



PATIENT EDUCATION

# *Primary Progressive Apraxia of Speech*

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BARBARA WOODWARD LIPS  
PATIENT EDUCATION CENTER



# An Overview of Primary Progressive Apraxia of Speech

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Primary progressive apraxia of speech is a neurodegenerative disorder. Neurodegenerative means that certain nerve cells in the brain have been damaged. Or they no longer work. You may see or hear primary progressive apraxia of speech called PPAOS.

Primary progressive apraxia of speech is a gradual loss of speaking skills. It starts slowly and progresses over time. Other language and thinking skills typically remain in place. But over time, they also may be affected.

Apraxia is a condition caused by brain disease or brain damage. The brain cannot make and deliver correct instructions to the body about how to move.

## Apraxia of speech

With apraxia of speech, the brain struggles to make the lips, jaw and tongue move as they typically do. People slowly lose their ability to speak. Other language and thinking skills may or may not be affected.

Apraxia of speech affects two areas of speech:

- **Motor planning.** This means your brain thinks of *what* it needs to do so that you say what you want to say.
- **Motor programming.** This means your brain thinks of *how* to say what it wants to. The brain selects certain movements from the specific muscles needed to speak.

With apraxia of speech, the signal between the brain and the mouth muscles is not sent correctly. You know what you want to say. But the mouth muscles do not move as they should. The sounds and words that come out of the mouth get mixed up with the movement of the mouth.

Apraxia of speech can affect other areas of speech, too, such as:

- **Sequencing.** The order of sounds or syllables as you say them.
- **Prosody.** The speed and animation with which you speak. Animation is the up-and-down sound of the voice as you speak.
- **Articulation.** How you form words.

In most cases, apraxia affects prosody and articulation. Often changes affect one of those areas more than the other.

# Primary Progressive Apraxia of Speech and Frontotemporal Degeneration

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Primary progressive apraxia of speech is a type of brain disorder. It is called frontotemporal degeneration. This name is a general term. It covers a group of brain disorders. They most often affect the frontal and temporal lobes of the brain. The area of the brain that affects speech is the frontal lobe.

With this condition, parts of the frontal and temporal lobes shrink. This happens because of a loss of brain tissue over time. Signs and symptoms vary. They depend on which part of the brain the loss affects. Some people lose the skill to use language correctly. Others may have changes in their personality or behavior.

You may hear frontotemporal degeneration called FTD. It includes different disorders. This resource explains primary progressive apraxia of speech. It is a specific type of FTD.

# Signs and Symptoms of Primary Progressive Apraxia of Speech

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The early signs and symptoms of primary progressive apraxia of speech may include:

- Slow overall rate of speech.
- Increased pauses between words.
- Increased pauses within words that have more than 1 syllable.
- Less ability to show expression and emotion through voice.
- Trouble forming words. You know what you want to say. But the words do not come out clearly. This may be easier to notice with longer and more complex words.
- Saying yes when you mean to say no. Or saying no when you mean to say yes.

As this condition progresses, you may notice more signs, such as:

- Trouble with language. This is aphasia. It includes trouble putting words in the right order. It includes trouble understanding what you hear. And it also can include trouble thinking of the words you want to say.
- Trouble with the muscles involved in speaking. This is dysarthria.
- Trouble swallowing. This is dysphagia.
- Muscle stiffness becomes broader. Or a group of muscles tightens. This is called spasticity.
- Not being able to use an object or do a familiar task. This is apraxia. It also can occur in other areas of the body. It can affect more than speech.

These later signs may happen over time. They often are less severe than trouble with speech.

Each person with PPAOS is different. It is hard to predict when or if other symptoms or signs may happen. Regular visits with your healthcare team can help check for these later symptoms.

# Cause of Primary Progressive Apraxia of Speech

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The brain contains billions of nerve cells called neurons. Neurons travel through the nervous system. They send messages to all areas of your body. They allow the body to function as it should.

Neurons have small tubes called microtubules. They carry a protein called tau. Tau proteins work with the microtubules. But with some neurodegenerative disorders, tau proteins separate from the microtubules. They stick together and form tangles within the neuron. That harms the ability of the neurons to send messages. They cannot work as they should within the nervous system.

Primary progressive apraxia of speech affects the neurons in the frontal lobes of the brain. Most people with this condition also have one of two diseases that cause their symptoms although other less common causes can occur:

- **Corticobasal degeneration**, also called CBD. This is a rare condition in which areas of the brain shrink. Over time, the nerve cells stop working and die. The disease affects the areas of the brain that process information and control movement.

This causes problems with movement on one or both sides of the body. The condition may cause poor coordination, stiffness, trouble thinking, issues with speech and language, and other problems.

- **Progressive supranuclear palsy**, also called PSP. This is a brain condition that is not common. It causes serious problems with your walk and balance. It causes serious problems with eye movement and how you swallow. The condition results from the deterioration of cells in areas of your brain. These are areas that control body movement, coordination, thinking and other important functions.

The exact disease that causes the symptoms of PPAOS often cannot be known until after death. The condition does not appear to run in families. No environmental risk factors are known.

# Diagnosing Primary Progressive Apraxia of Speech

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It may be hard to diagnose this condition. Symptoms can be confused with other conditions. Apraxia of speech can be confused with aphasia. Apraxia of speech also can be confused with dysarthria.

Your primary care team may refer you to a neurologist. A neurologist diagnoses and treats disorders of the brain, spinal cord and nervous system. You also may see a specialist in behavioral neurology. Behavioral neurology specialists work with people with brain conditions affecting memory and thinking.

You may see a speech-language pathologist. This specialist can help diagnose and treat a wide range of conditions. They include speech, language, thinking and swallowing. Together you and speech-language pathologists create a treatment plan that fits your needs.

Your healthcare team may recommend the following imaging exams:

- **Magnetic resonance imaging, called MRI.** This imaging exam uses a magnetic field and radio waves. It shows detailed views of the body from different angles.
- **Positron emission tomography, called PET scan.** This is an imaging test that uses radioactive medicine. The test creates multiple images of the body. A PET scan is the most sensitive brain test used to diagnose PPAOS.

Your healthcare team also may refer you for neuropsychological testing. This testing examines memory, reasoning and judgment. It also examines problem-solving ability. It examines language skills and visuospatial abilities. The results of this testing often are in the typical range for people with PPAOS.

Most people have never heard of PPAOS. When you get the diagnosis, you may have many questions. Your healthcare team understands what you may be going through. Be sure to talk with the team about your questions and concerns.

# Treatment of Primary Progressive Apraxia of Speech

Primary progressive apraxia of speech has no cure at this time. But treatment options can help ease or slow the progress of symptoms.

Each person with this condition is different. Your treatment options depend on the progress of your condition. Treatment options include:

- Speech therapy. This helps maintain your speech. It also allows you to adapt to changes. And it helps you prepare for future changes in your speech. Speech therapy can help you explore other ways to communicate.
- Physical and occupational therapy. Specialists help you manage movement problems.
- Botox injections. They may help lessen some muscle stiffness.

Together, you and your care team decide the best therapies to meet your needs.

## **Do you often need to repeat yourself?**

Some people with primary progressive apraxia of speech often need to repeat what they said. People they talk to may not understand them.

If this happens to you, try to:

- Speak face-to-face with the person.
- Make sure you are close to the person.
- Lessen noise and movements that distract you. Turn off the TV or other background noise.
- Speak slowly and pause between words.
- Choose a different word that might be easier to say. For example, use TV for television or phone for telephone.
- Ask the person you speak with to repeat what they understood. You may not have to repeat everything you just said.



# Common Questions

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## **How does primary progressive apraxia of speech differ from primary progressive aphasia?**

PPAOS affects speech. For example, it affects the speed and correctness with which you can say something.

Aphasia affects mainly language, not speech. Some of the things affected by primary progressive aphasia include:

- Putting words in the right order.
- Thinking of words.
- Understanding what you hear.
- Reading and writing.

As these two diseases advance, they show similar symptoms or signs. For example, some people may develop aphasia along with apraxia.

But those who have apraxia of speech without aphasia can think of what they want to say. And it is not difficult for them to understand people.

## **How does primary progressive apraxia of speech relate to corticobasal syndrome and progressive supranuclear palsy?**

PPAOS is the term used when a person has an isolated speech problem.

When other symptoms appear, such as falling or problems with movement, a person may receive a broader diagnosis. A diagnosis of corticobasal syndrome or progressive supranuclear palsy is a broader diagnosis that includes these other symptoms.

## **Is there any research going on for primary progressive apraxia of speech?**

Research is ongoing. You may be asked whether you want to take part in a research study. The decision is up to you. Your decision does not affect your care.

If you decide to take part in a research study, make sure you understand:

- The purpose of the study.
- Any risks the study may have.
- How long the study lasts.
- Whether you can leave the study at any time.
- What you do as a part of the study.

If you want to take part in a research study, talk with your healthcare team.

### **For more information**

If you have questions after you read this information, please talk with your care team. You also may look on the internet for National Aphasia Association for Patient Chats. Type **PPA Aphasia Chat Signup** in the website search engine.



This information is for your education only. It does not replace medical advice, diagnosis, or treatment. New medical research or practices may change this information. If you have questions about a medical condition, talk with a member of your healthcare team.

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#### BARBARA WOODWARD LIPS PATIENT EDUCATION CENTER

Mrs. Lips, a resident of San Antonio, Texas, was a loyal Mayo Clinic patient of more than 40 years and a self-made business leader who significantly expanded her family's activities in oil, gas and ranching. Upon her death in 1995, Mrs. Lips paid the ultimate compliment by leaving her entire estate to Mayo Clinic. By naming the Barbara Woodward Lips Patient Education Center, Mayo honors her generosity, her love of learning, her belief in patient empowerment and her dedication to high-quality care.

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