

Make Your Voice Heard! Healthy Communication and Parkinson's Disease



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The information contained in this booklet is solely for the information of the reader. It should not be used for treatment purposes, but rather for discussion with the patient's own physician.

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A LETTER TO THE READER

The American Parkinson Disease Association (APDA) is here to provide you with the necessary information and resources to better manage Parkinson's disease (PD). If you or someone close to you has been diagnosed with PD, you may feel overwhelmed. This booklet has been designed to help you with information about speech and communications.

As you read through this booklet, keep in mind that PD affects each person differently, so don't worry if you come across information that does not apply to you or your loved one's current situation. This booklet is intended to provide information for all of those affected by PD.

In dealing with PD, your partnership with your neurologist is extremely valuable. It is important to consult with a qualified physician you trust about the course of PD management that is best for you. The information in this booklet should better prepare you to talk to your physician and the additional healthcare providers with whom you will work. Managing any challenge is easier when working with a team, and PD is no exception. Ideally, you will be collaborating with a group of healthcare professionals with expertise in PD to better manage your care.

Your personal support team is also extremely valuable when living with PD. Maintaining your current networks of support (family, friends, groups you belong to) is crucial but also consider branching out to find others who can support your care.

At APDA, every day, we provide the support, education, and research that will help everyone impacted by PD live life to the fullest. To accomplish this, APDA funds important research and provides education and support to individuals living with PD, their family members, and the community at large. In addition to this booklet, visit APDA's website at apdaparkinson.org for more information and also consider contacting an APDA Information & Referral Coordinator who provides services in your community.

APDA is here to help you take a more active role in the successful management of PD. As President and CEO of APDA, I want to welcome you to the Association and its many resources. The American Parkinson Disease Association wants you to look to the future with hope and optimism.

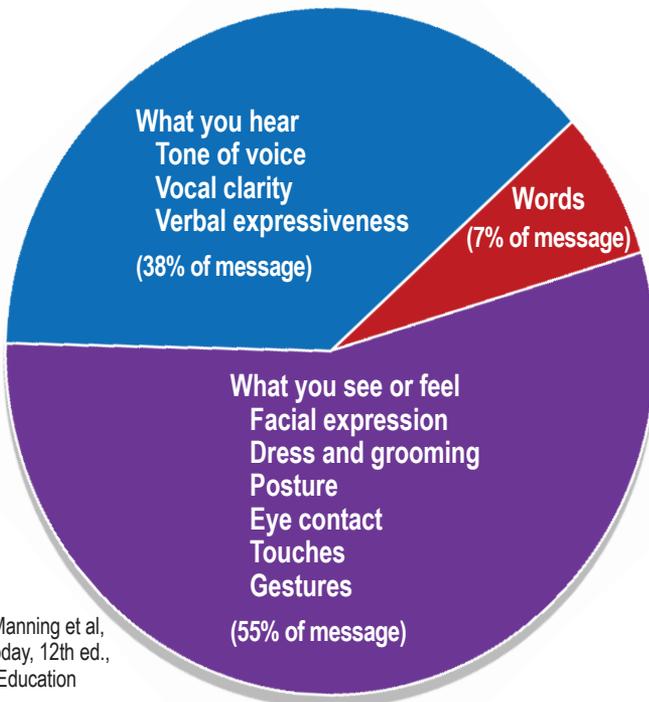
Sincerely,



Leslie A. Chambers
President and CEO
American Parkinson Disease Association

INTRODUCTION

The ability to communicate with others is an extremely important aspect of life. It is a holistic and complex process involving not only the words that we speak, but many elements of our voice, speech, body, facial expressions, and thoughts. Approximately 90% of persons with Parkinson's disease (PD) experience changes in their ability to communicate. If you have been diagnosed with PD, you may notice that your voice is softer and breathy or hoarse, or that your speech is unclear and comes out too slowly or too fast. You might feel it is harder to think of words you want to say in conversation. Perhaps you have grown tired of being asked to repeat yourself in social situations and are gradually becoming more withdrawn and socially isolated. Many individuals with PD report that these changes to communication are more detrimental to their quality of life than anything else they experience with PD.



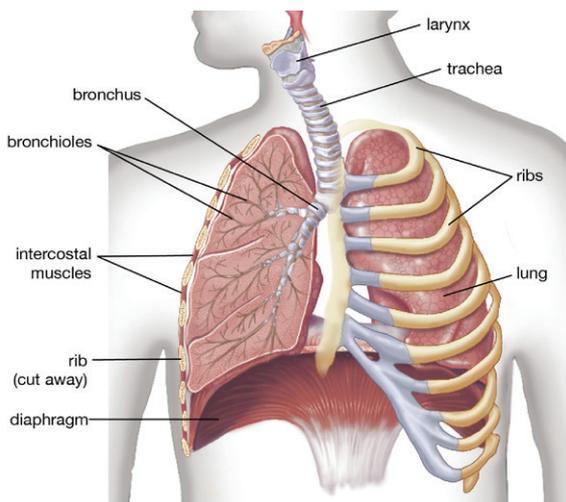
Source: Manning et al.,
Selling Today, 12th ed.,
Pearson Education

This booklet is intended to provide individuals with PD and their loved ones with information on the many aspects of communication that are affected by PD, as well as treatment options and strategies for daily communication needs. It is highly recommended that a speech-language pathologist (SLP) is consulted soon after a diagnosis of PD, in order to address any emerging communication difficulties as early as possible. SLPs are trained to evaluate and treat individuals with voice, speech, language, cognition, and swallowing problems, and can often partner closely with persons with PD to ensure communicative well-being. You can typically find an SLP (<https://www.asha.org/slp/>) at your local hospital or rehabilitation center, as well as private practices or university clinics.

CHANGES TO THE VOICE

Individuals with PD often experience changes in their voice. In fact, a hoarse or breathy voice can be one of the first symptoms of PD! This is because the widespread motor symptoms associated with PD such as tremor, bradykinesia

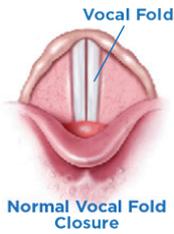
(*slowness of movement*), rigidity and reduced amplitude of movement also affect the structures and movements involved in breath support (*respiration*) and voice production.



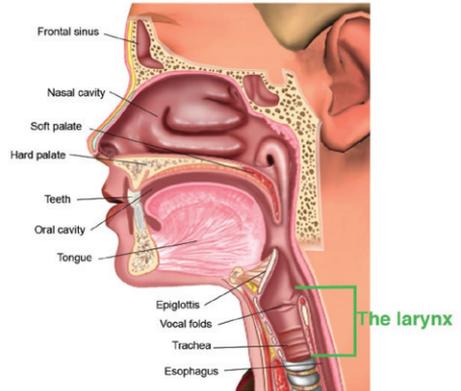
Respiration

When we speak, we need sufficient air supply to rush from our lungs and through the vocal folds in order to produce the vibration needed for voice and maintain an appropriate speaking volume. If the muscles of *respiration*, or breathing, are rigid, move in an uncoordinated fashion, and/or have a reduced range of movement, the person with PD will likely have reduced breath support. When the airflow is reduced, it lowers the volume of the voice and makes the voice breathy and/or hoarse in quality.

Phonation



The vocal folds are located at the top of the trachea (*windpipe*). When we speak, the vocal folds move close together in order to vibrate and generate sound (*phonation*).



In a healthy individual, the vocal folds will close all the way when using the voice, but for some individuals with PD, the vocal folds may become bowed in appearance, making it more difficult for them to close completely. This changes the quality of the voice, making it sound breathy and/or hoarse, and makes it more difficult to achieve a louder voice as air is lost in this open system.

Inflection

As we speak, the pitch of our voice goes up and down to reflect the message behind our words. This is called *inflection*. Questions typically rise in pitch at the end of the sentence (e.g., “are you hungry?”), whereas statements tend to end on a lower pitch (e.g., “I want a sandwich”). Further, it is inflection in the voice that communicates emotional content such as joy, sadness, anger, sarcasm, and humor. Vocal pitch is controlled by how fast the vocal folds vibrate, which can also be affected by the muscle rigidity that accompanies PD. This means that persons with PD tend to have very little pitch variation in their voice, leading to monotone speech that lacks liveliness and may be easily misinterpreted. People with PD often complain that listeners think they are serious when they are joking, or that they are depressed when they are perfectly happy. This is due, in part, to the lack of inflection in the voice of persons with PD.

It should be noted that these physiological and neurological changes to the vocal folds and laryngeal muscles can also have a negative impact on one's swallowing ability.

What are some treatment options for voice problems?

After a speech-language pathologist has conducted a full evaluation, an individualized treatment program can be created for the person with PD to help him/her achieve a louder, clearer voice. Here are a few of the most effective, research-based treatment options that are available for persons with PD:

Lee Silverman Voice Treatment (LSVT) LOUD®

LSVT LOUD® is an effective voice treatment program for individuals with PD. Developed in 1987, the method is named after Mrs. Lee Silverman, a woman with PD for whom the treatment was originally created. LSVT LOUD® involves intensive retraining of vocal use and focuses on increasing the volume of the voice for conversation. The program requires participation in 16 sessions of individual voice therapy over a period of four weeks, with additional homework assignments. The intensive nature of the program provides a daily opportunity to practice increasing vocal effort and increasing awareness of the effort needed to achieve a normal volume voice. While this treatment schedule may seem overwhelming, the large body of research that has been conducted on LSVT LOUD® demonstrates that this level of intensity of treatment delivers significant improvements not only in vocal volume, but also in respiratory strength, clarity of speech, inflection in speech, facial expression, and swallowing function.



For more information on LSVT LOUD®, or to find a clinician who is certified in this therapy approach visit www.lsvtglobal.com.

Speech Vive™

Another approach for improving voice in persons with PD is the SpeechVive™. The SpeechVive™ is a device that is worn in one ear, similar to a hearing aid, and plays background noise whenever the person is speaking. The background noise turns off when the person with PD is not speaking, so it does not interfere with their ability to listen to others. The SpeechVive™ uses a normal reflex called the “Lombard Effect,” which causes us to automatically raise our speaking volume when we are speaking in a noisy environment.



In order for a person with PD to use a SpeechVive™ device, a trained SLP must set up the device and calibrate the level of the background noise with regard to the patient’s speaking volume. To find out more about the SpeechVive™ device or to contact a trained clinician visit www.speechvive.com.

Voice Amplification



Another option to help increase speaking volume for individuals with PD is the use of a voice amplifier. A small microphone is worn near the mouth and an amplifier is worn somewhere on the body. The amplifier effectively increases the volume of the person’s voice without increased effort by the speaker. This can be particularly helpful in noisy situations, or in work

environments that require a lot of fatiguing voice use. This can also be an effective option for individuals with PD who face significant cognitive challenges, and find it difficult to learn the vocal use techniques introduced in traditional voice therapy. A speech-language pathologist can work with PD patients and their family members to determine the best amplifying device for their individual needs.

Alternative & Augmentative Communication (AAC)

Some persons with PD may experience such severe impairments in communication and/or cognition that they have unintelligible speech that does not respond to these other therapy approaches. In this case, alternative forms of communication such as picture boards or speech generating devices may be used to help the individual communicate with others. A speech-language pathologist can work with patients and their families to decide which augmentative and alternative communication option best suits their needs and provide training to support communication in daily life.

Maintaining a Healthy Voice

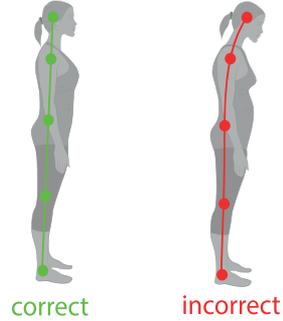
Just as physical exercise requires intense effort and a regular training program, speech and voice gains are maintained with the regular completion of voice exercises. When the exercise regime is abandoned and when persons with PD stop speaking louder, they quickly revert back to using a quiet voice that is difficult to understand. However, results from treatment (e.g. a louder, clearer voice) can be maintained if a regular exercise regime is followed and if the focus on maintaining a louder speaking volume is continued.

It is also critical to remember that the best way to maintain gains in treatment is to put yourself in social situations that are enjoyable, that give you meaning, and that force you to be socially engaged. Voice therapy may help you to return your voice to a normal volume, but the best therapy of all is using your louder voice in the real world! This can include participating in a singing group, talking with others about things you enjoy (e.g., a book club or art club), volunteering in the local community, etc.

What can I do for my voice right now?

Here are some strategies to help you use a louder, clearer voice:

- 1. Maintain a good posture.** If you are slouched or bent it can be difficult to draw a full breath which decreases the breath support available for speech. It is a good idea to consult with a physical therapist to work on balance and postural stability.
- 2. Take a deeper breath before speaking.** This can help make your voice louder and allow you to speak for a longer period of time before running out of air.
- 3. Speak in shorter phrases.** When you speak in longer sentences you may notice that you start to run out of air towards the end of the sentence. This will make your voice quieter. So instead of saying “I went to the store yesterday and I bought all my groceries for a dinner party we’re going to on the weekend,” you might want to break it up into several short phrases. For example: “I went to the store yesterday (breath) and I bought all my groceries (breath) for a dinner party we’re going to on the weekend.”
- 4. Practice diaphragmatic breathing:** This is a breathing method that increases the efficiency of your breath and strengthens your respiration muscles. Below are some guidelines to practicing diaphragmatic breathing at home:



Diaphragmatic Breathing

Lie on your back on a flat surface or in bed, with your knees bent and your head supported. You can use a pillow under your knees to support your legs. Place one hand on your upper chest and the other just below your rib cage. This will allow you to feel your diaphragm move as you breathe.



Breathe in slowly through your nose so that your stomach moves out against your hand. The hand on your chest should remain as still as possible.



Tighten your stomach muscles, letting them fall inward as you exhale through pursed lips. The hand on your upper chest must remain as still as possible.

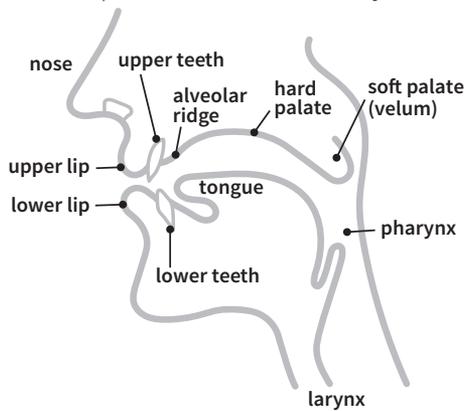


When you first learn the diaphragmatic breathing technique, it may be easier for you to follow the instructions lying down. As you gain more practice, you can try the diaphragmatic breathing technique while sitting in a chair or standing.

CHANGES TO SPEECH

People with Parkinson’s disease can also experience negative effects on their speech. When we speak, our lips, tongue, jaw and soft palate (which are called *articulators*) move with extreme speed and precision to create all the speech sounds within our language. These articulators are controlled by many tiny muscles which, just like other parts of the body, can become slower, more rigid, and less precise in their movements due to the presence of PD.

Some common effects on speech for persons with PD may include unclear or imprecise speech, changes in speech rate, or stuttering behaviors. Persons with PD may find themselves talking either faster or slower than usual and may notice that it can be difficult to control the speed of their speech. *Palilalia* is another symptom that can occur in PD, which is the involuntary repetition of sounds, words, or phrases during speech. The presence of one or more of these effects can significantly decrease a person’s intelligibility, and be a source of frustration for the person with PD.



What are treatment options for speech problems?

You can work with a speech-language pathologist to determine the best treatment method to improve your speech. Some of the most common methods are listed below:

Voice Therapy Methods

Several of the previously mentioned voice treatment programs may also have positive effects on speech rate and clarity of speech. The research conducted on the treatment effects of LSVT LOUD® and SpeechVive™ indicates that these are not only helpful for improving vocal loudness, but also vocal quality, and articulation as well. With a treatment emphasis on increasing vocal loudness, there is evidence of increased activation of the entire speech neuromuscular system. This means that the muscles used while speaking are more engaged when a louder voice is used, thus making speech clearer and easier to understand.

Speech Rate Control

Controlling how fast you speak can help make your speech clearer and can also help alleviate stuttering symptoms or palilalia. Several treatment methods exist to help persons with PD control their rate of speech. Some people benefit from practicing speech with a *metronome* and basing their speech rate on its methodical click. Another common tool that can be used to improve a person's speech rate is a *pacing board*. When using a pacing board, the person speaking uses a visual tool to separate out syllables or words within a sentence, touching a different shape, letter, or image each time he/she says a different syllable or word. This helps the speaker to slow down their rate of speech and to articulate sounds more clearly.

Want to try it out? Say the phrase below aloud while touching a finger to each of the dots in the box, alternating between the dots for each word you say:

I hope you have a nice day!



What can I do for my speech right now?

The following are some strategies that can help people with PD and their care partners achieve more effective communication when speech is unclear or imprecise due to the effects of PD:

1. **Talk in a quiet environment.** Ensure you are not trying to speak over background noise such as a loud television or radio, and that you are in a well-lit area where your listener can see your face as you speak.
2. **Avoid communicating over long distances.** Make sure you have your listener's attention before you speak, and that you are in the same room so he/she can watch your face, lips and body gestures.
3. **Be clear about the topic of conversation.** If your listener knows what the topic of conversation is, it can help him/her to better understand what you are saying. In addition, avoid abruptly changing the conversation topic whenever possible.
4. **Incorporate gestures, pointing, and environmental cues.** Your listener can use these supplemental messages to better understand you.
5. **Rephrase your message.** If your listener does not understand or asks you to repeat, try communicating your thoughts using different words.

CHANGES TO FACIAL EXPRESSION AND GESTURES

Although we often think of communication as being about the words we say, over half of our communicative messages are conducted through body language and facial expression. People with PD often experience changes in these important nonverbal aspects of communication.

Facial Masking

A common symptom of PD is reduced body language and/or facial expression (*hypomimia*). Body language and facial expressions greatly enhance the communication process, making it clear to the listener whether the speaker is sad, angry, happy, worried, surprised, bored, etc. When body language and facial expressions are reduced, the intent and mental state of the person with PD is often misperceived. Frequently, friends and family of persons with PD will report that the individual with PD seems depressed, angry, or generally disinterested in conversation, leading to frustration and miscommunication in social interactions.

How can I improve body language and facial expression?

Although no specific treatment focuses directly on body language and facial expressions, LSVT LOUD® has been shown to increase facial expression along with vocal loudness. In addition, here are some strategies to help improve your nonverbal communication:

1. **Always make eye contact with your conversation partner,** both when you are talking and when you are listening. This will show that you are interested in the conversation.
2. **Use your body posture to show feelings when talking and listening to others.** For example, if you lean slightly forward in your chair, it demonstrates interest; leaning back in your chair and breaking eye contact indicates that you are disinterested in the conversation.
3. **Express your emotions verbally.** Instead of relying on your facial expressions, tell people if something they say makes you happy, sad, or upset, and don't be afraid to tell them you are joking if they take something you say too seriously!

CHANGES TO COGNITION

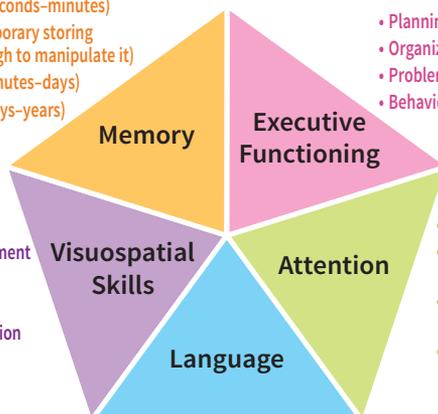
Communication can also be affected by changes to cognition for those with Parkinson's Disease. Cognitive impairment can arise for individuals with PD in many different forms and varies widely in rate of progression and severity. Some individuals may experience few or no changes to their cognition, while others may be more severely affected and have difficulty performing daily activities. These changes to cognition can be frightening, frustrating and emotionally distressing, but it is important to be aware of these changes so you can receive the support you need.

What is Cognition?

Cognition refers to the mental abilities we use to process information and apply knowledge in a variety of ways. Cognition is commonly divided into five domains, which reflect different types of cognitive processes:

- Immediate memory (seconds-minutes)
- Working memory (temporary storing information long enough to manipulate it)
- Short-Term memory (minutes-days)
- Long-Term memory (days-years)

- Spatial map of environment
- Sense of direction
- Mental imagery
- Distance/depth perception



- Planning
- Organization
- Problem-solving
- Behavior initiation/regulation

- Sustained attention
- Alternating attention between stimuli
- Selective attention (ignoring unimportant stimuli)
- Divided attention/multi-tasking

- Comprehension of spoken/written language
- Verbal expression
- Written expression
- Linguistic concepts

How is cognition affected by Parkinson's disease?

A common overall effect on cognition for individuals with PD is *bradyphrenia*, or a slowed thinking process. This applies to all areas of cognition and can cause delays and frustration when trying to communicate with another person. Here are some more specific examples of how cognition may be affected in PD:

- **Attention:** You may find it more difficult to multi-task or shift your attention quickly between items (for example, talking to somebody while walking or driving). You may also find it difficult to make mathematical calculations or concentrate on a task for long periods of time.
- **Executive Functioning:** You may begin to have difficulty organizing or planning activities in your daily life, such as preparing and cooking a meal or organizing a social event. Decision-making may also become more challenging.
- **Memory:** While long-term memory tends to remain relatively unchanged for people with PD, short-term memory functions may become more difficult. For example, you may find yourself forgetting where you left your glasses, or what time you agreed to meet up with friends for lunch.
- **Visuo-spatial Skills:** Since distance and depth perception can be affected by PD, you may find it difficult to do activities that require strong visuospatial skills, such as driving or parking a car. Performing visual tasks such as reading a map or drawing may be affected.
- **Language:** Many people with PD describe word-finding difficulties (often called “tip-of-the tongue phenomenon”), where they find it challenging to come up with the right word in conversation. This often leads to the use of simpler language overall.

Effects of hearing loss on cognition



According to the National Institute for Deafness and other Communication Disorders (NIDCD), approximately one-half of adults over age 75 have hearing loss, but less than 25% of people who need hearing aids actually get them. Recent research indicates that hearing loss may be associated with cognitive decline. Ongoing research is being conducted to explain this connection; for now, it is recommended that

individuals who suspect hearing loss actively pursue diagnosis and treatment.

Hearing loss can also make it more difficult to participate in conversations in public places. If you find yourself avoiding public venues and social gatherings, this may lead to increased social isolation and sometimes depression, which can further affect communication and cognition skills.

What can I do to help my cognition?

There are several professionals who can help you if you begin to notice changes to your cognition:

- **Neurologist and Neuropsychologist:** If you are noticing changes to your cognition, your neurologist may recommend a neuropsychological assessment. This will better diagnose the specific cognitive changes that you are experiencing and provide you and your loved ones with the appropriate resources.

- **Audiologist:** If you suspect even mild changes to your hearing you should contact your primary care physician about a referral to an audiologist, who can perform an evaluation of your hearing and inform you about treatment options. Early detection and treatment of hearing loss may have a significant impact on your communication and cognitive function and on your overall quality of life.



- **Speech-Language Pathologist:** A SLP can provide cognitive-linguistic evaluation and therapy services to help individuals with PD strengthen certain cognitive skills. Those with PD can also learn various compensatory strategies to make daily activities easier.
- **Physical Therapist:** Staying physically active not only helps your body stay stronger and more flexible, but it also provides benefits for cognition! In addition, physical exercise can help combat common PD symptoms of anxiety and depression and can increase self-confidence. The ***Be Active and Beyond*** booklet is an excellent starting point.



Above all, it is important to continue to challenge yourself cognitively. Just as you need to push your physical limits at the gym to see improvements in your body, it is beneficial to keep pushing yourself to engage in cognitive tasks such as reading, solving puzzles, attending lectures, etc. In addition, learning something new such as a musical instrument, a language, or a new hobby will challenge your cognitive skills and provide you with a community to share your new interest, keeping you from becoming socially isolated. Find an activity that you like to do and then challenge yourself!

Summary

We often take our communication skills for granted, as they are such a central part of our daily lives. However, it is important to be aware of changes in order to improve impaired communication skills. Now that you are informed of the various ways in which voice, speech, body language, facial expression, and cognition can be affected by Parkinson's disease, here are a few final suggestions to help you increase awareness and take control of your communication:

- **Be aware of your medication cycles.** You may want to avoid too much vocal communication during an “off” cycle, or when you are tired or fatigued. Likewise, if you have important communication activities (such as an important phone call or a birthday party), you may want to schedule them during your “on” cycle.
- **Inform others of your communication challenges.** Just as you might ask for physical assistance to go up a flight of stairs, you may need to tell your communication partner what aspects of communication are difficult for you. For example, you may have to tell your listener that you need a moment to think of the word that you are trying to say.
- **Advocate for yourself.** Let others know if the environment you are in is making it difficult to participate in conversation (e.g., a loud TV is playing in the background).
- **Ask for help from professionals.** Your doctor and/or neurologist can connect you with the various professionals mentioned in this booklet who can help you receive the services you need to communicate well.
- **Share this booklet with others!** Care partners, professionals, and other individuals with PD will benefit from learning about the effects of PD on communication.

APPENDICES

A. Voice Handicap Index

Few of us realize the important role a healthy voice plays in our daily lives. If you are experiencing changes to your voice, we suggest you fill out this questionnaire, the *Voice Handicap Index*, to see if your voice problems are negatively affecting your daily activities:

These are statements that many people have used to describe their voices and the effects of their voices on their lives. Circle the response that indicates how frequently you have the same experience.

0-Never 1-Almost Never 2-Sometimes
3-Almost Always 4-Always

Part I-Functional

My voice makes it difficult for people to hear me	0 1 2 3 4
People have difficulty understanding me in a noisy room	0 1 2 3 4
My family has difficulty hearing me when I call them throughout the house	0 1 2 3 4
I use the phone less often than I would like to	0 1 2 3 4
I tend to avoid groups of people because of my voice	0 1 2 3 4
I speak with friends, neighbors, or relatives less often because of my voice	0 1 2 3 4
People ask me to repeat myself when speaking face-to-face	0 1 2 3 4
My voice difficulties restrict my personal and social life	0 1 2 3 4
I feel left out of conversations because of my voice	0 1 2 3 4
My voice problem causes me to lose income	0 1 2 3 4
SUBTOTAL	

Part II-Physical

I run out of air when I talk	0 1 2 3 4
The sound of my voice varies throughout the day	0 1 2 3 4
People ask, “What’s wrong with your voice?”	0 1 2 3 4
My voice sounds creaky and dry	0 1 2 3 4
I feel as though I have to strain to produce voice	0 1 2 3 4
The clarity of my voice is unpredictable	0 1 2 3 4
I try to change my voice to sound different	0 1 2 3 4
I use a great deal of effort to speak	0 1 2 3 4
My voice is worse in the evening	0 1 2 3 4
My voice “gives out” on me in the middle of speaking	0 1 2 3 4
SUBTOTAL	

Part III-Emotional

I am tense when talking to others because of my voice	0 1 2 3 4
People seem irritated with my voice	0 1 2 3 4
I find other people don't understand my voice problem	0 1 2 3 4
My voice problem upsets me	0 1 2 3 4
I am less outgoing because of my voice problem	0 1 2 3 4
My voice makes me feels handicapped	0 1 2 3 4
I feel annoyed when people ask me to repeat	0 1 2 3 4
I feel embarrassed when people ask me to repeat	0 1 2 3 4
My voice makes me feel incompetent	0 1 2 3 4
I am ashamed of my voice problem	0 1 2 3 4
SUBTOTAL	
TOTAL	

How much of an effect does your voice problem have on your quality of life?

0-30 = Mild **31-60** = Moderate **60-120** = Severe

B. Caregiver Questionnaire

Often it is a caregiver who first notices change in the voice, even before the person with PD. If you are a spouse, family member, or friend who regularly communicates with a person with PD, we suggest you take a minute to read and fill out the questionnaire below:

Instructions:

The following questions describe a variety of situations in which your care receiver might need to speak to others. For each question, please mark how much their condition interferes with their participation in that situation. By “condition” we mean ALL issues that may affect how they communicate in these situations including speech conditions, any other health conditions, or features of the environment. If their speech varies, think about an AVERAGE day for their speech – not their best or their worst days.

Does their condition interfere with:	Not at all	A little	Quite a bit	Very much
1. Talking with people they know?	3	2	1	0
2. Communicating when they need to say something quickly?	3	2	1	0
3. Talking with people they do NOT know?	3	2	1	0
4. Communicating when they are out in your community (e.g. errands; appointments)?	3	2	1	0
5. Asking questions in a conversation?	3	2	1	0

Does their condition interfere with:	Not at all	A little	Quite a bit	Very much
6. Communicating in a small group of people?	3	2	1	0
7. Having a long conversation with someone they know about a book, movie, show or sports event?	3	2	1	0
8. Giving someone DETAILED information?	3	2	1	0
9. Getting their turn in a fast-moving conversation?	3	2	1	0
10. Trying to persuade a friend or family member to see a different point of view?	3	2	1	0

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