and moister (ex. gravy, broth, sauce, or melted butter)
- take a drink after each bite of food to moisten your mouth and to help you swallow
- dunk or moisten breads, toast, cookies, or crackers in milk, tea, or coffee to soften them
- breath through your nose instead of your mouth
- keep hydrated, drinking lots of water (8 glasses a day will help) *Note: some people with Parkinson's disease who also have heart problems may need to limit their fluids, so be sure to follow your doctor's guidelines.
- if you smoke, try to cut down or even quit because this can be a major factor in drying out your mouth and causing gum problems
- try taking a cotton swab dipped in olive oil and rubbing it on the inside of your mouth and throat with it every hour or so
- don't use a commercial mouthwash because they often contain alcohol that can dry your mouth. Ask your doctor or dentist about alternative mouthwash products.
- limit caffeine (contained in coffee, tea, cola, and chocolate) as it may interfere with some of your medications and may actually make you more thirsty
- there are some artificial saliva products out there if you need them so you should ask your doctor about this
- you may need to make changes in your medications
What Are the Different Speech Therapy Techniques that Can be Used by a Person with Parkinson’s?

The following are some techniques to help with speech:

1. Pick an area that is quieter. It can be tiring to try to "talk over" the television or radio.

2. Talk slowly.

3. Be sure the person you are talking to can see your face. Look at the person while you are talking. A well-lit room can help face-to-face conversation, increasing understanding.

4. Use short phrases. Say one or two words or syllables per breath.

5. Over-articulate your speech by making your vowels longer and exaggerating the consonants.

6. Choose a comfortable posture and position that give you support during long and stressful conversations.

7. Be aware that exercises intended to strengthen weakening muscles may be counter-productive. Always ask your speech-language pathologist which exercises are right for you.

8. Plan periods of rest for your voice before you’re going to have a big conversation or phone call. Know that fatigue really affects your ability to speak. Techniques that work in the morning may not work later in the day.

9. If you are soft spoken and your voice has become low, you might want to use an amplifier.

10. If you are on a respirator (with fully inflated cuffs), an electrolarynx or respiratory tube that provides an alternative air source may be used.

11. If some people have difficulty understanding you, the following ideas may help:

   - If you are able to write without too much trouble, always carry a paper and pen as a backup so you can write down what you are trying to say.

   - If writing is hard, use an alphabet board to point or scan to the first letter of the words that are spoken.
• Spell words out loud or on an alphabet board if they are not understood.

• Establish the topic before you speak.

• Use telegraphic speech. Leave out words that you don’t need to communicate the meaning of what you’re trying to say.

• Use expressions and gestures to communicate.

Here's a sample of the devices that are available to help people with Parkinson's disease communicate more clearly:

• Palatal lift. A dental apparatus that is similar to a retainer. It lifts the soft palate and stops air from escaping out of the nose during speech.

• Amplification. A personal amplifier can be used to increase the volume of your voice. This also decreases voice fatigue.

• TTY telephone relay system. A telephone that has a keyboard so speech can be typed and read by a relay operator to the listener. Either the whole message can be typed or just the words that are not understood can be typed.

• Low technology devices. Notebooks and language boards can be used as alternative communication techniques.

• High technology electronic speech enhancers, communication devices. Computers with voice synthesizers and dedicated communication devices are available.

How to communicate in an emergency:

• Use an intercom system or baby monitor to alert others that there is an emergency.

• Use bells or buzzers if you are not able to speak. Use "codes" that signify urgency. For example, ringing a bell may mean, "I'd like some company" while an air-horn means there's an emergency.

• Carry a portable phone that is has pre-programmed numbers.

• Pre-program all of your telephones so they can automatically dial the necessary emergency number(s).
• Consider a "Life Call" button if you spend time alone

Your doctor can refer you to a **Speech-language pathologist** who can help you. Speech-language pathologists can help people with Parkinson’s disease maintain as many communication skills as possible. They also teach techniques that conserve energy, including non-verbal communication skills.
**What Can be Done to Help with Swallowing Problems?**

Many people with Parkinson’s disease have difficulty swallowing because they lose control of their mouth and throat muscles. Because of this, chewing and managing solid foods can be hard.

If you are having trouble swallowing, contact your doctor. He or she will recommend a speech pathologist to carefully examine your swallowing abilities and evaluate your aspiration risk.

Here are some suggestions to make chewing and swallowing easier:

- sit upright at a 90-degree angle
- tilt your head slightly forward
- remain sitting or standing up for 15-20 minutes after eating a meal
- keep the distractions to a minimum in the area where you eat
- stay focused on the tasks of eating and drinking
- don’t talk with food in your mouth
- eat slowly
- cut your food into small pieces and chew it thoroughly
- don’t try to eat more than 1/2 teaspoon of your food at a time
- you may need to swallow two or three times per bite or sip
- If food or liquid catches in your throat, cough gently or clear your throat, and swallow again before taking a breath. Repeat if necessary.
- concentrate on swallowing frequently
- drink plenty of fluids
- Periodically suck on popsicles, ice chips, lemon ice or lemon-flavored water to increase saliva, which will increase how often you swallow
- Minimize (or eliminate) foods that require chewing, and eat more soft foods.
• puree your foods in a blender

• If thin liquids cause you to cough, thicken them with a liquid thickener (your speech pathologist can recommend one for you.) You can also substitute thin liquids with thicker liquid choices such as nectars for juices and cream soups for plain broths.

• When taking your medications, crush your pills and mix them with applesauce or pudding *Note: some pills such as Sinemet CR should not be crushed because this can affect how the medications work. Ask your pharmacist for his/her recommendations on which pills should not be crushed.
How Can a Person With Parkinson’s Get a More Comfortable Sleep?

Here are some suggestions to help you get a more comfortable sleep.

If you have problems with moving in bed:
- try side rails, a trapeze, ropes or a handle to grip
- use satin sheets or pyjamas
- change to a firmer, lower or higher mattress
- ask a physical therapist as they may also be able to help with bed mobility, and occupational therapists may recommend other techniques

If you have foot and leg sensitivity or trouble turning in bed:
- adapt the bed with a bed hoop, blanket cradle, electric blanket or light down comforter in order to keep the bedcovers off your feet and legs
- talk to your doctor because it could be related to another medical problem

If you have problems with restless legs, painful cramping or abnormal movements:
- talk to your doctor because he or she might change the times or dosages of your medications or order other medications for pain, spasm, cramps or anxiety
- try going through some relaxation techniques or slow, relaxing stretching exercises

If you have problems with frequent urination:
- talk to your doctor or urologist to correct medical problems such as prostate problems, urinary retention or infections
- you could also put a urinal or commode near the bedside
If you are afraid of falling:

- make your home safer by getting rid of scatter rugs and putting in a nightlight
- try using a walker at night if you are able
- don’t get up too quickly or you might become dizzy if you change position too quickly

If you have problems with shortness of breath, heartburn or trouble getting out of bed:

- Raise the head of the bed with blocks or extra pillows.
- Discuss shortness of breath and heartburn with your doctor.
What Can Be Done to Help a Person With PD Get More Sleep?

It is common to have problems getting enough sleep if you have PD. This may be because the part of the brain that is affected by the disease (substantia nigra) is so close to the sleep and arousal centers in the brain stem.

Medications may also sometimes be responsible. Sinemet and Parlodel can cause vivid dreams, hallucinations, leg cramps, abnormal movements and daytime drowsiness. If you don't take a diuretic early enough, you may have to get up a lot during the night to go to the bathroom.

Some tranquilizers and sleep medications commonly used stay in your system a long time and can cause daytime drowsiness that disturbs your evening's sleep.

Some breathing, seizure, high blood pressure or allergy medications can keep you up at night. Sinemet can cause this sometimes as well. Do not forget that over-the-counter pills like decongestants or antihistamines may cause sleep problems too.

Many people forget that food is often at fault. Stay away from stimulants, especially caffeine. Caffeine is found in such things as tea and chocolate as well as coffee. Alcohol may initially make you tired but can ultimately be a stimulant causing you to wake up early in the morning.

If you are having sleep problems, it is important to discuss this with your doctor and give him or her the information to help you. Think about the specifics of your problem and see if you can see a pattern. For example, if you are having painful cramping, when does it occur? When was your last dose of Sinemet before going to bed? Did the problem start after you began a new medication?

A few more tips to help you get more sleep are:

- Don’t nap a lot during the day and try to have activities that keep you busy.

- Avoid using your bedroom for other activities like reading, watching TV or business.

- You can usually manage sleep problems by adjusting the timing of your medications and/or changing your diet.

- Depression can often cause trouble falling asleep. Your doctor may give you an antidepressant that can also work as an anti-Parkinson's and sedative drug.
• You should never take over-the-counter sleep aids without asking your doctor first. He or she can prescribe a short acting sleeping pill that doesn't interact with your PD.

• Try old time remedies like a warm glass of milk, back rubs or expressions of affection... These still work!
What Alternative Treatments are Available for Parkinson’s?

There are several alternative therapies available for treating Parkinson’s. These therapies include acupuncture, massage, yoga, tai chi, herbal and dietary therapies, (including amino acid supplementation, vitamins A, C, E, selenium and zinc therapy, B vitamin supplementation, and calcium and magnesium supplementation) as well as many others.

It’s very important to note that anyone using these therapies along with conventional drugs should check with their doctor to avoid the possibility of bad interactions.

For example, vitamin B₆ (either as a supplement or from foods such as whole grains, bananas, beef, fish, liver, potatoes) can interfere with the action of L-dopa when the drug is taken without carbidopa.

The following are some alternative therapies for Parkinson’s:

- **Exercise**

  Although not necessarily an "alternative therapy," exercises like Tai chi and yoga can lower your stress, help you to be more relaxed, and increase your energy, balance, and flexibility. In general, exercise is a safe, effective and easy way to improve your well-being. Remember to check with your doctor first.

- **Diet**

  By following your doctor’s and dietitian’s daily dietary guidelines, you can look and feel better with your PD. Check out the answers to questions #84 “Is there a special diet that would help?” and #88 “What nutritional supplements help with the treatment of PD?” for more information about vitamin and mineral therapy.

- **Massage**

  Massage can help reduce stress and tension and can loosen up tight muscles. Mom really loves this and goes once a week.

- **Acupuncture**

  This is a procedure where fine needles are inserted at specific points just under the skin to stimulate, disperse and balance the flow or energy and
relieve pain. You may have heard about this but have been afraid to try it. My mom certainly was but when she finally did, she couldn’t believe how good it felt! She said she didn’t feel the needles at all!

- **Positive Attitude**

  Having a positive outlook cannot cure Parkinson's disease, but it can lower your stress and help you feel better.

- **Guided Imagery**

  This is a form of *focused relaxation* that helps create harmony between the mind and body. Guided imagery helps you create calm, peaceful images in your mind, kind of like a "mental escape". It can help people overcome stress, anger, pain, depression, and insomnia.

  Because stress and depression can worsen the symptoms of Parkinson’s disease, using guided imagery can obviously be very useful to someone with PD.

  First you identify your **self-talk**, that is, what you are saying to yourself about your life, your PD, etc. Then you make **affirmations** to counteract any negative thoughts and emotions.

  **Here are some examples of positive statements you might want to say to yourself:**

  - I am healthy, vital, and strong.
  - Every day in every way I am getting stronger.
  - There is nothing in the world I cannot handle.
  - Let go of things I cannot control.

- **Homeopathy**

  Usually, the dose for the following treatments is 3 to 5 pellets of a 12X to 30C remedy every one to four hours until your symptoms get better.

  - **Argentum nitricum** for ataxia (loss of muscle coordination), trembling, awkwardness, painless paralysis
  - **Causticum** for Parkinson's with restless legs at night
  - **Mercurius vivus** for Parkinson's that is worse at night, especially with panic attacks
  - **Plumbum metallicum** especially with arteriosclerosis
• **Zincum metallicum** for great restlessness, and depression

Alternative therapy can be helpful in some cases, yet some therapies can be **ineffective, costly, and even dangerous**. The best way to evaluate your options is to **become educated**.

Weigh your options and decide whether the **benefits** outweigh the **risks**. If you do decide to try an alternative treatment, make sure your health is protected. **Talk about the therapy with your doctor**. Make sure your doctor knows what therapy you are considering so he or she can discuss possible interactions and/or side effects with your current treatments.

He or she can also provide you with information on other patients who may have tried the same therapy.
What is the Proper Treatment for Ongoing Acute Pain Associated with Parkinson’s?

The symptoms of Parkinson’s disease may cause you to move more slowly. You may also feel tightness, pain, and weakness, especially in the muscles and joints. Physical and occupational therapy may help with these symptoms.

Physical Therapy:

Physical therapy cannot cure Parkinson's disease but it can enable you to compensate for the changes in your body that you get from the disease.

A physical therapist can teach you exercises to strengthen and loosen muscles. Many of these exercises can be performed at home. The goal of physical therapy is to improve your independence and quality of life by improving movement and function and relieving pain.

Physical therapy can help with:

- Balance problems
- Lack of coordination
- Fatigue
- Pain
- Gait
- Immobility
- Weakness

Important note: Some physical therapists may apply diathermy (local heat application produced by high-frequency electrical current) to relieve muscle aches and pains. This could be dangerous to patients who have deep brain stimulators. It is very important that DBS patients inform all their health care professionals of their stimulators so potential complications can be prevented.

Occupational Therapy:

Occupational therapy can be helpful when symptoms of Parkinson's disease are making it hard for you to:

- Being productive at home or work.
- Having fun, such as enjoying pastimes and finding new ways to spend time.
• Taking care of yourself (for example, dressing, bathing, grooming, and eating).

Occupational therapy can help people with Parkinson's disease stay active in daily life. Occupational therapists can help improve your skills, show you different ways of doing things, introduce you to handy equipment and help you perform everyday activities more easily.

An occupational therapist may also recommend making changes to your home or work to promote your independence. If you think you could benefit from occupational therapy, ask your doctor for a referral.

Here's a list of some of the areas Occupational therapists can help with:

• Arm and hand therapy
• Handwriting aids
• Information on modifying your home
• Information on driver evaluations and making modifications to your car
• Cooking and homemaking adaptations
• Eating and dinnerware adaptations
• Ways to make the most of your energy
• Computer modifications
• Workplace or work equipment modifications
• Helping you develop your leisure skills
• Manual or electric wheelchair use
• Bathtub and toilet use
• Dressing and grooming aids
How Can You Help Toe Cramping?

Here’s a problem Mom has pretty frequently. She especially has this problem in the shower but it can happen anywhere.

The solution that she has found to stop the cramping is actually quite simple. She says you need to really concentrate, look down at your toes and tell them to uncramp. It sounds simple yet it really works. Just keep looking at them and focussing and she says they will stop cramping.
What Can Be Done to Help Prevent Panic Attacks?

About 40% of people with Parkinson’s are more anxious than they should be. Anxiety may be a reaction to PD or it may be part of PD, related to a loss of dopamine, norepinephrine, and serotonin nerve cells.

Researchers still haven’t figured out for sure what factors cause anxiety in people with Parkinson’s.

Some studies have shown that Levodopa therapy could possibly cause panic attacks.

Panic attacks are outbursts of anxiety that can be triggered by many things. These attacks can last for periods of time between a few seconds and a few hours.

If you are having a panic attack, you may feel things like shortness of breath, clammy sweat, irregular heartbeat, dizziness, faintness, and feelings of unreality.

A panic attack may be triggered by many things such as a fear of dying, fear of going insane, breathlessness, sweating, chest discomfort, choking, and dizziness.

A panic attack can sometimes look like a heart attack, and, sometimes, you will have to make sure that it’s not a heart attack. In many people the panic attacks happen only in certain situations and may be linked to immobility.

For instance, in people who have "on/off" episodes, panic attacks almost always occur during the "off" period. When panic attacks occur during the "off" period, their intensity parallels the difference in mobility between the "off" and the "on."

In these people treatment should be directed toward decreasing the fluctuations.

In some people, panic attacks may happen throughout the day, regardless of whether they are "on" or "off." Serotonin re-uptake inhibitors, a type of antidepressant, are also useful in treating panic attacks.

A lot of times, anxiety is seen together with depression. Studies have shown that possibly as much as 92% of Parkinson's people who have had an anxiety disorder have also had a depressive disorder.
It would make sense then, that treating the depression could play an important part in treating the anxiety.

There are quite a lot of available treatments for people who suffer anxiety. Unfortunately, very little research has been done to figure out the best course of treatment for those who have panic attacks.

Here’s a list of some drugs that are available for treatment of anxiety: (Yikes! Some of these drug names are pretty long. Your doctor will know more about them. Ask him or her about which drugs would be best for you)

- Tricyclic Antidepressants
- Selective serotonin reuptake inhibitors
- Nonselective monoamine oxidase inhibitors (Risk of hypertension when taken with levodopa)
- Benzodiazepines (Can worsen Parkinsonian symptoms when taking high dosages)
- Busiprone
Is There An Operation for People with PD Which Can Improve their Quality of Life?

There are a few operations that can help improve the quality of life in someone with Parkinsons. Not all operations are for everybody, and it's best to read up on them and discuss them with your doctor to find out if you might be a good candidate for any one of them.

1a. Deep Brain Stimulation (DBS):

Deep brain stimulation is a way to inactivate the parts of the brain that cause Parkinson’s, without purposefully destroying the brain.

In deep brain stimulation, electrodes are placed in the part of the brain called the globus pallidus. The electrodes are connected by wires to a type of pacemaker device (called an impulse generator, or IPG) implanted under the skin of the chest, below the collarbone.

Once it’s activated, the device sends continuous electrical pulses to the target areas in the brain, blocking the impulses that cause tremors.

This has the same effect as thalamotomy or pallidotomy surgeries without actually destroying parts of the brain.

The IPG can easily be programmed using a computer that sends radio signals to the device. Patients are given special magnets so they can externally turn the IPG on or off.

Depending on use, the stimulators may last three to five years. Replacing the IPG is a pretty simple procedure as well.

DBS has been successful in treating people of different ages. However, each person has to be assessed individually to see if they have the stamina and overall health before considering surgery.

Surgery is not recommended if the medications you are taking are still helping the symptoms of your PD. However, surgery should be considered for people who do not achieve satisfactory control with medications. Talk to your doctor to see if DBS is right for you.
1b. Subthalamic Nucleus Deep Brain Stimulation:

Subthalamic Nucleus Stimulation is a new form of the original DBS technique.

Subthalamic nucleus DBS has been recognized as the most effective surgical treatment for Parkinson's disease because it treats not only the tremors, but also the rigidity, slowness of movement, stiffness, and problems with walking and balance.

People who have this surgery often experience a great reduction in their dyskinesia mostly because they are able to reduce their medications following the surgery.

In addition to this, the surgery to place the stimulator in the subthalamic nucleus is generally easier than surgeries for the thalamus or globus pallidus.

Advantages of Deep Brain Stimulation:

- First, it does not require purposeful destruction of any part of the brain and therefore, has fewer complications than thalamotomy and pallidotomy.

- In addition, the electrical stimulation is adjustable and can be changed as the person's disease changes or his or her response to medications change. No further surgery is necessary to make the adjustments.

- Another significant advantage of deep brain stimulation relates to future treatments. Destructive surgery, like thalamotomy or pallidotomy, may reduce the persons' potential to benefit from future therapies.

For example, future brain cell transplantation may be of great help to people with Parkinson's disease. There is concern that a pallidotomy or thalamotomy may prevent patients from benefiting from brain cell transplantation. This would not be the case with deep brain stimulation, as the stimulator could be turned off.

- Deep brain stimulation is a relatively safe procedure.

- The procedure can treat all the major symptoms of Parkinson's disease.

- Daily living tasks and quality of life are also improved.

- With subthalamic nucleus stimulation, medications can usually be reduced.
The stimulator can also be turned off at any time if deep brain stimulation is causing excessive side effects.

The vast majority of people (over 70%) experience a significant improvement of all their symptoms related to Parkinson’s disease. Most people are able to significantly reduce their medications.

Most people experience little discomfort during the procedure.

**Possible Disadvantages of Deep Brain Stimulation:**

- Increased risk of infection. Implanting any foreign object in your body carries that risk.

- Additional surgery may be needed if the equipment stops working or for battery replacement.

- It will take time to adjust your medications afterwards.

- As with any surgical procedure, there are risks. There is a 2%-3% risk of a serious and permanent complication such as paralysis, changes in thinking, memory and personality, seizures, and infection. Talk to your doctor to see if these risks apply to you.

- DBS of the globus pallidus seems to be somewhat less effective for problems with walking and balance than does Subthalamic DBS.

- Some devices, like theft detectors and screening devices (like those found in airports, department stores and public libraries) can cause your neurotransmitter to switch on or off.

  Usually, this only causes an uncomfortable sensation. However, your symptoms could get worse suddenly. Always carry the identification card given to you. With this, you may request assistance to bypass those devices.

2. **Pallidotomy:**

It is thought that the part of the brain called the globus pallidus becomes overactive in Parkinson’s disease. This overactivity acts like a brake and slows or diminishes bodily movement.
Pallidotomy surgery permanently destroys the overactive globus pallidus to lessen the symptoms of Parkinson’s disease. This treatment can eliminate rigidity and significantly reduce tremor, bradykinesia, and balance problems.

Pallidotomy can also help the medications work better in people with an advanced form of Parkinson’s disease.

3. Thalamotomy:

It is thought that the abnormal brain activity that causes tremor is processed through the thalamus. Thalamotomy destroys part of the thalamus to block the abnormal brain activity from reaching the muscles and causing tremor.

Because thalamotomy is used only to control tremors, it is not generally recommended as a treatment for Parkinson’s disease.

Although thalamotomy and pallidotomy surgeries are still done today, they are done less frequently because of the risk of serious side effects and the availability of deep brain stimulation, which is safer and has fewer complications.

4. Gamma Knife:

The gamma knife is a machine that shoots out hundreds of powerful, highly focused gamma radiation beams. The gamma knife allows for a more precise and concentrated treatment than do other radiation treatment options.

This helps the doctors target the diseased area of the brain while sparing the healthy areas surrounding it.

Even though it is not as effective as deep brain stimulation, gamma knife does offer another treatment option for some who may not be able to undergo deep brain stimulation surgery.

For example, some people taking anti-coagulant medicines (blood-thinners) can’t go without their medicine even for a short period of time. For these people, a non-invasive surgical approach, like gamma knife surgery, may be beneficial.

Gamma knife treatment is considered only when a person is not able to get relief from medication and when deep brain stimulation, which is a more effective therapy, is not appropriate.

There are many important issues to be addressed when considering gamma knife treatment. You should talk to your doctor about these before considering this surgery.
Patients who undergo the gamma knife treatment experience very little, if any, discomfort and serious side effects are rare. Gamma knife treatment usually is performed on an outpatient basis.

The benefits of gamma knife treatment occur over time, usually several months to several years, depending on the person's medical condition.

Gamma knife treatment has up to a 70%-90% success rate, which depends on the patient.

As with all surgical procedures, there is a small risk of complications. Make sure you talk to your doctor about these risks when considering gamma knife treatment.

Gamma knife treatment is not considered experimental. Many insurance carriers provide coverage for this procedure.
Are There Any Developments Leading to Better Treatment for Parkinson’s?

Because researchers’ understanding of how the brain works has greatly increased in recent years, many believe that a cure for Parkinson’s may be just around the corner.

There is research being done on something called embryonic stem cells. This is pretty controversial research and involves stem cells from embryos that are a few days old. Most of these embryos result from in vitro fertilization efforts.

Stem cells are the parent cells of all tissues in the body. This means they can turn into any type of cell. The hope is that they will eventually be able to make these cells into specific types of cells, like dopamine-producing neurons, that can be used to treat Parkinson’s disease.

There is also hope that adult stem cells, which are harvested from bone marrow, might be able to work the same way as embryonic stem cells.

There are fewer ethical questions about this kind of research, but some researchers believe that adult stem cells may be more difficult to work with than those from embryos.

Either way, most all researchers believe that working on all forms of stem cells is important for the continuation of their work.

Some researchers are looking at the possible role of genetic and environmental factors in causing Parkinson’s. Making progress in discovering what causes Parkinson’s will open a whole new world of research into curing the disease.

In the end, the more research that can be done, the sooner a cure or new therapies that can stop the progression of the disease will be discovered.
What Is Fetal Cell Transplantation?

Fetal cell transplantation is a procedure in which fetal cells are implanted into the brains of people with Parkinson’s disease to replace the dopamine-producing cells in the substantia nigra.

Although promising, this area of research is one of the most controversial. Some studies have found that fetal cell transplantation caused an increase in severe involuntary movements (dyskinesia) due to too much dopamine in the brain. There are also moral and ethical objections to the use of fetal cell implants. As a result, other methods of treatment are being explored.

Some of these methods include the use of cells from other mammals, cells from human placentas or umbilical cords, and synthetic microspheres (basically really small sponge-like balls) that deliver dopamine directly to the brain.

Some researchers hope to use cloning techniques on animal fetuses as a source for dopamine-producing nerve cells. Animal and laboratory studies are also using gene therapies and other advanced treatments for transplanting dopamine-producing cells or nerve-protecting cells into the brain.
How Can Stem Cells Help Someone With Parkinson's?

Stem cells are the parent cells of all tissues in the body. This means they can turn into any type of cell. The hope is that they will eventually be able to make these cells into specific types of cells, like dopamine-producing neurons, that can be used to treat Parkinson's disease.

However, there are concerns that patients may have the same risk of increased involuntary movements as those who undergo fetal cell transplantation. And, like fetal cell transplantation, stem cell therapy is surrounded by moral and ethical controversy.
Where Can I Find More Information About the Most Recent Parkinson’s Treatments?

There are definitely many resources out there for information but your best bet is to start with your National Parkinson’s Foundation. They can put you in touch with many resources and can provide books, pamphlets and videos regarding the types of treatment available.

One resource Mom has found to be very handy is a Parkinson’s magazine which she subscribed to through her National PD Foundation and this has very up to date information on the new medications, surgeries, and the current research that is being done.

You can also try looking in your local phone book in the yellow and/or white pages for your local Parkinson’s chapter, as well as the library.

Most of all National Foundations also have websites where you can get more information and contact numbers if you need them.
How Can People With Parkinson’s Make Their Life Better?

To start off, you must not be afraid to ask for help when you think you need it. Yes, it's important to keep your independence as long as possible, but this doesn't mean that you can't have a little help along the way.

A few things Mom said were important for her were first to think long term. Ask yourself "How's this going to work for me down the road?" when thinking about making changes to your house, or even buying new clothing. It's not meant to be depressing, just practical.

Always allow extra time for everything so you won't be rushed. Every time Mom starts to feel rushed, she just about shuts down and then we can't go anywhere.

Also, if getting ready to go out takes up all your energy so that you end up not enjoying your outing, you need to get help in getting ready. Don't try to be too independent, Mom says.

Another thing Mom says is very important is to concentrate on one task at a time. People with PD often tend to jump from one task to another without completing either of them so concentrating could help you get more things done.

Getting discouraged while exercising is something that happens even to the best of us. Try not to get discouraged if your exercise is difficult. Keep trying and don't give up!

Finally, support groups can be very helpful, especially if you have problems talking to your doctor. Connecting with other people who really know what it is like to have Parkinson's disease can be very helpful in coping.

Support groups offer a safe place to talk about your feelings, questions and concerns and to get valuable information. There are many available Parkinson's support groups in the community that are free of charge. Most cities have some form of a support group, and if not, a list of support groups will be available with your National Parkinson's foundation.

Here are some more things you can do to make your life better:

• Be Informed

Learn as much as you can about Parkinson's and its treatment (like reading this book!) Knowledge is power. The more you understand, the more you can discuss with your doctor about your treatment.
• **Socialize**

Isolation can only make you feel worse if you are depressed. It is important to keep up your **social life**, be **involved in activities that you like** and talk things over with your family and friends. Dealing with Parkinson’s is not something you need to do by yourself. Your family and friends will want to be involved in helping you.

• **Do Things You Enjoy**

Doing something **fun** that gets your mind off of Parkinson’s disease can be really helpful in coping with the disease. Go to a movie, listen to some beautiful music, read a good book, garden or help other people.

• **Don’t Be Afraid!**

Don’t be afraid to **ask your doctor** to repeat any instructions or medical terms that you don’t understand or remember. It’s very important that you are able to talk things over with your doctor and not be afraid of what he or she might say. Doctors should **always be available** to answer your questions and address your concerns.

• **Learn to Manage Stress**

This will help you to maintain a positive physical, emotional, and spiritual outlook on life. Being stressed out will only make the situation worse. You should try to organize a daily routine that will reduce stress, with down time for both you and your family members.

• **Exercise**

Exercise has been found to be **very helpful** in minimizing the symptoms of Parkinson’s disease, **increasing mobility and improving quality of life**. It can also be very **emotionally beneficial**. It has been found to help in improve a depressed or anxious mood. Consider trying yoga or Tai Chi, which are relaxing and improve flexibility and balance.

• **Counselling**

You may find it helpful to find a counsellor for yourself and/or your family. Counsellors can be very helpful in dealing with the emotional issues you might be facing with Parkinson’s. If you decide this is for you, your doctor can provide you with a referral. Your doctor might also prescribe antidepressants if you are depressed.
• **Humor and Positive/Hopeful Attitude**

Yes, the disease may be out of your control, but you do have control over your attitude towards it. It is important not to let the disease define who you are. Focus on all the other aspects of your life that are positive. Be thankful for all that you have. Don't beat yourself up about things because it will only make things worse.

• **Humor**

There is definitely some truth to the adage, *"Laughter is the best medicine"*. Being able to laugh a little about your situation helps to keep it in perspective and relieves some of the stress. It can also help in awkward situations because it tends to put people around you at ease, and that often opens up communication.

• **Take Care of Yourself**

Treating Parkinson’s involves more than just medications. **Diet, exercise, support from friends and family**, as well as a **good attitude** all need to be a part of your treatment. Be good to yourself, be patient with yourself and be a friend to yourself. You deserve it!
Is There a Special Diet that Would Help?

Although there is no special diet required for people with Parkinson's disease, eating a well-balanced, nutritious diet is really helpful. With the proper diet, your body works more efficiently, has more energy, and your medications will work properly.

As always, it is important to talk to your doctor and possibly a nutritionist before you make any changes in your diet.

As a general rule, you should eat a variety of foods from each food category, and ask your doctor if you should take a daily vitamin supplement.

Here's a list of some other foods you may want to add to your diet that may help your PD:

**Foods To Eat:**

- **Water!**
  
  Drink at least six to eight 8-ounce glasses of pure water daily to help flush toxins from your body.

- **Glutamine**
  
  Raising glutamine levels (a potent antioxidant and detoxifier) will provide a protective effect.

- **Amino acids**
  
  Low-protein diets may help control tremors. However, D-tyrosine (100 mg per kg per day) increases dopamine turnover.

- **Raw seeds (such as sunflower and pumpkin)**

- **Sprouted grains**

- **Seaweeds**

- **Vegetable juice (especially carrot)**
• Vegetables (especially leafy greens)

• Fruit

Fruits are a good source of antioxidants.

• Fibre

People often eat bran in hopes of helping relieve constipation that results from their PD.

Recent research shows that bran is high in vitamin B-6, which interferes with the effectiveness of levodopa when the drug is taken alone.

Instead of bran, try prune juice, grains, and fiber laxatives. You may also want to include high-fiber foods such as vegetables, cooked dried peas and beans (legumes), whole-grain foods, cereals, pasta, rice, and fresh fruit in your diet.

• Spelt (made as congee)

Spelt is an ancient grain that is a nutritious and flavorful relative of wheat. It has been used in the treatment of many disorders, including Parkinson's.

• Fava beans

Also called broad beans, are a natural source of levodopa. One-half cup contains 250 mg, or the same amount as one pill. But don't substitute beans for pills without first asking your doctor.

• Grape Seed Extract (Pycnogenol)

Flavonoids, and in particular the proanthocyanidins (grape seed and pine bark extracts) have been found to help prevent and slow the progression of PD.

Proanthocyanidins are water-soluble antioxidants that are stronger than vitamin C and which can quickly cross into the brain fluid.

• Caffeine/Coffee

A team of researchers looked at the relationship between coffee intake and the incidence of Parkinson's disease among 8,004 Japanese-American men over a 30 year period.
Of these men, 102 developed Parkinson's disease. People who drank coffee were less likely to get PD. In fact, the men who drank the most coffee were the least likely to get Parkinson's disease.

Men who did not drink any coffee were five times more likely to show symptoms of Parkinson's disease than men who drank more than 28 ounces of coffee each day.

Caffeine from other sources such as green tea, black tea, chocolate and soda were also associated with a lower risk of Parkinson's disease.

It is thought that caffeine may protect against Parkinson's disease by blocking something called adenosine receptors, and increasing the amount of dopamine in the brain.

Though there may be a link between caffeine and PD, it is too early to say that caffeine will prevent Parkinson's disease. Maybe the brains of people who like and dislike coffee are different, with differing rates of Parkinson's.

The study also included older, Japanese-American men which means we don't know if this caffeine/Parkinson disease relationship would be the same for other ethnic groups, women or younger people.
How Much Protein is Allowable in the Parkinson’s Diet?

First of all, a person with PD needs to consider how severe their symptoms are. If a person has problems with mobility that interfere with activities or has noticed that food seems to interfere with how well Sinemet works, a low protein diet may help these problems.

People who need to lower the protein in their diet might try reducing it to the recommended daily allowance of protein. The recommended daily allowance (RDA) for protein is 0.8 grams of protein per kilogram of body weight (.36 grams per pound).

Timing when you eat protein is important as well. If you have most of your protein at your evening meal, you will increase the amount of time you are mobile. But, if you evenly distribute your protein throughout the day, you will be less mobile in the evenings.

You will have to decide which option is best for you and your needs, but in the meantime, here are a few ways to incorporate protein into your mealtimes so that it won’t interfere with the effectiveness of Sinemet:

- Take Sinemet about 30 minutes before meals
- Eat foods that are high in protein, with large helpings of grains, fruits, and vegetables
- Remember that meals high in fat take longer to digest

Remember if you do cut down on your protein, you may want take vitamin and mineral supplements as a low-protein diet can lead to low levels of calcium, iron, and B vitamins.
Are There Certain **Foods** That People With Parkinson’s Should **Avoid**?

The following are some suggestions on foods that a person with Parkinson's might avoid.

**Foods to avoid if you have Parkinson’s:**

- Tobacco

- Spicy Foods

  Foods seasoned with hot spices have been known to cause **uncontrollable physical movement** in some people with Parkinson's.

- Aspartame (Nutrasweet)

  Parkinson's disease can be **triggered or worsened** by ingesting aspartame according to researchers studying its possible adverse effects.

- High Protein

  High amounts of protein in the diet **decreases the effectiveness of Sinemet**. The timing of protein intake can increase the effectiveness of Sinemet and make it so you don’t require as much medication.

- Alcohol

  This creates an acidic internal environment and is **over-stimulating** to a stressed nervous system.

**Foods, minerals and metals to avoid to help decrease risk of Parkinson's:**

- Chemicalized and Processed Food

  As much as possible, buy organic fruits, vegetables, and grains to lower the amount of **exposure you get to pesticide residues**. (Direct contact with herbicides and pesticides can put you at increased risk of Parkinson's)
• **Animal/ Saturated Fats**

  American researchers have concluded that a high intake of animal fats is associated with a **five-fold increase in the risk** of developing Parkinson’s disease.

• **Sugar**

  People with a high intake of sugar (mono- and disaccharides) may **increase their risk** of developing Parkinson's disease by a factor of three as compared to people with a more moderate intake.

  **Minerals:**

• **Iron**

  Avoiding overexposure to some metals, especially iron, may help **reduce the risk** of developing Parkinson's disease.

• **Manganese**

• **Copper**

  **Metals:**

• **Aluminum**

  People who live in areas where the aluminum content of the drinking water is high might have a **higher risk** of developing Parkinson's disease.
Are there any Food Additives that a Person with Parkinson's Should Avoid?

There have been studies that have suggested that something called "excitatory amino acids" might play a role in Parkinson's disease.

These types of amino acids are found naturally in many protein food sources and are often added to food in the form of monosodium glutamate (MSG), a flavor enhancer you've probably heard about (if you haven't, check out the labels of your soup cans—it's often in the ingredients list).

The studies that have been done haven't been conclusive yet but some researchers have said it might be a good idea to limit the use of MSG and similar additives, as well as the artificial sweetener aspartame.
What Nutritional Supplements Help with the Treatment of Parkinson’s?

Well, there’s lots of information out there about taking this, that or the other thing to help with your Parkinson’s. Some say one thing works, and others say it doesn’t. Obviously, you need to talk to your doctor about this but here are some recommendations that some researchers have found to help with PD.

Vitamins and Minerals:

- **Multivitamin**

  These are great to help out your diet if you aren’t getting all the vitamins and minerals you need. Try taking a high-potency multivitamin and mineral supplement daily. Soft gel-caps are the best form of multivitamin because you can digest them easier.

- **Vitamin B6**

  Vitamin B6 is recommended regardless of the cause of the disease and of the patient's age, and can be given either alone or in combination with anti-Parkinsonian drugs aside from DOPA. (10 to 100 mg per day may help with symptom control, but should be given with 30 mg per day of zinc).

  **High doses of B6 are not recommended, however, for people with angina or coronary insufficiency.**

  **NOTE:** Vitamin B6 (also called pyridoxine), found in bananas, beef, fish, liver, oatmeal, peanuts, potatoes, and whole grains, **interferes with the action of L-dopa. If you are taking L-dopa, take these foods only in moderation, if at all.** (If you are taking a combination Levadopa and cardidopa such as Sinemet, you don’t have to avoid the intake of Vitamin B6.)

- **Vitamin E**

  A study showed that taking large amounts of vitamin E (from food only) **reduced the risk** of Parkinson’s disease. This study involved over 124 000 men and women who were followed for at least 12 years.

  Vitamin E supplements were **NOT** associated with the risk of developing Parkinson's (taking 400 to 800 IU per day).
Note: If you have high blood pressure, limit your intake of supplemental vitamin E to a total of 400 international units daily. If you are taking an anticoagulant (blood thinner), consult your physician before taking supplemental vitamin E.

- **Vitamin C**

  Some studies have shown that supplementing your diet with vitamin C can really slow down the progression of the disease in its early stages and may be an excellent protector against Parkinson’s disease (taking 1,000 mg three times a day).

  Other research has shown that synthetic vitamin E (this is vitamin E that is still in the pill form, but just has “synthetic” as opposed to “natural” written on the side of the bottle) by itself may not slow the progression of Parkinson’s disease, but in combination with vitamin C, it may.

- **Vitamin A**

  Vitamin A works with other antioxidants (like vitamin E and C) to provide a protective effect.

- **Vitamin B Complex**

  Adding a vitamin B-complex to your diet may be necessary, especially if you take l-dopa medications.

- **Trace Mineral Selenium**

  Taking 200 mcg may slow down the progression of Parkinson’s. Selenium is an antioxidant that works with vitamin E. It also helps to increase circulation and tissue oxygenation, thereby limiting damage to nerve cells.

- **Calcium and Magnesium**

  These are very important for maintaining a healthy nervous system. Take a multimineral supplement that supplies 500 milligrams of calcium and 250 milligrams of magnesium, as well as trace minerals, twice daily.

- **Folic Acid**

  Folic acid is a B vitamin. It is used in our bodies to make new cells.

  Some studies have shown that low levels of folic acid increase your chances of getting Parkinson’s disease.
Researchers think that consuming enough amounts of folate or folic acid may help protect older adults from Parkinson’s disease as well as from other degenerative neurologic diseases.

Folate naturally occurs in dark green vegetables like spinach, in citrus fruits, and in whole-wheat bread. Half a cup of cooked spinach contains about 130 micrograms of folate.

**Nutrients:**

- **CoQ10 (Ubiquinone)**

  Researchers have done a study where they found that Parkinson's patients have reduced levels of coenzyme Q10 in their mitochondria (cells' power sources).

  This led the researchers to see whether the antioxidant would be useful in treating the disease.

  In their study there were 80 people who had been diagnosed with Parkinson’s who had not received treatment yet. These people were randomly assigned to take a daily dose of 300mg, 600mg or 1,200mg of coenzyme Q10 or an inactive pill called a placebo. They were evaluated at the start of the study and after one, four, eight, twelve and sixteen months.

  The progression of Parkinson’s disease was a lot slower in people taking the highest dose of coenzyme Q10. These people experienced a slower decline in all the areas measured by the researchers, including mental and motor skills, but the greatest effect was in the activities of daily living.

  The results of this study suggest that doses of coenzyme Q10 as high as 1,200 mg/day are safe (30 milligrams two or three times daily is the average dose) and may be more effective than lower doses.

- **Alpha Lipoic Acid**

  Alpha-lipoic acid is an antioxidant that also helps to "recharge" other antioxidants in the body. Take 50 to 100 milligrams three times a day.

- **TMG (Tri-methyl-glycine)/SAMe**

  TMG is a nutrient that can enable a person to function at more optimum mental and physical levels. It helps the body in overcoming a number of bad health conditions, and is an important part of human metabolism. TMG has been shown to improve Parkinson's disease.
• **Essential Fatty Acids**

These are **anti-inflammatory**. A mix of omega-6 (evening primrose, black currant, borage, pumpkin seed) and omega-3 (flaxseed and fish oils) may be best (2 tbsp. oil per day or 1,000 to 1,500 mg twice a day).

**Herbs:**

Herbs may be used as **dried extracts** (capsules, powders, teas), **glycerites** (glycerine extracts), or **tinctures** (alcohol extracts). Unless otherwise indicated, teas should be made with 1 tsp. herb per cup of hot water. Steep, covered 5 to 10 minutes for leaf or flowers, and 10 to 20 minutes for roots. Drink 2 to 4 cups per day.

• **Gotu kola (Centella asiatica):**

  This herb was used historically to treat Parkinson's disease.

  Gotu kola has been known to have remarkable wound healing properties, as well as improving memory and increasing mental stamina. Dosage is one cup tea twice a day, or 30 to 60 drops tincture twice a day.

• **Ginkgo (Ginkgo biloba):**

  Taken as a supplement of 120 mg per day, Ginkgo biloba chases after and captures free radicals, as well as boosts circulation to the brain.

  Select a product containing at least 24 percent ginkgo heterosides (sometimes called flavoglycosides). If you feel fine with the 120 mg dosage, you can gradually increase to as much as 80 milligrams three times daily.

• **Hawthorn (Crataegus monogyna):**

  Taking 2 to 5 g per day, it increases the efficiency of the heart by increasing circulation, it helps to stop palpitations and arrhythmias, and helps to prevent and treat angina.

• **Milk thistle (Silybum marianum), globe artichoke (Cynara scolymus), and Bupleurum species:**

  Provide support for the liver.

• **St. John’s wort (Hypericum perforatum), skullcap (Scutellaria lateriflora), oats (Avena sativa), and lemon balm (Melissa officinalis):**

  Help support the structure of the nervous system.
Does Exercise Help Parkinson’s?

Because Parkinson’s disease affects your ability to move, exercise helps to keep muscles strong and improve flexibility and mobility. Exercise will not stop the disease from progressing but it will improve your balance and it can prevent joint stiffening.

Exercise has been found to be very helpful in minimizing the symptoms of Parkinson’s disease, increasing mobility and improving quality of life. It can also be very emotionally beneficial. It has been found to help in improving a depressed or anxious mood.

You should check with your doctor before beginning any exercise program. Your doctor may make recommendations about:

- The types of exercise best suited to you, and those which you should avoid
- The intensity of the workout (how hard you should be working)
- The duration of your workout and any physical limitations
- Referrals to other professionals, such as a physical therapist who can help you create your own personal exercise program
Are there any **Special Exercise Regimens** that are Recommended for a Person with PD?

The type of exercise that works best for you depends on your **symptoms**, **fitness level**, and **overall health**. Generally, exercises that stretch your arms and legs through the full range of motion are encouraged.

It’s important that you find a kind of exercise that you **enjoy**, or else you’re probably not going to stick with it. Mom likes **puttering around in her garden** and **going for walks** when she’s mobile (she also has a treadmill that she can use inside when the weather’s not so great).

Some other ideas other than gardening and walking are; **swimming**, **water aerobics** (easier on the joints and require less balance), yoga and Tai Chi (both of which are relaxing and improve flexibility and balance).

**Here are some tips to keep in mind when exercising:**

- Talk to your doctor first about what exercise you think you might like to do and whether or not it’s a good choice for your overall health.

- Always warm-up before beginning your exercise routine and cool down at the end.

- If you plan to workout for 30 minutes, start with 10-minute sessions and work your way up.

- Exercise the muscles in your face, jaw, and voice when possible: Sing or read aloud, exaggerating your lip movements. Make faces in the mirror. Chew food vigorously.

- Work out in a safe place; avoid slippery floors, poor lighting, throw rugs, and other possible hazards.

- If you have difficulty balancing, exercise within reach of a grab bar or rail. If you have trouble standing or getting up, try exercising in bed rather than on the floor or an exercise mat.

- If at any time you feel sick or you begin to hurt, stop.

- Pick an exercise, activity or hobby you enjoy and stick with it.
What is Tai Chi and Can it Help Someone With Parkinson’s?

Tai chi is a **martial art** developed in fourteenth century China. In the tradition of karate and judo, tai chi was originally used for self-defence, and has evolved over the course of time into a practice for **promoting health**.

Tai Chi is also a philosophy. It's the philosophy of yin and yang. Literally, it means "supreme ultimate." Tai chi is represented by the yin/yang symbol. It's sort of the law of opposites (like you and me, night and day, etc.)

Through the movements, you're trying to bring your **body, mind and nature together to become one**.

You've probably seen someone in a park sometime doing a very beautiful, slow, ballet-like series of motions that looked a little strange to you if you didn't know what it was, because there are many people now practicing this on their own. If you saw someone doing that in the park in your town, it was probably tai chi.

Tai Chi has been recommended for helping people with Parkinson's because it is **relaxing and can improve flexibility and balance**. Whether you take a class or practice on your own, you may want to try this exercise as part of your PD treatment plan.
Is Weight Loss a Symptom of Parkinson’s or a Side Effect of the Drugs?

Many people with PD lose weight because of the nausea, stress, and loss of appetite that they get from the disease and the drugs.

Losing weight may weaken your immune system, cause you to lose muscle and you may also be missing out on important nutrients.

Because of this, it’s really important to eat healthy, well-balanced meals. If you find that you can’t eat a lot at once, eat 5-6 smaller meals over the course of the day. You may also try a meal supplement such as Ensure.
How Can a Person with Parkinson's Maintain Body Weight?

Here are some general tips to help you maintain a healthy weight:

- Weigh yourself once or twice a week, unless your doctor recommends weighing yourself more often. If you are taking diuretics or steroids, such as prednisone, you should weigh yourself daily.

- If you have an unexplained weight gain or loss (2 pounds in one day or 5 pounds in one week), talk to your doctor. He or she may want to change your food or fluid intake to help manage your condition.

Here are some tips for gaining weight:

- Ask your doctor about nutritional supplements. Sometimes supplements in the form of snacks, drinks (such as Ensure or Boost), or vitamins may be prescribed to eat between meals to help you increase your calories and get the right amount of nutrients every day.

  Make sure you check with your doctor before making any dietary changes or before adding supplements to your diet. Some can be harmful or interfere with your medication.

- Avoid low-fat or low-calorie products (unless your doctor has recommended otherwise). Use whole milk, whole milk cheese, and yogurt.

Sometimes you might be losing weight because you don’t have much of an appetite.

Here are some tips for improving poor appetite:

- Talk to your doctor; sometimes, poor appetite is due to depression, which can be treated. Your appetite will probably improve after depression is treated.

- Avoid non-nutritious drinks like black coffee and tea.

- Eat small, frequent meals and snacks.

- Walk or get involved in another light activity to stimulate your appetite.
Here are some tips to help you eat more at meals:

- Have your drinks after a meal instead of before or during a meal so that you do not feel full before you start eating.
- Plan meals to include your favorite foods.
- Try eating the high-calorie foods in your meal first.
- Increase the variety of food you're eating (use your imagination, or a good cookbook)

Here are some tips to help you eat snacks:

- Don't waste your energy eating foods that have little or no nutritional value like potato chips, candy bars, colas and other snack foods.
- Choose high-protein and high-calorie snacks. Some examples of these kind of snacks are: ice cream, cookies, pudding, cheese, granola bars, custard, sandwiches, nachos with cheese, eggs, crackers with peanut butter, bagels with peanut butter or cream cheese, cereal with half and half, fruit or vegetables with dips, yogurt with granola, popcorn with margarine and parmesan cheese, bread sticks with cheese sauce.
- Make food preparation easy. Choose foods that are easy to make and eat.
- Make eating a good experience, not a chore. To liven things up at meal times, try putting on background music and using colorful place settings.
- Try not to eat alone. Invite somebody over for dinner or go out.
CAREGIVING

What Can You Do to Help Someone You Know with Parkinson’s Realize They Need Help?

Let’s assume that you know someone with Parkinson’s who is living on their own and has so far refused help from anyone, despite the fact that they probably need it.

First off, if they have refused treatment altogether (including medications), you might tell them that research has shown that you may be able to slow down the progression of the disease if you start treatment sooner than later.

If they are taking medications for their PD but are still requiring some help with their daily activities, you may suggest a home support worker, or someone who could help them out from time to time (like a family member or friend).

This might be a good option for them, especially if they are afraid of losing their independence. The support worker (or whoever) could come out on a trial basis and that way the person could see what the benefits of having outside help are.

Express to them your concerns about them refusing help. Would they be able to help themselves in an emergency? They need to know that in the end, help is there to make them feel better, not worse.
Caregivers can help in many ways to help make the life of a person with Parkinson’s easier. To start, Mom says it’s very good to be supportive, encouraging, and positive.

Try to avoid stressful situations if at all possible. Try to talk in a "happy voice" Mom says, because the Parkinsonian can hear (yes, not just see, but hear as well!) when you are stressed and this stress really affects them negatively.

Because depression is so common, it never hurts to offer a hug or two, or any kind of physical touch. Mom really appreciates these I know.

As much as possible, be accessible. Ask if you can help them, but don’t assume they want help because they may not. Asking is important because often the person with Parkinson’s won’t ask for help for fear they are being a pain all the time.

You may want to participate in their exercise program with them if they have one, to help them stay motivated.

One very important thing you need to know as a caregiver for someone with Parkinson’s is that patience goes a long way. You need to remember that things will often take longer than they might have before and trying to rush someone with PD will only get them frustrated and stressed and slow them down even more.

Always plan ahead and allow extra time for things. Mom loves to shop and somedays we can get ready in 15 minutes to go to the mall, while other times it may take an hour. “It’s okay” we tell her,” ‘cause the mall ain’t goin' nowhere!”
How Can I Take Advantage of Outside Help Without My Loved-One (who has PD) Getting Upset?

First of all, you need to help make your loved one understand why you need help. You might explain about burnout and how this will eventually happen to you if you don't get outside help. This will mean that you will no longer be able to care for them.

Next, you need to explain why having some outside help in the home could be good. Mention to them that this could be a way to learn new things, as well as having some new company in the house for him or her. You might suggest having a "trial" period so that the both of you could see how and if this would be good for your situation.

Finally, remind them that in the end, what helps you as the caregiver will also help them.
What Resources are Available for Caregivers?

There are many resources available for caregivers, but the best place to start is with your National Parkinson’s Foundation or Society. They can quickly and easily direct you to the best places for you to get the resources you want and need. You can find them online, or in the phone book.

The next place you might try looking is in your local newspaper for community announcements of meetings for caregivers. You can also try looking in the yellow and/or white pages of your phone book for your local Parkinson’s chapter, who will be able to tell you about any support groups that may be in your area.
Are there Any Organizations that Give Monetary Support for a Person with Parkinson’s?

Outside of government funding, there aren't a whole lot of organizations that give straight cash. Well, not that we could find anyway (If you know of some, let us know!).

One non-government organization that we found that does help is called "The Melvin Weinstein Parkinson's Foundation". This a non-profit organization dedicated to purchasing equipment and health supplies necessary to maintain a safe and healthy environment for Parkinson’s Patients. With the aid of support groups they locate Parkinson’s Patients who have financial and medical needs, and find a way to help them.

The best way to receive monetary support is through either employment disability benefits, or various federal health and or disability support plans.
Do People with Parkinson’s Receive any Financial Help from the Government?

Yes! It is possible that you may qualify to receive financial help from your government. It is very important that you investigate this to see if you qualify because there are many ways in which they might be able to help you.

First of all, your condition will need to be assessed to see what stage of the disease you’re in and what assistive devices (if any) would make life easier for you.

Some governments provide help to buy things like wheelchair ramps, or help in providing funding to make any needed renovations to your house to make things easier for you. In most cases, you would pay part of the amount, and the government the other.

Some governments (e.g. US) have established or authorized some type of program to provide pharmaceutical (as in prescribed medication) coverage for low-income seniors or people with disabilities who do not qualify for Medicaid, or their federal health benefits program.

Many governments will offer income tax relief to people with Parkinson’s. You will need to fill out forms to apply for this, but it’s definitely worth checking into to see if you qualify for this.

Sometimes, applying for benefits can be complicated, time-consuming, and maybe frustrating. Two things you need to remember when going through this process are: 1) do not throw away any potentially relevant paperwork you receive from an employer, an insurer, a government agency, or an advocate on your behalf and 2) keep copies of everything that you submit.

As was said before, you will need to do some research to find out whether or not you qualify for government assistance. You might start with your local chapter for Parkinson’s (check the phone book in yellow or white pages) and they can tell you where you need to go. Depending on what country you live in, you may receive more or less benefits.
How Does the Law Cover People With Parkinson’s in Employment?

First and foremost, remember that just because you have Parkinson’s does not mean you have lost all (if any) of your rights at your place of work. Don’t let any employer tell you differently!

Yes, countries will be different in their laws, but it’s important that you find out from your local government officials as to what exactly your rights are as a person with Parkinson’s.

One piece of advice Mom found to be very helpful when she was diagnosed with PD and still working, was to go and meet with her Human Resources Department at work right away.

This is done to inform them of your new “condition” and to find out any information they may have to offer you.

It’s important that when you go though, you don’t go alone. Bring someone with you to take notes and be your “witness” to prevent possible problems down the road.
Is it Safe to Drive if You Have Parkinson’s?
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Many people think that once they have been diagnosed with Parkinson’s they will have to give up driving. **This isn’t necessarily true.** Each case of Parkinson’s is different and the disease progresses at a different rate in each person.

Although driving isn’t safe in the **advanced stages** of Parkinson’s, people with milder symptoms who can control their impaired motor abilities can continue driving.

There are several issues that are involved in deciding on whether or not you should be driving with your PD. Your **physical ability, legal permission, safety, and the importance of keeping your independence** all play a part.

You will probably be able to drive safely and legally for several years, depending on your age and general physical condition. However, PD eventually affects **reaction time, ability to handle multiple tasks, vision, and judgment.**

A good way to figure out whether you should be behind the wheel is to ask yourself, "If a loved one were my passenger, would I be risking that person's safety because of my PD?"

Also, pay attention to how others react to your driving. If your loved ones have said negative things about how you drive or they aren’t sure whether or not they want to be your passenger, you may want to think carefully about their concerns.

My mom chooses not to drive most of the time because it causes her to tense up and this causes her muscles to hurt.