

Speech and Swallowing

A Body Guide to Parkinson's Disease



About this book

GLOSSARY

Definitions for all words underlined in blue can be found in the glossary starting on page 46.

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PARKINSON'S FOUNDATION RESOURCES

Certain pages include tip sheets with practical pointers. You can find more helpful tips for managing Parkinson's-related speech and swallowing changes in the books, fact sheets, videos, webinars and podcasts in our PD library at [Parkinson.org/Library](https://www.parkinson.org/Library).



Most people with Parkinson's disease (PD) will experience changes in speech, voice and swallowing at some point during the course of the disease. The same PD symptoms that occur in the muscles of the body – tremor, stiffness and slow movement – can occur in the muscles used when speaking and swallowing.

Changes in language and cognition include: thinking skills, how quickly you process information (i.e., speed of processing), focus/attention, finding words, memory and problem solving can also affect communication. Changes associated with Parkinson's disease may also affect the ability to express and understand voice pitch changes (i.e., prosody) and facial expressions that convey emotion (e.g., happiness, sadness, humor).

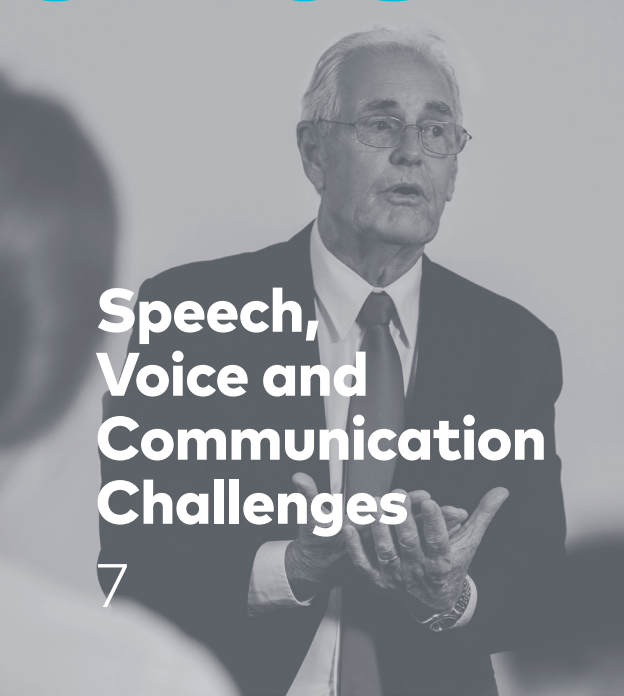
Like other symptoms of PD, difficulties with speech and swallowing will vary from one person to another. This book will provide you with information, tools and exercises to help you better understand and manage speech, swallowing, voice, communication and cognitive problems in PD. However, it is important that people with PD and their family members advocate for a referral to a [speech-language pathologist](#). This book is not intended to replace a consultation with a speech-language pathologist or other allied health specialist, but can help you to advocate for yourself or a family member by increasing your awareness of how a speech-language pathologist can help you.

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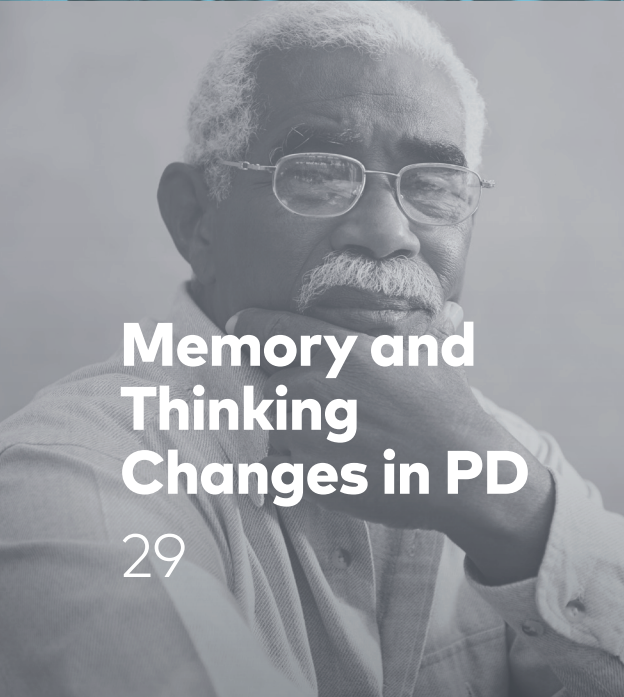
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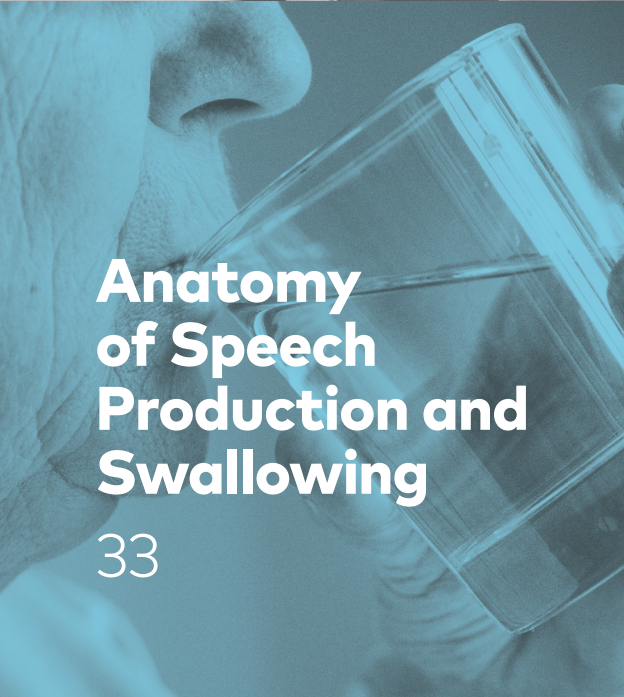
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CHAPTER ONE

About Parkinson's Disease

If you're reading this book, you are probably already familiar with Parkinson's disease, but here are some basics: Parkinson's is a progressive, neurodegenerative disorder that affects about one million people in the United States and 10 million people worldwide. It is called a movement disorder because of the tremors, slowing and stiffening movements it can cause, but its symptoms are diverse and usually develop slowly over time.

Parkinson's disease is not diagnosed with a test or a scan; instead it is diagnosed by your doctor, who asks you questions about your health and medical history and observes your movement. Your doctor may want you to have some tests or imaging. An MRI (magnetic resonance imaging) can help rule out other conditions, and a DaTScan can help confirm a Parkinson's diagnosis, if there is uncertainty. The goal of treatment is to help you manage your symptoms. Good symptom management can help you to stay healthy, maximize your quality of life and keep active. Although there is no way now to correct the brain changes that cause Parkinson's, we know that exercise can help you fight the disease and that staying healthy can prevent setbacks that make PD progress faster. Great care is the key to living your best life with Parkinson's.

Lack of dopamine in people with Parkinson's was first described in the 1960s. Dopamine is a neurotransmitter, one of several chemicals your brain cells use to send signals to one another. Soon after, dopamine-replacement therapy using levodopa became – and remains – the gold standard treatment. However, just as your doctor looks at tremors as a sign of changes in your brain, neuroscientists know that the reduction in dopamine in the brain is a sign of changes occurring in brain cells. Neuroscientists think of Parkinson's as a disease linked to several things in brain cells, from mitochondria, the power plants of the cell, to lysosomes and proteasomes, the garbage disposals of the cell. You might also hear that Parkinson's is linked to a protein in the human brain called alpha-synuclein. The exact way that all these pieces fit together remains unknown. Researchers continue to study how cells and brain networks are affected in Parkinson's to improve our understanding of the disease and potential for treatments. We do know that dopamine is not the only neurotransmitter to be affected by Parkinson's. The disease process also disrupts other brain chemicals like serotonin, norepinephrine, and acetylcholine. Changes in these chemicals can affect mood, behavior and thinking (cognition).

Your family may have questions or fears about Parkinson's and genetics. While there are several genetic mutations that can increase your risk, for the vast majority of people, Parkinson's is not inherited. There is no test that can accurately predict who will develop Parkinson's. Extensive gene and biomarker research is underway to uncover the possible precursors – not necessarily causes – to disease development.

CHAPTER TWO

Speech, Voice and Communication Challenges

About 75 percent of people with PD experience changes in speech and voice at some time during the course of the disease. These changes usually come on gradually and can vary from mild to severe.

Communication is a vital part of daily life and extends beyond speech and voice abilities. It also includes the ability to formulate your ideas into a message; understand messages and words conveyed by others; and the ability to put your ideas into words. Communication also includes the ability to use body language, gestures and voice pitch/loudness changes to emphasize ideas, add humor and convey emotions. Problems communicating can lead to feelings of frustration, depression and withdrawal. Learning how PD affects communication and what you can do about it can help you better cope with problems that you might experience.

Many of these problem areas can be improved with PD-specific exercise programs, devices that help communication and strategies/techniques that can help you and your conversation partners to communicate more effectively and efficiently.

What Can I Do to Improve My Speech and Communication?

In addition to seeing a speech-language pathologist, there are some strategies that you, your family and your friends can use to improve communication.

Take Care of Your Voice

It is important to take care of your voice. Here are some simple suggestions for good "voice hygiene."

- Drink plenty of water or other liquids each day (non-caffeine and non-alcoholic).
- Do not strain your voice by shouting over loud noise when you talk.
- Rest your voice when it is tired. Like other muscles in your body, the muscles controlling your speech need a break sometimes.
- Reduce throat clearing or coughing. Use a hard swallow or soft sound instead.
- If you have frequent heartburn or a gastroesophageal reflux disorder, talk to your physician about ways to reduce and/or eliminate these symptoms.
- Some medications can also affect your voice quality. While most PD medications do not negatively affect your voice, some medications used for other symptoms (e.g., antidepressants, allergy medicines, high blood pressure medications) can affect your voice. If you are taking one of these medications, maintaining good 'voice hygiene' becomes even more important.
- If the air is dry in your home, consider using a humidifier.

Posture

Posture is important for voice and speech. Keeping an upright posture and a straight neck (and slightly lifted chin) helps you to move air from your lungs through your vocal cords, which then vibrate to produce the sound waves that make your voice. These vibrations and sound waves are shaped by the jaw, lips, nasal cavity, teeth, and tongue to produce speech sounds. Having good posture is important for creating airflow to these structures. However, the motor changes associated with PD (and aging) can make it more difficult to maintain ideal voice and speech posture. Physical exercise, stretching, and yoga can help you to have better posture. Focusing on good posture, especially during moments where voice loudness is important, is also helpful.

Try this Posture and Breathing Exercise

Clear and understandable speech consists of sitting up as straight as possible, taking a deep abdominal breath, exhaling with good energy, closing and vibrating the vocal folds, opening the mouth widely and using precise tongue and lip movements for articulation. Try the following steps for practice:

1. Sit up straight.
2. Take a deep breath and feel your stomach area expand as you fill your lungs.
3. As you begin to exhale, start your voice on a loud and clear "ah." Think of your "ah" as coming from your breathing and being thrown across to the other side of the room in an arc.
4. Continue taking deep breaths and start your voice as you exhale. Give each word a new breath as you say any of the following:
 - Days of the week
 - Months of the year
 - Numbers 1–20
 - Letters of the alphabet

Remember to use plenty of breathing energy to power your voice and to exaggerate your tongue and lip movements. Do not strain to push your voice from your throat area.

Remember a Good Conversation Takes Two (or More) Partners

Conversation, the mechanism we use to exchange messages with others and to build/maintain relationships, is critical. Social engagement and maintaining social ties are important for both emotional and cognitive health. Remembering that an effective and efficient conversation takes at least two people is important. While there are steps that the person with PD can take, it is important that conversation partners also improve their skills for listening, sending clear messages and looking for signals of conversation breakdowns.

- Minimize distractions and focus on your conversation partner.
- Choose to have important or more challenging conversations when the person with PD and their conversation partner are well-rested and at their 'best' time of day.
- Learn to look for signals that your conversation partner is having difficulty following or understanding what you said. These signals can include: requests for repetition or responding with 'huh' or 'I didn't get that'. However, these signals can also be as subtle as a quizzical facial expression, failure to respond at all or appropriately, fidgeting, looking distracted or gradually withdrawing from the conversation. Make sure you send clear signals when you need help or when you need a message clarified by your conversation partner.
- Provide help when needed. Use a calm and reassuring approach. Repeat or rephrase what you said (without elevating your voice loudness or excessively slowing your speech rate).
- For those with more severe cognitive impairments, you may want to use multimodal cues such as pictures, gestures or words to get your meaning across or to clarify your message in multiple ways.
- Resist blaming your conversation partner (or yourself) when a conversation breakdown occurs. Conversations break down because the interaction between two (or more) people went wrong. Work to find the source of the misunderstanding (e.g., a word not understood, changing topics without ample warning). When found, repair the breakdown (i.e., resolve any misunderstandings) and get the conversation back on track.
- Resist the urge to give up or walk away from a conversation. When possible, try to clarify the misunderstanding and keep the conversation going. However, sometimes taking a break from the conversation does help. Coming back to a topic or a conversation at a later time can be useful, especially when partners become frustrated.

- Verify that you understood the message correctly. Restate, rephrase or ask a direct question for clarification if you are unsure that your message was understood or whether you understood your partner's message before moving on in the conversation. (e.g., "Are you enjoying this show?"; "Did you say you wanted to go to the movies tonight?").
- Be patient with your conversation partner. Be empathetic in the context of difficult communication moments.
- Remember that conversations are also about bonding and maintaining relationships. The words and speech sounds do not always have to be 'perfect' for there to be an emotional connection about the topic. Minimize attempts to correct words or speech sounds and instead focus on the intent, the general message and the emotions being expressed.

Facial Exercises

Many individuals with PD request face and mouth exercises to reduce the effects of rigidity of muscles in the face and to increase facial expression. Some people with PD may find exercises helpful. Try the exercises below.

Start with 10 repetitions of each of the facial movements explained below. Each exercise should be completed with purposeful movements and sustained effort. For instance, if smiling is the exercise, try to smile as wide as you can, and hold each smile for 5–10 seconds. Make sure you continue to breathe throughout the exercises. Try practicing in front of a mirror, so you can see your muscles work.

1. Smile – hold – relax – repeat.

2. Pucker your lips – hold – relax – repeat.

3. Alternate puckering and smiling.

Pucker as tightly and smile as hard as you can. To increase the benefit of this exercise, knit your eyebrows together when you pucker, and raise the brows when you smile.

4. Open your mouth and move the tip of your tongue all around the lips.

The tongue should touch every part of the lips: bottom, top and both corners. Movements should be deliberate, not darting.

5. Open your mouth and move the tongue around the gumline.

Move your tongue over the back of top and bottom teeth, front of top and bottom teeth and edges of top and bottom teeth.

6. Open your mouth as wide as you can – hold – relax – repeat.

7. Say KA – a prolonged sound – as loud and hard as you can.

8. Say PA-TA-KA as loud and fast as you can.

Monitor Your Hearing Health

Hearing loss is the third most common health problem in the United States. It is more common in people over the age of 60. While PD does not cause hearing loss, recent studies suggests that people with PD may be at higher risk for hearing loss. Hearing loss negatively affects communication whether it occurs in the person with PD or their conversation partners. People are often unaware of how severe their hearing loss is. Signs of hearing loss may include turning up the radio or TV, more difficulty understanding speech in restaurants or noisy situations, difficulty understanding others over the telephone and asking others to repeat themselves. If you suspect that you have hearing loss, contact your physician or local audiologist for a hearing assessment and treatment options.

Keep Talking

The best way to practice talking is to talk! Do not limit your speaking because you feel self-conscious or have difficulty. The saying "use it or lose it" applies to speech, too. Here is a list of possible conversation topics. If you don't have a companion to talk to, talk out loud to yourself!

- Talk about your family: who is related to whom, where everyone is from, etc.
- Describe a favorite hobby or pastime in detail.
- Give a report about a trip or vacation you enjoyed.
- Discuss a period of time or particular event you recall from childhood.
- Describe your favorite food or restaurant.
- Give your opinion and thoughts about a favorite topic.
- Talk about things you hope to accomplish in the next year.
- Acknowledge people by sharing what it is you most appreciate about them.

Singing and Voice

Singing is a great exercise for the voice! Singing uses the same muscles that are used for speech. Try taking a deep breath and singing your favorite songs. Gently reach for the high and low notes and sing the lyrics as clearly as you can. This is not only great exercise – it can help you feel good emotionally, too. If you are a singer, you may notice that your vocal range changes with PD. Be careful not to strain or force your voice beyond what is comfortable and to use your good 'voice hygiene' tips. You should not feel any pain when singing or speaking. If you do feel pain, it may be a sign that you are straining your voice or may indicate a more serious condition. If pain occurs when singing or speaking, discuss these symptoms with your doctor.

See Chapter 6 for details about the anatomy of speech production.

Tips for Family and Friends

Family and friends are often the best support system for people with PD. There are several things you can do to help your loved one communicate more effectively.

The first and most important thing is to encourage your family member or friend to consider speech therapy when changes in communication are noticed. A speech-language pathologist can develop a program tailored to the person with PD's needs. The following tips and strategies are also helpful:

- Get face-to-face when talking. Try to maintain a distance of no more than 3-6 feet. Minimize having conversations between rooms or across long distances. Make sure that the lighting in the room is optimized so that you can see your partner's face and mouth movements clearly. Words, facial expressions and gestures are easier to understand when you can see and hear them being produced.
- Reduce background noise. Turn off the radio and TV, close car windows and shut doors to noisy areas.
- Be aware that people with PD may not accurately express their emotions through facial expressions because of rigid facial muscles. This can be complicated by their quieter voices and sometimes difficult to understand words. Instead of assuming that your family member/friend does not understand your message or that you understood theirs correctly, check in and verify that the message was understood correctly.
- Be patient. Allow ample time for the person with PD to communicate. Don't rush or force responses.
- When necessary, 'make room' in the conversation for the person with PD by opening the conversation for their turn or slowing down the pace of conversation. For example, "Tom and I were just talking about this yesterday and he had some great ideas... Tom I'm sure Sarah would love to hear your thoughts."
- Preserve dignity and personhood. Minimize talking 'for' the person with PD or filling in their responses unless they ask you to do so or you have asked (and received) their permission to respond for them.

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- In cases where cognitive decline is more severe:
 - Use shorter sentences with one idea per sentence when communicating with the person who has PD.
 - Use common vocabulary and words that are familiar to the person.
 - Ask questions that can be answered in a short sentence or with a "yes" or "no" response.
 - Alternatively, ask questions and then provide two or three options to help to help the person make their choice clear (e.g. Do you want juice? Apple or orange?)
 - Use multimodal supports including writing down key words/short phrases that capture what you are trying to communicate, pictures and gestures to help reinforce the message you are conveying. These multimodal supports can also help provide a way for the person with PD to respond by pointing to a picture or to a word printed on a page. Provide messages in a number of different ways to help enhance understanding.
 - Provide shorter chunks of information and allow extra time to process information. Resist slowing down your speech in an exaggerated way or overexaggerating your speech production – in some cases this can worsen communication.
 - Stay calm. Do not raise the loudness of your voice in an exaggerated way when repeating or rephrasing information. This can be emotionally upsetting for the person with cognitive impairment.

CHAPTER THREE

Swallowing Changes

People with PD may notice changes or difficulty with chewing, eating or swallowing. These changes can happen at any time, but they tend to increase as PD progresses.

While there are some common signs of difficulty swallowing, it is important to remember that people with PD may not always show (or be aware of) these signs. For example, PD can negatively affect the cough response, a natural reflex that protects the airway during eating, drinking or swallowing saliva. For this reason, people with PD may not always demonstrate coughing during meals even though they have problems with swallowing.

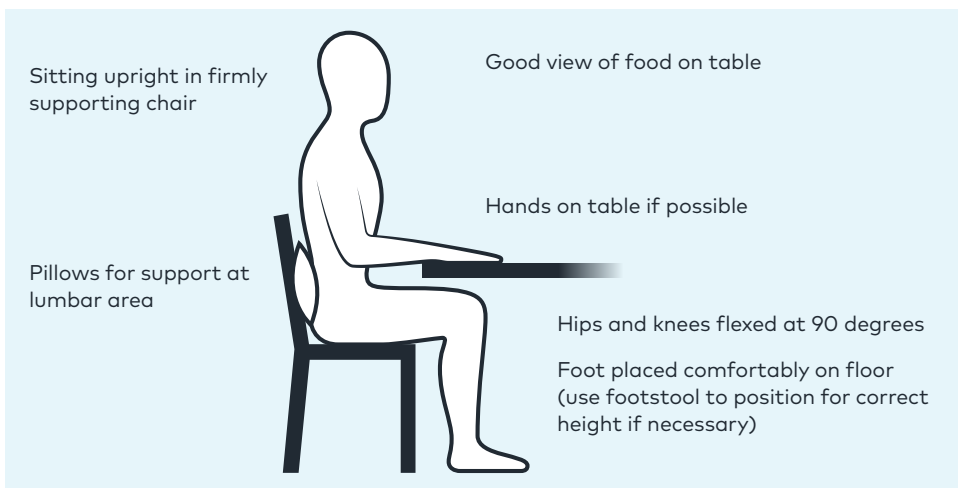
Assessment by a speech-language pathologist, which may include an X-ray of your swallowing (i.e., a [modified barium swallow study](#), also called a [videofluoroscopic swallow study](#)), or a [fiberoptic endoscopic exam](#) of your swallowing (i.e., direct examination of your throat during swallowing using a flexible tube with a camera on the end), is important for assessing swallowing problems in PD.

Common symptoms of swallowing problems include the following:

- Slowness in eating.
- A sensation that food is caught in the throat.
- Coughing, throat clearing or choking while eating or drinking.
- Difficulty swallowing pills and drooling.
- Food sticking in the mouth or difficulty chewing.
- A sensation that swallowing takes effort and a feeling of fatigue when eating.

How Can I Manage My Swallowing Problems?

People with PD can have a variety of different problems swallowing that range from mild to severe. The techniques and strategies for improving your swallowing are best developed with a medical team that includes a speech-language pathologist and may also include a registered dietitian. Some problems with swallowing may require you to change the texture of your food and possibly the thickness of the liquids you consume. Other problems may require you to learn to swallow in a different way using a swallowing strategy. Your speech-language pathologist can develop a customized strategy, diet modification and exercise program for you. When it comes to swallowing problems, there is no 'one-size-fits-all' approach. The same strategies that may be helpful for one person may not work (or may create more difficulties swallowing) for another. The following are general tips and techniques that can help improve your eating, chewing and swallowing.



- Always sit upright (preferably in a chair) when eating, drinking and taking pills. If you are able, sit upright for 30–60 minutes after eating.
- Chew small amounts of food well and swallow it all before eating more.
- Put your fork down between bites to slow yourself down.
- If food feels stuck, swallow multiple times (at least twice) after every bite.
- Take small sips when drinking. Take one sip at a time. Do not gulp or tip your head backward when drinking.
- Be wary of straws. Straws are useful when someone has severe tremors or [dyskinesias](#) but can put too much liquid, too far back into the mouth, too quickly before the airway has a chance to close. Try to keep the straw only at the front of your tongue.
- Keep your chin slightly down or at least parallel to the table. There is sometimes a tendency to lift the chin when drinking the last little bit of liquid in a cup or bottle. When the chin is raised, there is an increased risk of getting fluid in the lungs. Be cautious when drinking from cans, soda/pop bottles, and water bottles. Consider using a cup or water bottle with a lid or removable cap, instead of those with valve-type nozzles (e.g., push/pull valves, spouts).



- Don't talk with food in your mouth.
- Minimize distractions during meals. Distractions may cause you to be less aware of your chewing and swallowing and may increase the risk of choking.

- Consider eating several small meals during the day. This may help reduce fatigue during eating that occurs because of difficulty swallowing or difficulty feeding yourself.
- Be aware of food sticking in your mouth. Use your tongue to help clear food. Make sure that your mouth is clear of all food before taking additional bites.
- If you have difficulty chewing or clearing food from your mouth, choose soft, moist foods (e.g., lasagna, pureed soups). Avoid, dry or crumbly foods that fall apart easily. Use caution when eating foods with both a liquid and solid component (e.g., fruit cocktail) and consider draining off the liquid portion.

The types of foods you eat can affect chewing and swallowing. A speech-language pathologist or registered dietitian can recommend foods and beverages that are easiest to swallow. An occupational therapist can recommend various types of helpful tools that can make eating a more pleasant experience.

You can also consult our online resources for Caregivers, including two videos on Mealtime and Swallowing, at Parkinson.org/Mealtime.

What Can I Do About Drooling?

If you tend to drool, you probably don't have more saliva than you used to have; you are just not swallowing it as frequently or as automatically as before. Frequent sips of water or sucking on ice chips during the day can help you swallow more often. When you are not talking or eating, keep your head up, with your chin parallel to the floor and your lips closed. Sugar tends to produce more saliva in the mouth, so reducing sugar intake can be helpful.

One trick is to suck on hard candy or chew gum, preferably sugarless. Candy and gum activate the jaw and the automatic swallowing reflex and can help clear saliva, providing temporary relief from drooling.

Another tactic is to wear a sweatband on your wrist. This can be used to discreetly wipe the mouth as necessary and is a relatively inconspicuous accessory.

If these lifestyle strategies are not effective, there are prescription medication options that may help manage drooling by decreasing saliva production. These medications should be used with caution, as they can lead to dry mouth, which can increase tooth decay and impact overall oral health.

The following anticholinergic medications, though not FDA approved for drooling, can decrease saliva production as a side effect:

- **Glycopyrrolate, trihexyphenidyl, benztropine and hyoscyamine.** Oral anticholinergic side effects include drowsiness, confusion, dizziness, blurred vision, constipation, flushing, headache and urinary retention. These medications should be used with caution in older adults.
- **Scopolamine transdermal patch.** Applied behind the ear, this patch slows saliva production as the medication is absorbed into the bloodstream. Side effects are similar to oral anticholinergics.
- **1% atropine eye drops.** One to two drops are placed under the tongue each day. Although atropine is another anticholinergic drug, side effects are much less likely with this local treatment.

Botulinum toxin injections are another option for treating excess saliva and drooling:

- **Incobotulinum toxin A (Xeomin) and rimabotulinum toxin B (Myobloc)** are FDA-approved for excess saliva and drooling.
- **Onabotulinum toxin A (Botox) and abobotulinum toxin A (Dysport)** are not FDA approved for drooling but are used off-label to decrease saliva production.

An injection of botulinum toxin into the salivary glands in the cheek and jaw area can decrease saliva production with minimal side effects. Potential side effects include dry mouth, difficulty swallowing and weakness of the muscles in the jaw area. The benefit of botulinum toxin injections can last up to three months (or longer in some cases) before repeat injections are needed. Although botulinum toxin can be effective for drooling, it is costly, so doctors may recommend other treatments first.

Many people with PD struggle with thick phlegm or mucus in the throat. Drinking more water will help thin this phlegm. Drinking carbonated beverages or tea with lemon may also help. Eating or drinking dairy products can make phlegm worse.

CHAPTER FOUR

Getting the Help You Need

Early intervention with a speech-language pathologist is key to maintaining and improving communication and swallow function. It is easier to learn strategies and techniques than it is to rebuild what has already been lost. Still, it is never too late to get help for speech and swallowing. Improvements following therapy at whatever stage of PD are often surprising and rewarding.

What Is a Speech-Language Pathologist?

Speech-language pathologists are licensed healthcare professionals trained to evaluate and treat people with speech, voice, language, thinking skills, memory and swallowing problems. Many have completed additional training for working with people who have PD. In the United States, a speech-language pathologist has a graduate degree and is certified by the The American Speech-Language-Hearing Association (ASHA). Speech-language pathologists in the United States are licensed by the state where they work.

You can find speech-language pathologists at local hospitals, rehabilitation centers and at some university-based training clinics. They also provide

services to individuals living in care centers and those living at home. In addition, many speech-language pathologists have private practices. In some states, provinces and countries and under some payment systems, speech-language pathologists may provide telehealth services for certain types of interventions (e.g., services provided typically through a computer or teleconferencing system). Your speech-language pathologist can let you know if you are eligible for telehealth services. Depending on the clinic and the payer (your insurance company or other service funder) a referral from a physician may be required. Evaluation and treatment costs are usually covered in part by Medicare, Medicaid or other medical insurance providers.

How Can I Find a Speech-Language Pathologist?

Your physician or other health care provider may be able to recommend a speech-language pathologist who is experienced with PD. To find a speech-language pathologist in your area, call the Parkinson's Foundation Helpline 1.800.4PD.INFO (1.800.473.4636). You can also visit the website of the American Speech-Language-Hearing Association at www.asha.org/profind or call 1.800.638.8255.

What Happens When I Visit a Speech-Language Pathologist?

At the appointment, the speech-language pathologist will likely evaluate your speech, voice, communication, swallowing and memory/thinking function. If indicated, you and your speech-language pathologist will establish your treatment goals and develop a plan of care that is consistent with your goals. Treatments may focus on improving specific aspects of or overall communication skills and, in some cases, swallow function and/or thinking skills.

When Should I See a Speech-Language Pathologist?

As soon as you or a care partner notice changes in speech, swallowing or memory and cognition, it is time to seek help from a speech-language pathologist. Self-assessments included on pages 41–44 can help you decide if you should see a speech-language pathologist.

What Types of Treatments are Available

The number of treatments available for speech, voice, communication and swallowing problems is expanding. Your speech-language pathologist may suggest general strategies and exercises for helping your speech, voice, communication and swallowing. There are also therapies designed specifically for and tested in PD. The following is a brief overview of some of the PD-specific speech, voice and communication treatments currently available:

Treatments for Speech, Voice and Communication

THE LEE SILVERMAN VOICE TREATMENT

The Lee Silverman Voice Treatment (LSVT) LOUD is an evidence-based, intensive speech therapy method for people living with Parkinson's disease and other neurological conditions. Treatment is designed to help people with PD relearn the habit of using a louder voice and clearer speech by strengthening the muscles used to produce voice and speech. Treatment consists of:

- Four, one-on-one speech therapy sessions a week for four consecutive weeks.
- Daily home practice on therapy days and non-therapy days.
- Ongoing daily home practice after initial treatment to maintain speech improvements.

A speech-language pathologist who has been certified in LSVT delivers the treatment. For more information about LSVT or to find an LSVT-certified provider, visit www.lsvtglobal.com or call 888-438-5788.

PARKINSON VOICE PROJECT SPEAK OUT!

SPEAK OUT! is an evidence-based speech therapy approach developed by Parkinson Voice Project. The program is designed to help people with Parkinson's strengthen the muscles used for speaking and swallowing and to speak with intent. Treatment consists of:

- Eight to 12 speech therapy sessions.
- Daily home practice using the SPEAK OUT! Workbook.
- Speech and singing groups.
- Re-evaluation every six months.

A speech-language pathologist who has been certified in SPEAK OUT! delivers the treatment. For more information about SPEAK OUT! or to find an SPEAK OUT! provider, visit www.parkinsonvoiceproject.org or call 833-375-6500.

SPEECHVIVE

The SpeechVive device is a wearable device that plays multi-talker babble noise in one ear while the person wearing the device is talking. The noise is voice-activated, and therefore, is only present when the person speaks. As a result, it does not interfere with the ability to hear others in conversation.

The noise creates the “Lombard” effect, which prompts speakers to automatically speak louder, clearer and more slowly over the background noise. The SpeechVive device has been shown to improve vocal intensity, speech rate, and speech clarity in people with PD.



Research into the lasting benefits of SpeechVive treatment is ongoing. However, this treatment may have several benefits over traditional behavioral therapy. First, the use of a natural external cue (noise) and an automatic response (Lombard Effect) may reduce the amount of mental effort required. The person does not need to remember to speak loudly or use therapeutic strategies while speaking with others because the device prompts the individual to use a louder and clearer voice automatically. Since the device is portable and wearable in everyday life, people may see immediate benefits in conversations.

VOCAL FOLD INJECTIONS

Vocal fold injections have been used to treat voice quality and loudness in PD. The purpose of these injections is to build up vocal folds that do not close completely while talking. The procedure involves injecting natural or synthetic materials directly into the vocal folds to improve the voice, specifically loudness and quality. The effect typically lasts about three to six months, though sometimes longer. Injections can be repeated. However, if benefits are noted, more permanent options may be explored.

The research on the effectiveness of vocal fold injections is preliminary and ongoing. An ear, nose and throat (ENT) specialist performs this procedure and can help you understand if it is an appropriate treatment for you.

Treatments for Rapid Speech Rate

Treatment options for speech rate problems are not as extensive as for other areas of speech. Treatments such as LSVT, Speak Out! and SpeechVive can help reduce speech rate, in addition to their primary goal of improving voice loudness and speech clarity. Your speech-language pathologist may try several additional techniques to help you slow down your speech rate. Pacing boards and pacing smartphone apps can help some people speak at a slower rate while using the device, although gains are typically modest. Devices that play your own voice back to you using either a slight delay (delayed auditory feedback – DAF) or a shift in frequency/pitch (frequency-shifted auditory feedback – FSF) have been explored in a limited number of studies in PD. DAF and FSF are approaches usually used with people who stutter. Using a device (either a hearing aid-like device or earphones) when speaking, the person's voice is played back to them in an altered way. SpeechEasy is one such commercially available device being studied in PD. Listening to your own speech at this small delay (or frequency shift) while talking affects how you perceive your own speech and makes it difficult to speak quickly. Consequently, people tend to slow down automatically. One concern is that these devices may affect the naturalness of speech production. These approaches continue to be examined in PD.

ASSISTIVE COMMUNICATION DEVICES

In some cases, advancing PD, fatigue or other illness may make it difficult for you to use your normal voice. At times, it may seem difficult to talk at all. When this happens, using an augmentative or assistive communication device can make it easier to communicate.

Assistive devices come in all shapes, sizes and prices. A personal amplification system is the device most often used by persons with PD. It is most effective for people who have a soft voice. Using a microphone and speaker system, the device amplifies speech. The microphone can be hand-held, worn on the head like a pair of glasses or as a headset or attached to a shirt pocket or collar. The amplifiers do not improve breath, articulation or rate of speech. They may not be particularly effective for individuals who have difficulty producing any (or only intermittent) voice output or those with excessively rapid/stutter-like speech.

Other communication devices range from hand-made communication boards to sophisticated computerized equipment. While these devices can be used by anyone with PD, they are usually more appropriate for individuals with advanced motor disease and those with parkinsonism disorders such as multiple system atrophy and progressive supranuclear palsy. Recent advances in computers, smartphones, tablet devices, and apps mean that devices to support communication are becoming more accessible. Depending on the device, the cost may be covered in part by private insurance companies, Medicare, Medicaid or other provincial/state-based funding programs. Some people may be hesitant to use a device to help them to communicate. They worry that using a device may make them 'stick out' to others or that using a device will be cumbersome. However, for some individuals with PD (and for many individuals with other Parkinson's-like disorders), communicating more effectively outweighs the potential burden and stigma of using a device.

New technologies allow individuals to 'bank' their own voice, also known as voice banking. Banking your voice when it is still strong may allow you to use your own voice later, if it becomes necessary to use a device. Voice banking means that a device that generates speech can be trained to use your own voice (banked earlier by you) instead of a more generic computer voice. Voice banking can also be used to preserve your voice for use in voice mail messages or other technologies should your voice/speech become more difficult to understand or more difficult to use. There are several apps and software programs that allow you to self-bank your voice. However, speech-language pathologists and clinics that specialize in augmentative and assistive communication devices also are able to help you with voice banking.

A speech-language pathologist can help recommend a device that is appropriate for you. However, because of the complexity of symptoms in PD you may see a team of professionals including a technology expert and an occupational therapist to help you select and set up the best device for you.

CONVERSATION PARTNER TRAINING

Speech-language pathologists are communication experts. Conversation partner training is an established intervention in other disorders (e.g., stroke, traumatic brain injury) and is increasingly studied in PD. Conversation partner training involves working with the person with PD and their family members (or friends) to learn ways to support the person with PD in expressing and understanding messages during conversations and daily activities. These treatments do not address voice loudness specifically, nor do they improve those motor systems used to produce voice and speech. Instead, they focus on strategies for improving how people get their messages across and how they understand messages expressed by others. Currently, PD-specific strategy and conversation partner-training programs are in the development and testing stage by researchers.

Swallowing Treatments

A speech-language pathologist can develop a treatment plan for eating and swallowing challenges that is consistent with your quality of life goals. Left untreated, issues with eating and swallowing can lead to weight loss, nutritional deficiencies, respiratory infections/pneumonia, difficulty meeting hydration needs and, in more serious cases, death. These treatments largely fall into three categories: diet modification, swallowing techniques and strategies and exercises.

DIET MODIFICATION

Diet modification includes changing the consistency of the foods you eat and the liquids you drink (e.g., thickness) to make them easier to chew and safer/less fatiguing to swallow. In severe cases where people cannot swallow safely (or consume enough food), taking nutrition through alternative means, such as a gastrointestinal feeding tube, may be recommended. Changes in diet may be temporary or permanent. Because food plays such an important role in our society, our health and our culture, decisions around diet changes and whether to take nutrition through tube-feeding methods are often emotional for people with PD and their families. Your speech-language pathologist, physician and your dietitian will work with you to develop a plan that balances your safety, quality of life and values.

Sometimes swallowing problems can be limited to taking pills. There are a number of ways that swallowing pills can be made easier. A speech-language pathologist can work with your physician, nurse, pharmacist or dietitian to identify the best options for you. In some cases, medications can be taken with thicker liquids or foods to make them easier to swallow. In other cases, crushing medications or converting them to a liquid form can be helpful. Because modifying a medication's texture (such as crushing) and taking it with some foods may impact its effects, always be sure to make decisions on modifying medications in consultation with your physician, nurse, pharmacist and/or dietitian.

SWALLOWING TECHNIQUES/STRATEGIES

A speech-language pathologist may also work with you on different ways of positioning your head during eating, chewing/moving food in your mouth and swallowing that can help you to clear food from your mouth and move it into your esophagus while minimizing the risk of food/liquid entering your lungs (aspiration). Other strategies may require you to use special utensils, cups and/or restrict your bite size. Swallowing techniques, postures and strategies are commonly used alongside diet modification to help people with PD eat safely and with less fatigue.

EXERCISES

More research is needed into specific treatments that improve swallowing for people with PD. Your speech-language pathologist may recommend exercises for the lips, tongue, jaw and throat that help you better clear food from the mouth and help you swallow with less risk of food/liquid going into your lungs (aspiration, choking). Some speech-language pathologists may use videos of your swallow or other forms of biofeedback to help you develop a stronger swallow. Other exercises target the breathing muscles, alongside the muscles that close off your airway during swallowing. By strengthening the muscles that help you to close your airway and those that help you to have a stronger cough response when food/liquid gets close to your airway, you can swallow more safely. Expiratory Muscle Strength Training is one such exercise program currently being investigated that uses a special device to help strengthen your breathing and airway closure muscles. Because many of the muscles used for swallowing and chewing are also used in speech, speech treatments such as the Lee Silverman Voice Treatment have also been shown to improve swallowing in some individuals with PD.

CHAPTER FIVE

Memory and Thinking Changes in PD

Speech-language pathologists can be helpful when dealing with changes in memory and thinking that sometimes occur as PD progresses. Slowness in responding, day-to-day forgetfulness, trouble concentrating, difficulty dual-tasking, or retrieving common routines for completing daily activities can be signs of changes in thinking.

It is important that your healthcare team separate out symptoms of cognitive impairment from changes that occur in depression, which can mimic some signs of cognitive decline. Sometimes PD medications, which are so important in helping the physical symptoms of PD, can make a person less alert and more likely to be confused and can even cause hallucinations.

Most of us probably have experienced short-term memory lapses. Trying to remember all of the items needed at the grocery store, what you went into the basement to get or what you did three days ago can be difficult at times. Some changes in memory seem to be a part of the normal aging process. People with PD experience these same challenges but report that their problems seem more severe or happen more often than would be expected due to normal aging.

Thinking changes can be a challenge. They may include any or all of the following:

- Reduced ability to concentrate or think through an activity.
- Reduced ability to solve problems.
- Slowness in responding or needing increased time to think through information.
- Requiring additional time to think of what you want to say.
- Difficulty thinking of a specific word you want to use.
- Loss of your train of thought while speaking.
- Being easily distracted.

If you are concerned about changes in your memory, thinking or concentration, ask your physician for an evaluation. Adjusting the dose of or discontinuing a particular medication can often correct the problem. The physician can also assess the cause of cognitive problems, such as undetected depression or underlying infection.

Your physician may refer you to a speech-language pathologist, neuropsychologist or occupational therapist who can further evaluate memory and thinking skills and their impact on your daily activities. He or she may work on a team with other health care professionals, such as nurses and social workers. A comprehensive evaluation can pinpoint the exact nature of the memory and thinking changes. It can lead to therapy or other strategies to make living with PD easier and safer, giving you more independence and self-confidence.

TIP

For more information on thinking changes, get your free copy of our book *Cognition* by calling the Helpline at 1-800-4PD-INFO (473-4636) or online at Parkinson.org/Books.

Memory Joggers

- Keep a detailed diary of events and review it every day. Note important events or tasks that you need to complete.
- Keep a calendar of appointments and engagements and review it daily.
- Have paper and pencil by each phone in your home so that you can take messages easily.
- Organize lists in categories to stimulate memory.
- Focus on remembering main points, not trying to recall every detail.

Brain Power Boosters

- Exercise daily. To boost mental and cognitive health consider outdoor activities, such as short walks in the neighborhood, sweeping sidewalks or gardening. Consider joining a new class that is both physically and mentally stimulating such as yoga or dancing.
- Read and discuss articles in the newspaper or in magazines.
- Read for pleasure. Use a red pen or highlighter to underline or circle important information as you read.
- Do crossword puzzles or word search puzzles.
- Go through old photos and make memory books for your children and grandchildren. If you enjoy storytelling, consider writing or recording your life history (or the history of other family members) for your family and friends. This is a great activity to do jointly with other family members.
- Play board or card games.
- Consider getting involved in a social or service organization. Volunteer for a local organization (e.g., library, sports programs), or even with the Parkinson's Foundation. Many people find that giving to others helps them to maintain a healthy outlook on their own life.
- Learn a new skill, take a class, learn a new language or musical instrument. Many community centers, colleges, and universities offer programs for adult learners that will engage you mentally, provide opportunities to meet others and help you maintain brain health by learning new information.
- Create regular opportunities to socialize with others.
- If you are working, continue to do so as long as you can and have a desire to. Work with your employer and rehabilitation therapists (e.g., speech-language pathologists, occupational therapists, physical therapists, vocational rehabilitation specialist) to make any necessary adjustments that help you perform your best at work.
- Plan a household job to do every day.

Rehabilitation therapists, especially occupational therapists and therapeutic recreation specialists, can help adapt most activities and hobbies so that you can engage in meaningful life events at all stages of PD. Discuss any activity limitations with your physician to help guide their medical management and their referrals to experts who can help you stay engaged in meaningful activities that are physically and mentally stimulating.

Tips for Family and Friends

- **Socializing in small groups or one-on-one will probably be more satisfying than trying to socialize in large groups.** Talk beforehand about who will be in the group and what possible topics may come up. A little preparation ahead of time may be helpful.
- **Allow individuals with PD ample time to process what has been said and to respond.**
- **Don't jump from topic to topic during conversation.**
- **Plan activities that are important and meaningful to the person with PD.** Learn to break activities down into manageable steps so that the person with PD can fully participate in their life (e.g., helping prepare the salad for dinner, even if he/she can no longer stand and cook at the stove).
- **Avoid quizzing the person with PD.** Daily activities are not an opportunity to test people about the date or what they remember. Provide help and support instead of quizzing.
- **If the person has difficulty initiating an activity, guide them in getting started and let them know that you are there to help.** Once started, people with cognitive problems can sometimes retrieve the steps of the task and take over on their own.
- **Be concise when speaking about specific people and events.** Use proper names rather than pronouns (say "Sally" instead of "she").
- **Every morning, review upcoming activities for that day.** Write down important information, such as where you are going and when you will return, on a dry erase board in a highly visible area of the home.
- **Keep routines the same and perform activities of daily living in the same order every day.** People who have memory problems function better during the day if they know what is going to happen and when.
- **Remember that changing environments, people and routines can be distressing for people with cognitive challenges** (even when those changes are associated with something pleasant – like a vacation). This can cause distress and may result in resistance behaviors or increased confusion and agitation. Prepare people (reminding them frequently if need be) for changes and give ample time for them to adjust.
- **Leave ample time to get from place to place.** People with PD need more time – and that is exaggerated in the context of cognitive impairment. Rushing people through tasks or from place to place may only increase confusion, levels of frustration and risks making the situation less safe.

CHAPTER SIX

Anatomy of Speech Production and Swallowing

Sometimes it can be difficult to adjust how we do things when we don't have a full understanding of the process in which the action takes place. In this chapter, you will find explanations of the anatomy behind speech and swallowing, which may help you understand specifically where in the process you are struggling.

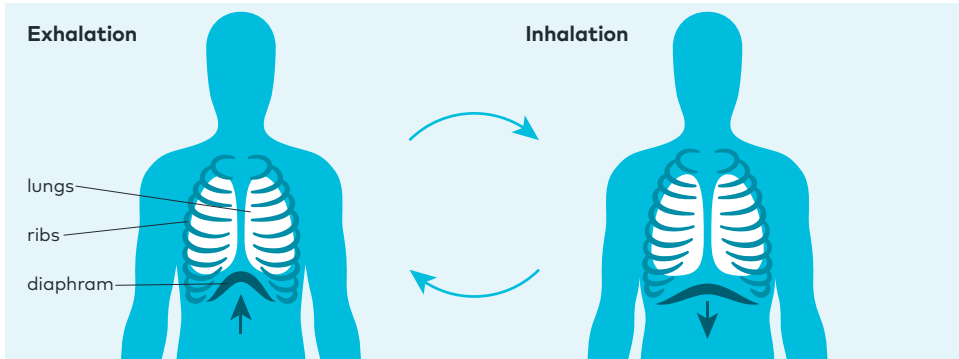
Anatomy of Speech and Voice: How Do We Produce Speech and Voice?

To improve communication, it is helpful to understand the five parts of speech and voice production. Each part builds upon the next, and all work together as a system.

1. Respiration

Respiration, or breathing, is the fuel for speaking. The respiratory system is composed of the lungs, ribs and [diaphragm](#). The diaphragm is a dome-shaped muscle that sits just under the lungs and on top of the stomach area. As we fill our lungs with air, the diaphragm flattens and the rib cage expands outward and rises slightly. This part of the respiratory cycle is called inhalation. Once the lungs have filled, the exhalation part of the

respiratory cycle begins. As the air leaves the lungs, the diaphragm rises and the rib cage moves inward and downward. It is this cycle of inhalation and exhalation that supports our voice and gives us the power for a strong voice. Voice starts at the top of the breath, at the moment when the cycle changes from inhalation to exhalation. Muscle stiffness and reduced muscle movement make it more of a challenge for people with PD to fill the lungs completely and to forcefully exhale.



Control of inhalation and exhalation enables a person to maintain adequate loudness of speech throughout a conversation. If the breathing muscles are not well-controlled, the voice tends to fade away at the end of a sentence. If too few breaths are taken, there is not enough respiratory support for a strong voice. A person with PD may speak at the bottom of his or her breath – inhale, exhale, then speak – rather than at the top of the breath – inhale, speak, exhale remaining air.

2. Phonation

Your vocal folds, also called vocal cords, are two small bands of muscle that sit horizontally across the top of the airway and lie within the larynx, or voice box. During the exhalation portion of the breathing cycle, as air is rushed up through the windpipe, the vocal folds meet and begin to vibrate rapidly. This vibration is the “buzz” of our voice. If the vocal folds do not meet well or do not maintain a consistent vibration, the voice may sound hoarse or breathy and soft. If the vocal folds do not stretch well, the voice may sound monotone or flat.

Vocal cords from above



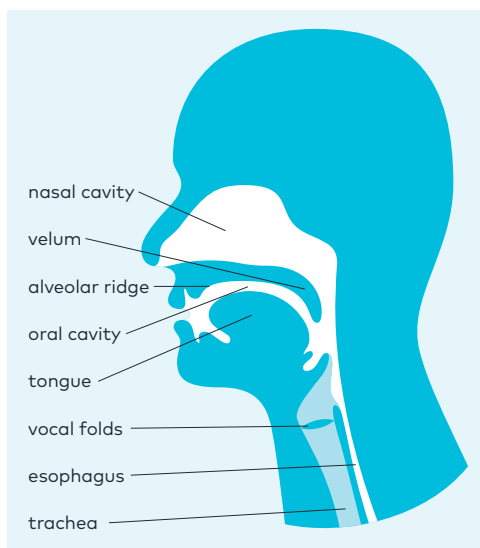
At rest
During normal breathing, the vocal folds, commonly called the vocal cords, are open



Speaking
When speaking or singing, the folds resonate, or move back and forth. This produces sounds that become words.

3. Resonance

Resonance determines the richness of the voice. As the buzz of the voice moves up from the vocal folds, the amount of opening of the throat, mouth and passage to the nose subtly change the tone. People with PD have a tendency to resist opening the mouth widely enough, resulting in the voice sounding thin or flat. If the soft palate, located at the back of the roof of the mouth, doesn't close off the passage to the nose, the voice may have a nasal quality.



4. Articulation

The articulatory system is comprised of the muscles of the face, lips, tongue and jaw. While speaking, these muscles move at rapid speeds in a coordinated manner, turning the buzz of the voice into understandable sounds and words. If these movements are slowed because of muscle stiffness, or if they don't move to all of the right targets within the mouth, the speech will sound slurred or mumbled. Sometimes people with PD have a rate of speech that is simply too fast to allow the tongue or lips to reach all of the targets. Tremor or dyskinesias in the oral structures can make this coordination even more difficult.

5. Facial Expression

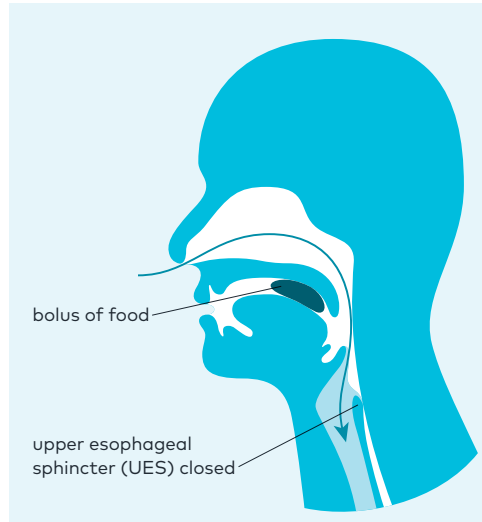
Much of what we say is communicated by our facial expression. Unfortunately, due to muscle rigidity, many people with PD have difficulty moving the facial muscles. Think about a time when your face was very cold. You might have noticed that it was difficult to move your facial muscles, and your speech became slightly slurred or unclear. This sensation is similar to the one experienced by individuals with reduced movement in the facial muscles. When there is reduced facial expression, the listener may think that the person with PD is uninterested in conversation, not understanding what is said or even angry.

Anatomy of Swallowing

There are three stages of a swallow: oral, pharyngeal (also called transition) and esophageal. All three work together as a system, and all may be affected by PD.

1. Oral Stage

The oral stage begins when food is placed into the mouth, chewed, formed into a ball on top of the tongue and moved to the back of the mouth. Because the tongue, lips, jaw and face are all composed of muscles, the oral stage of swallowing can be affected by muscle rigidity, reduced movement, tremors or dyskinesias in the same way mobility in an arm or leg can be affected. Changes due to PD in this stage of swallowing can include a feeling of excess saliva in the mouth, food or liquid slipping out from the lips, dry mouth, food trapped around the gumline and teeth, difficulty moving food to the back of the mouth and difficulty starting the swallow itself.



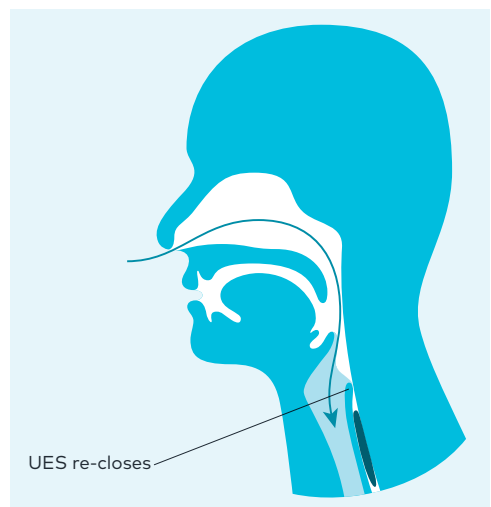
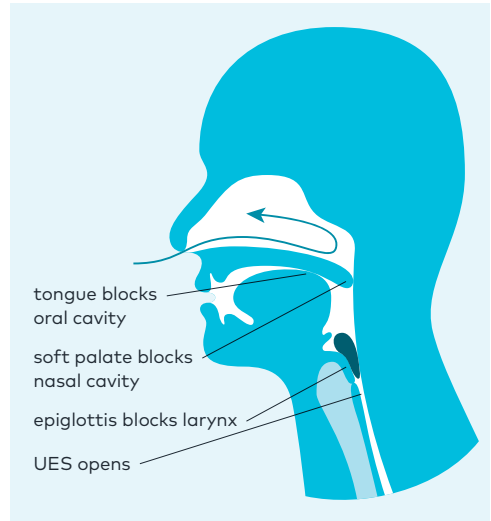
2. Pharyngeal Stage

The second stage of a swallow starts the moment the food is propelled from the tongue into the throat. The stage ends when the food has moved down the throat and enters the esophagus, or food tube, bypassing the trachea, or windpipe. Correct movement of food and liquid during this stage of swallowing is important because of the proximity of the trachea to the esophagus. Difficulty can occur at this stage due to a reduced or delayed swallow trigger, reduced contraction and downward pushing by the throat muscles, reduced elevation of the voice box and vocal folds that do not close completely or fast enough to protect the airway.

Symptoms that can occur during this stage are coughing or choking before, during or after the swallow as well as aspiration, when foreign material enters the lungs by way of the trachea. There can be a delay in the swallow causing a buildup of food in the throat, which gives the feeling that food is stuck in the throat. Food may also sit at the top of the esophagus because that muscle doesn't open as well as it once did.

3. Esophageal Stage

The third stage of a swallow starts once food enters the esophagus. One symptom that may be noticed is the sensation of food stuck in the esophagus or going down very slowly. You may feel full even though you have not eaten very much. Heartburn or acid reflux may occur during or after eating. Consult a physician, such as a gastroenterologist, if you suspect difficulty with this stage of swallow.





Summary

While PD medications help improve many symptoms, they are not as helpful for speech, communication, cognitive and swallowing problems. Most people get the best improvement when medications are paired with a treatment from a Speech-language pathologist (SLP).

Because these changes are common and can worsen over time, it is recommended that people with PD consult with a SLP as soon as difficulties begin, and then annually once problems are identified.

Your physician or other health care professional can recommend a qualified SLP who can develop a personalized therapy program for you. Depending on the facility and who is paying for the services, a physician's referral may be required, but will likely be covered by your medical insurance. Seeing a professional who has experience with PD may help you obtain access to the most current programs.

Appendices

Training the Therapists

Learn best-care Parkinson's disease (PD) knowledge while earning continuing education unit (CEU) credits through various Parkinson's Foundation expert training courses.

Online Course for Allied Health Professionals: Speech and Language Pathology Course

Designed by expert speech and language pathologists in the PD field, this course helps other speech and language pathologists improve care for people with Parkinson's. The course was designed by the Parkinson's Foundation.

In viewing this multi-module course, participants will learn how to best examine the complexities that Parkinson's has on speech, swallowing and cognition.

Register and view "Let's Talk About Parkinson's: How Can Speech and Language Pathologists Deliver the Best Care?" at Parkinson.org/SLP.

Allied Team Training for Parkinson's (ATTP®)

ATTP is a unique curriculum, offered just twice a year, in which healthcare professionals from diverse disciplines learn the best techniques in Parkinson's disease care through a dynamic, team-based approach. The interactive training program includes care strategies for all stages of Parkinson's, interdisciplinary training to foster stronger care teams and continuing education credits.

Through online modules and a three- to four-day in-person training, participants receive in-depth knowledge of how to assess and treat persons with Parkinson's disease in an interdisciplinary setting. Trainees practice integrated care planning in teams, using case study vignettes and videos of actual persons with Parkinson's. Trainees practice integrated care planning in teams and meet persons with Parkinson's disease to hear first-hand the impact of PD on people's lives.

Learn more at Parkinson.org/ATTP.

Learn More

Discover our Blogs

Learn more about the Speech Language Pathologist's role in the PD interdisciplinary care team in our blog post "The Expert Care Experience: Speech, Swallowing, and Parkinson's." This post is the third in a series detailing the roles of each member of a comprehensive care team. You can read more at [Parkinson.org/ExpertCareTeamSLP](https://www.parkinson.org/ExpertCareTeamSLP).

Learn more about collagen gel injections, which was highlighted at the 2018 Movement Disorder Society (MDS) international congress, on our blog post "Inject, Cool Tech and Keto Effect" at [Parkinson.org/MDS2018](https://www.parkinson.org/MDS2018).

Speech changes don't just affect the person with Parkinson's, they also have a significant effect on the relationship shared by those with Parkinson's and their care partner. The blog post "Building Stronger Caregiving Partnerships Through Better Communication" dives into this shared experience as it summarizes the 2018 Caregiver Summit presentation by Angela Roberts, PhD, from Northwestern University. Read more at [Parkinson.org/CommunicationBlog](https://www.parkinson.org/CommunicationBlog).

Discover our Podcast:

"Substantial Matters: Life and Science of Parkinson's"

Cameron Jeter of the dental school at the University of Texas Health Science Center describes what she calls the "Dreaded D's" – dry mouth, drooling, dysphagia or swallowing difficulties, and deadly bacteria on Episode 47, "Practicing Oral Health Care with Parkinson's" at [Parkinson.org/Podcast](https://www.parkinson.org/Podcast).

Lisa Mann, the nurse and education director for the Oregon Health and Science University Parkinson's Center in Portland, a Parkinson's Foundation Center of Excellence, discusses who should be part of the core team of health professionals, highlighting the importance of Speech Therapists on Episode 30, "Team Care for PD: Why It's Important" at [Parkinson.org/Podcast](https://www.parkinson.org/Podcast).

How Do I Know if I Have Problems with Speech and Communication?

This self-test can help you determine if you have a communication problem. Think about the following statements and place a check mark next to the ones that apply to you.

If you think you or your loved one may be ready for a referral to a speech-language pathologist, cut this tip sheet out from your book or bring the whole book in to your next doctor's appointment.

- I am often asked to repeat a statement.
- People look slightly confused or as if they are trying hard to listen when I speak.
- My care partner says that I sometimes slur or mumble words.
- My care partner asks that I speak louder.
- I feel that my care partner is ignoring me or may need a hearing aid.
- I do not attend social gatherings as often as before.
- I notice that I often stop trying to communicate in a group where others seem to talk over me.
- I feel like people do not listen to me anymore.
- I feel like people think that I don't have anything interesting to say.
- I try to avoid the telephone.
- I need to clear my throat often.
- I cannot complete a conversation without feeling frustrated about my inability to communicate what I have to say.

If you checked any of these statements, you are probably experiencing changes in communication related to PD.



Care Partner Speech and Communication Survey

If you are a care partner, family member or friend who has regular contact with a person with PD, complete this questionnaire. Check the statements that are true for your family member/friend.

NAME	ROLE	DATE
<input type="checkbox"/> I have difficulty hearing when s/he speaks.		
<input type="checkbox"/> I have difficulty understanding his or her speech.		
<input type="checkbox"/> S/he does not talk as much as in the past.		
<input type="checkbox"/> S/he does not attend social functions as frequently as in the past.		
<input type="checkbox"/> S/he often asks me to make phone calls or order from a menu for him or her.		
<input type="checkbox"/> S/he clears his or her throat often.		
<input type="checkbox"/> S/he often sounds as if s/he is running out of breath when speaking.		
<input type="checkbox"/> S/he suspects that I need a hearing aid.		
<input type="checkbox"/> S/he thinks I ignore what s/he has to say.		

If you checked more than one box, your family member or friend probably has problems with speech and communication.



How Do I Know if I Have a Swallowing Problem?

This self-assessment can help you determine if you have a swallowing problem. Carefully consider each statement below as it relates to you and your swallowing. Check the statements that apply to you.

If you think you or your loved one may be ready for a referral to a speech-language pathologist, cut this tip sheet out from your book or bring the whole book in to your next doctor's appointment.

- | |
|---|
| <input type="checkbox"/> I have recently lost weight without trying. |
| <input type="checkbox"/> I tend to avoid drinking liquids. |
| <input type="checkbox"/> I get the sensation of food being stuck in my throat. |
| <input type="checkbox"/> I tend to drool. |
| <input type="checkbox"/> I notice food collecting around my gumline. |
| <input type="checkbox"/> I tend to cough or choke before, during or after eating or drinking. |
| <input type="checkbox"/> I often have heartburn or a sore throat. |
| <input type="checkbox"/> I have trouble moving food to the back of my mouth. |
| <input type="checkbox"/> I have trouble keeping food or liquid in my mouth. |
| <input type="checkbox"/> It takes me a long time to eat a meal. |
| <input type="checkbox"/> I sometimes have trouble swallowing pills. |
| <input type="checkbox"/> My eating habits have changed recently or I have a loss of appetite. |
| <input type="checkbox"/> I notice changes in my voice quality after eating or drinking. |

If you checked any boxes above, you may need to see a speech-language pathologist for a swallowing assessment. Your physician or other health care provider can help you with a referral.



Care Partner Swallowing Survey

If you are a care partner, family member or friend who has regular contact with a person with PD, complete this questionnaire. Check the statements that are true for your family member or friend.

NAME	ROLE	DATE
<input type="checkbox"/>	S/he seems uninterested in food.	
<input type="checkbox"/>	S/he often coughs during meals.	
<input type="checkbox"/>	S/he often coughs following a meal when we are doing other activities such as watching TV or reading.	
<input type="checkbox"/>	It takes him/her longer to eat a meal than it used to.	
<input type="checkbox"/>	S/he sounds "wet" or "gurgly" when s/he speaks.	
<input type="checkbox"/>	I have had to use the Heimlich maneuver on him/her.	

NAME	ROLE	DATE
<input type="checkbox"/>	S/he seems uninterested in food.	
<input type="checkbox"/>	S/he often coughs during meals.	
<input type="checkbox"/>	S/he often coughs following a meal when we are doing other activities such as watching TV or reading.	
<input type="checkbox"/>	It takes him/her longer to eat a meal than it used to.	
<input type="checkbox"/>	S/he sounds "wet" or "gurgly" when s/he speaks.	
<input type="checkbox"/>	I have had to use the Heimlich maneuver on him/her.	

Checked boxes are symptoms of chewing, swallowing or eating difficulties. Encourage the person with PD to seek referral for a swallowing evaluation by a qualified speech-language pathologist. A physician or health care provider can help with a referral.



Glossary

Glossary terms are identified with a blue underline the first time they appear in this book.

A Acetylcholine A chemical messenger (see neurotransmitter) released by cholinergic nerves; involved in many brain functions, such as memory and control of motor activity

Alpha-synuclein A protein in the human brain that is associated with the development of Parkinson's. It is the main component of Lewy bodies

Anticholinergic medications Substances that block the neurotransmitter acetylcholine in the central and peripheral nervous system; typically the main ingredient in over the counter sleep aids and many allergy medications (e.g., Benadryl)

Assistive devices A device that helps someone do something that they otherwise may not be able to do or to do well

C Collagen injections A procedure involving the injection of collagen directly into the vocal folds, which may improve in vocal volume and quality

Conversation partners Two or more people who participate in a conversation together

D DaTScan Ioflupane I 123 injection, also known as phenyltropane, is a radiopharmaceutical agent which is injected into a patient's veins in a procedure referred to as SPECT imaging

Diaphragm A dome-shaped muscle that sits just under the lungs and on top of the stomach area

Dopamine A chemical messenger (see neurotransmitter) that is primarily responsible for controlling movement, emotional responses and the ability to feel pleasure and pain; in people with Parkinson's, the cells that make dopamine are impaired or die

Dyskinesias Involuntary, erratic, writhing movements of the face, arms, legs or trunk

E Esophagus The tube-like body structure that leads to the opening of your stomach

F Fiberoptic endoscopic exam A direct examination of your throat during swallowing using a flexible tube with a camera on the end

L Levodopa The medication most commonly given to control the movement symptoms of Parkinson's, usually with carbidopa. It is converted in the brain into dopamine

Lombard Effect The natural tendency for speakers to speak louder, clearer and more slowly under conditions of background noise

M Magnetic resonance imaging (MRI) A medical exam using magnetic resonance imaging

Modified barium swallow study A radiographic procedure designed to determine swallowing function. Also called videofluoroscopic swallow study

Multiple System Atrophy (MSA) A term encompassing several neurodegenerative disorders in which one or more systems in the body deteriorates

N Neurodegenerative disorder A disease characterized by the loss of cells in the brain or spinal cord, which over time leads to dysfunction and disability

Neurotransmitter A chemical messenger, such as dopamine or acetylcholine, that transmits nerve impulses from one nerve cell to another, allowing them to communicate with each other

Norepinephrine A neurotransmitter that plays a role in mood disorders and is released in response to stress

- P Progressive Supranuclear Palsy (PSP)** The most common degenerative type of atypical parkinsonism. Symptoms tend to progress more rapidly than PD with frequent falls early in the course of disease
- R Registered Dietitian** A dietitian is an expert in human nutrition and diet regulation. A registered dietitian (RD) or registered dietitian nutritionist (RDN) is a dietitian who meets all of a set of special academic and professional requirements
- S Serotonin** A neurotransmitter that affects the regulation of mood, appetite and sleep
- Shy-Drager Syndrome** A progressive disorder of the central and sympathetic nervous systems, also called multiple system atrophy with postural hypotension
- Speech-language pathologist** Rehabilitative therapists who assess and treat communication, speech and swallowing problems
- V Videofluoroscopic swallow study** A test in which the person with Parkinson's has x-rays taken of their mouth and throat to assess how they swallow different liquids and foods mixed with barium
- Voice hygiene** Habits that support a healthy and strong voice

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