

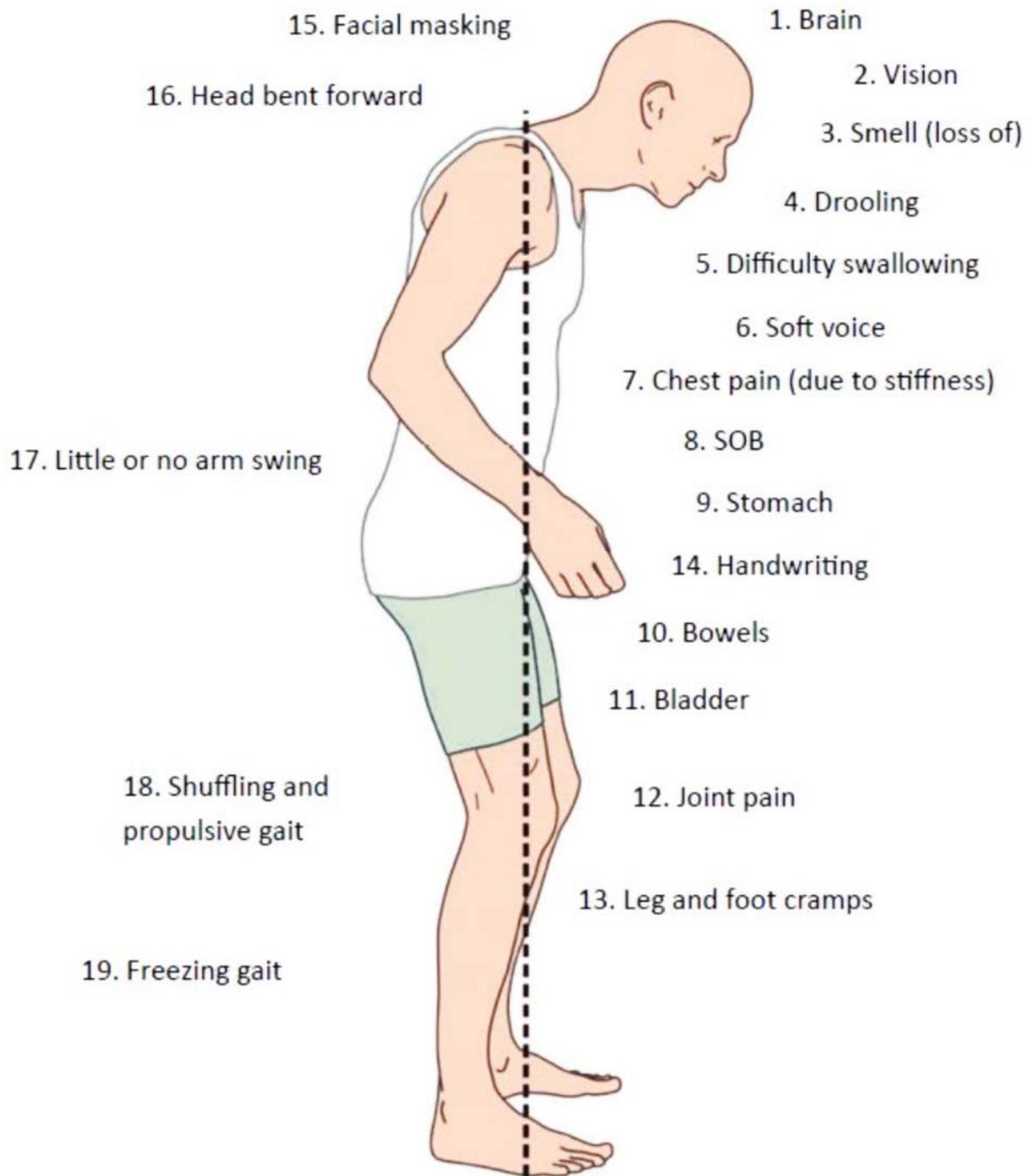
The Experience of Parkinson's

What Person Feels

What Person Needs

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Parkinson's Head To Toe



SYMPTOMS OF PARKINSON'S

1. Brain. Your brain has slowed thinking. Do word games, crosswords. Anything new that makes you think.
2. Vision. People with Parkinson's do not blink often enough so eyes become dry. Use over the counter eye drops for dry eyes.
3. Smell. Loss of smell often occurs in Parkinson's. This is an early symptom. The sense of taste is often affected also.
4. Drooling. Occurs because the person with Parkinson's does not swallow often enough. Sucking on hard candies or chewing sugarless gum helps.
5. Difficulty swallowing. Occurs due to slowness in the act of swallowing and is often a symptom seen late in the disease. Sips of ice water awaken the swallowing reflex. Chin to chest while swallowing may also help.
6. Soft voice. The muscles used for speech are affected. LSVT Loud therapy will help.
7. Chest pain. These occur when the muscles in the chest become stiff. NEVER assume these symptoms are PD-see your doctor if they occur.
8. Shortness of breath. See above (#7).
9. Digestion. Slowing of digestion can cause heartburn, bloating and nausea. Antacids help as does prescription drugs like Nexium, or Protonix etc.
10. Bowels. Slow peristalsis occurs because the food is not moving through the gastro- intestinal tract fast enough. Seek a natural remedy for constipation and eat a diet rich in fiber, drink plenty of water and exercise.
11. Bladder. People with Parkinson's may have urge incontinence. (need to void in a hurry)
12. Joint pain. This pain is especially in the shoulder, although it can affect almost any joint and is often thought of as a sign of aging or arthritis, when in fact it is Parkinson's.
13. Leg and foot cramping. This most often happens during the night or early morning when the Parkinson drugs have worn off. A pillow at feet will help.

14. Handwriting. Handwriting becomes tiny cramped and hard to read. Practice writing large using lined paper. Use a label maker for notations on your calendar.
15. Facial masking. People with Parkinson's often show little facial expression, which causes people to think them disinterested, bored or depressed. Stand in front of a mirror and exercise the facial muscles by doing exaggerated facial expressions.
16. Posture. Stooped posture, exaggerated forward head position. This causes balance issues and falls. Also it may contribute to swallowing problems.
17. Arm swing. Lack of arm swing when walking is an early sign and tends to occur on one side only. This is a diagnostic sign of Parkinson's.
18. Shuffling & Propulsive gait. People with Parkinson's s tend to take short shuffling steps, often accompanied with propulsive gait which contributes to falls. LSVT BIG & LOUD physical therapy will help with this problem.
19. Freezing gait. Abrupt and temporary inability of People with Parkinson's to move. Occurs when beginning to walk, moving through doorways, or turning around.
20. This is not an all-inclusive list and no one will have all of these symptoms. Any of these symptoms can be caused by something other than Parkinson's. See your physician.

Source: Parkinson's Network North

Parkinson's Information

What is Parkinson's?

- First characterized by John Parkinson, MD in 1817.
- A chronic, degenerative neurological disorder results in loss of cells in various parts of the brain, including the substantia nigra.
- The substantia nigra cells produce dopamine, a chemical messenger responsible for transmitting signals within the brain that allows for coordination of movement.
- Loss of dopamine causes neurons to fire without normal control so person is less able to control their movements
- Also effects the non-dopamine cells contributing to non-movement symptoms
- Effects one in 100 people over age 60
- Average age of onset is 60, but has been diagnosed as young as 18.
- Not test or biomarker to diagnose so can be misdiagnosed
- Many not diagnosed until overt symptoms are present
- One million people in USA and five million worldwide

Causes of Parkinson's

- The cause is not known
- Men more likely than women
- Biggest risk factor is advancing age
- Researchers in last 10 years have identified a number of rare incidences where Parkinson's appears to be caused by a single genetic mutation which can be passed down from generation to generation
- Exposure to certain pesticides may increase risk
- A higher intake of Vitamin D, caffeine and tobacco may lower incidences
- For most people, it may be both genetic and triggered by something environmental

Source: Michael J. Fox Foundation for Parkinson's Research

Parkinson's Fact Sheet- NIH.gov

LIVING WITH PARKINSON'S

A Caregiver or Care Partner Perspective

WHAT IS THE ROLE OF THE FAMILY CAREGIVER?

When a person moves into an assisted living community or other setting, this means that the caregiver has a range of emotions.

- Concern that the staff will not know them as a person and understand their unique experience with Parkinson's.
- Loss of control in a role of advocate in real time as the person experiences assistance with Activities of Daily Living and being in a new environment
- Worry that the medication will not be given on time so that the person experiences more symptoms
- Anxiety about continuity of care. Will the staff be told all the details related to bathing, toileting, eating and dressing that are important for care?
- Feelings of loss and sometimes guilt about not being able to manage at home.

WAYS TO SUPPORT THE FAMILY CAREGIVER

- Ask about routine and preferences of the person.
- Show that you are person-centered. Find ways for staff to see that person as a unique individual.
- Give them feedback about how the person is doing. Ask questions and try to understand their emotions.
- Find ways to make them feel like a part of a team.
- Always smile when you pass them in the hallway. It tells families more than we know.

TIPS FOR ASSISTING PERSONS WITH PARKINSON'S

John's Tip-

"I always take time to see how my clients with Parkinson's are doing when I arrive at their home. They can have days when they feel more shaky and unsteady and that is really important when I am providing care."

Bonnie's Tip-

"When Mr. Johnson looks at me and seems angry, I remind myself that facial expressions often don't match their feelings. I don't take things personally."

Connie's Tip-

"When I am serving a meal, I put a small amount on a smaller plate. Sometimes a lot of food seems overwhelming."

Beth's Tip-

"I am always reminding myself to be patient. If it takes a long time for the person to get out of their chair, or they walk really slowly, I just allow them the time they need."

Marilyn's Tip.

"Reminding people to take their medicine on time is really important. Staying on schedule helps to avoid symptoms and they feel much better."

Sue's Tip-

"I always encourage persons with Parkinson's to enjoy plenty of fruits and vegetables that they like. It helps them because constipation can be very uncomfortable."

Maureen's Tip-

"Some days Mr. Sonoma has a lot of fatigue. I help him to be comfortable in his chair and work quietly so he can get rest. He feels a lot better after his nap."

Tom's Tip-

"I pay attention to how Mr. Johnson gets out of his chair. He knows how to do it so I wait until he is ready to stand up. I don't offer to help unless he asks for assistance. It is safer that way."

Jack's Tip-

"People with Parkinson's experience fatigue. A nap in the morning or afternoon can be really helpful. I encourage the person to consider a nap if they look really tired."

Izzy's Tip-

"If a person has Parkinson's, I make sure that the pathways in the rooms are clear. Challenges with balance increase the risk of falls.

Monica's Tip-

"Mr. Gomez has Parkinson's and swallowing can be difficult. I make sure that he has soft food he enjoys which are easier for him.

Abdul's Tip-

"Mr. Gordon has a really soft voice so I always make sure I am facing him when we talk. I ask permission to turn down the volume on the TV so we can communicate better."