



Parkinson's Disease:

Speaking Out

National Parkinson Foundation Speech Team

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Janet Schwantz, M.S., CCC-SLP, author of the chapter on memory and concentration, has been a speech-language pathologist since receiving her master's degree in 1982 from the University of North Texas. She lives with her husband and two children in Lubbock, Texas, where she practices at the Neurology Research and Education Center, an NPF Center of Excellence at Covenant Health Systems, formerly St. Mary of the Plains Hospital. Ms. Schwantz serves as therapist for the Parkinson Outreach Program in West Texas, and is involved in ongoing research regarding cognition in PD.

Jennifer Camburn, M.S., CCC-SLP, has done admirable work editing this comprehensive manual, skillfully arranging author contributions into a format that is appealing and highly readable. Ms. Camburn received her M.S. in Speech-Language Pathology from the College of Saint Rose in Albany, New York; the focus of her practice has been in adults and older persons with neurological deficits. She lives in Bryn Mawr, Pennsylvania and is the POP Clinical Coordinator for the Pennsylvania region.



Forword

"If only we could hear and understand her speech..."

This was the expressed wish of the family of Mrs. Lee Silverman, a woman with Parkinson's disease (PD), when I met her in 1986. At that time I was invited to develop an effective speech treatment for individuals with Parkinson's disease at the Lee Silverman Center for Parkinson's Disease in Scottsdale, Arizona. Over the next three years, speech-language pathologist Carolyn Mead Bonitati and I collaborated to create a model treatment method. The Silverman family wish was the beginning of what is known today as the Lee Silverman Voice Treatment (LSVT).

As the Silverman family expressed, and as families living with PD recognize today, the ability to communicate with friends and loved ones is at the heart of coping with Parkinson's disease. Since the beginning of the LSVT, our clinical research team has shared the joy of helping hundreds of people with Parkinson's disease improve their communication. While we are very proud of our program and grateful for support from the National Institutes of Health (NIH) and the Office of Education (OE), our greatest satisfaction comes when individuals we have treated make comments such as. *"I can now talk to my grandchildren on the phone!"*

Stefanie Countryman, primary author of this NPF manual, has been an important part of our LSVT clinical research team since we began our studies at the Wilbur James Gould Voice Research Center in Denver in 1990. She is an outstanding clinician, teacher and scholar. Stefanie recognizes the importance of communication in daily living and is passionately committed to helping individuals with Parkinson's disease improve their communication skills. Her manual provides valuable advice for individuals and their families on issues regarding speech and swallowing.

Successful communication can build confidence and motivation when facing the challenges of Parkinson's disease. We encourage you, your family and friends, to build successful communication through speech treatment so that you too can begin *"Speaking Out"*.

Lorraine Olson Ramig, Ph.D., CCC-SLP
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*..Hope is the thing with feathers
That perches in the soul,
And sings the tune without words,
And never stops at all..*

- Emily Dickinson -

CHAPTER 1

Communication Issues in Parkinson's Disease

Communication is an essential part of human nature. It is used in a variety of ways: to maintain social ties, give and receive information, gain or hold employment, and share thoughts and feelings. An inability to communicate effectively can result in withdrawal, depression, or hostility directed toward others.

This booklet is intended to provide individuals with Parkinson's disease (PD), care partners, and friends with information on speech, voice and swallow function related to this condition. Strategies and exercises to improve or maintain good communication are included.

The manual is also designed to encourage individuals with PD to seek *early* intervention from a qualified speech-language pathologist. Many people report improved communication and swallow function following speech therapy. Therapy graduates have stated; "I feel like my voice is alive again!", "I have more confidence", "It is easier to swallow my medication now", and other testimonials to the numerous benefits of speech therapy.

Elements of Communication

Speech, voice tone and inflection, and facial expressions are all important aspects of communication. Consider all the instances in which speech is crucial: talking on the phone, sharing stories with the family, summoning a pet, making financial transactions, scheduling appointments, etc.

Voice tone and inflection project emotions and feelings. The use of voice tone varies with different people: a grandchild, telemarketer, boss, doctor, store clerk - all elicit different inflections.



Facial expressions are also an essential aspect of communication. When first meeting someone, much information is conveyed through facial expression alone: happiness, excitement, fear, or sadness.

Imagine talking with someone whose speech is unclear, whose voice is flat, and whose facial expression appears "blank". What message is conveyed? These features may be interpreted as lack of comprehension or lack of interest in the conversation. However, these same features may be symptomatic of Parkinson's disease.

Facial masking or lack of facial expression is common in PD. This symptom is often described as having a "poker face". This masking is a result of rigidity and reduced movement in the muscles of the face. Some people with PD report feeling like friends, family members and even strangers do not think they are interested in everyday conversations or perceive them as not understanding the conversation due to this lack of expression.

Changes in Speech and Voice

Parkinson disease, a slowly progressive neurological condition, can affect the coordination of muscles used for speech and voice. It is estimated that 75% of individuals with PD experience changes in speech and voice production at some point through the course of the disease. These changes range from mild to severe, but usually fall within the moderate range. Four percent of individuals report changes in speech and voice as the *first* PD symptom noticed.

Changes within the speech and voice system typically occur over an extended period of time. Often, the individual with PD is unaware of these changes because of the very gradual decline in function. Just as a spouse or friend may be the first to notice reduced arm swing or altered gait, the same may be true for changes in speech and voice.

The same physical symptoms that can occur in the limbs - reduced movement, rigidity, tremors, etc. - can also occur in the speech system. These symptoms are classified as *hypokinetic dysarthria*. "Dysarthria" simply refers to a speech disorder due to a change in muscle control. "Hypokinetic" means reduced movement. Thus, hypokinetic dysarthria is reduced movement of the muscles used for speech production.

Parkinson dysarthria can affect respiration (breathing), phonation (voice production), resonance (richness of voice), and articulation (clarity of speech). This includes muscles for breathing and muscles within the voice box, throat, soft palate, tongue, lip and jaw. Parkinson's disease, however, primarily affects the coordination and movement of the muscles used for respiration, phonation, and articulation.

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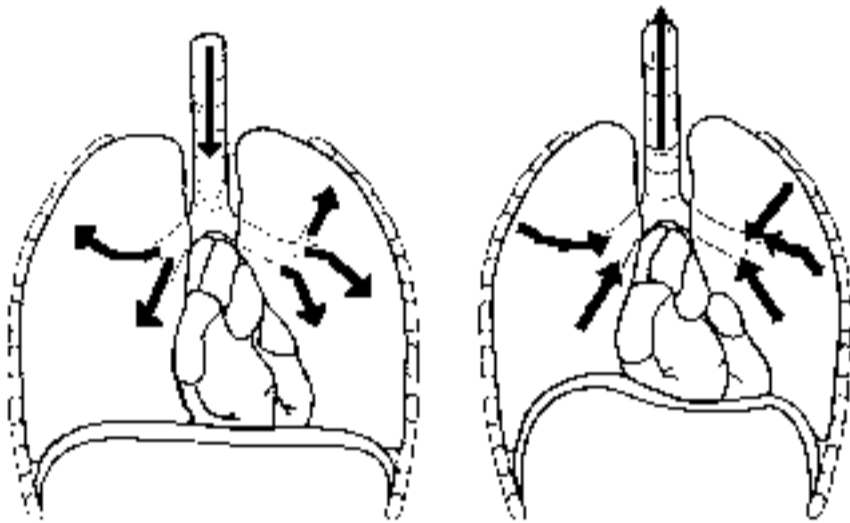
CHAPTER 2

Anatomy of Speech Production

To better understand how Parkinson's disease affects the speech system, one must understand the anatomy of speech production. The four systems of speech production are respiration, phonation, resonance, and articulation.

Respiration

Respiration, or breath support, is considered the fuel for speaking. While at rest, the lungs move air in and out. This is accomplished through muscle contraction and relaxation in both the chest and abdomen. While speaking, the respiratory system moves air in and out, but in a controlled manner.



Control of inhalation/exhalation enables a person to maintain adequate loudness of speech through a conversation. If the muscles responsible for inhalation and exhalation do not move as well as they should, respiratory support is compromised and speech may be affected. Sometimes individuals with Parkinson's disease take too shallow breaths, less frequent breaths, or have difficulty coordinating their breathing and speaking.

The person with PD may speak on the "bottom" of his or her breath (i.e. inhale, exhale, then speak), rather than on the "top" of the breath (i.e. inhale, speak, exhale remaining air.)

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Phonation

The phonatory system or the voice is controlled through the voice box or larynx. The vocal folds (also known as vocal cords) lie within the voice box.

These folds are very fine muscles that open and close very quickly while speaking. Changes in the voice are the most frequently observed deficits in the speech and voice systems of individuals with Parkinson's disease.

The vibration (opening and closing) of the vocal folds creates the sound or *pitch* of the voice. The vocal folds vibrate very quickly during high-pitched sounds and vibrate more slowly during low-pitched sounds. Many individuals with PD notice changes in the pitch of their voices. Some males report higher pitch, while some females report lower pitch, though the opposite has been noted as well.

Monotone or lack of vocal inflection or melody in the voice is also a common complaint. Some people state that their voices sound uninteresting or flat.

Another voice characteristic that may be a result of changes within the voice box is reduced loudness or a softer voice. This is the single most common complaint in the Parkinson voice.

These characteristics may be the result of vocal folds that do not close completely while the person is speaking. This phenomenon is known as *vocal fold bowing*.

If the vocal folds do not close completely, air can escape through them causing a softer, weaker voice and occasionally, a complete loss of voice. A hoarse voice or changes in voice quality are also frequently observed in individuals with PD. Some people wonder if they have developed chronic allergies or post-nasal drip. when actually it may be changes occurring in the vocal folds. Such changes can create a hoarse or raspy voice.

Other vocal or phonatory system characteristics reported in PD are breathiness, vocal tremor or unsteadiness in the voice, and a strained or strangled-sounding voice. These characteristics all result from changes in the control of muscles of the voice box and respiratory system, or from compensatory techniques an individual may be using to counteract changes within the vocal system.

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Resonation

The resonating system determines the richness of the voice, and is judged by whether or not it sounds as if someone is "talking through the nose". Changes within this system may be a result of the soft palate or *velum* not moving as well as it should.

Normally, the soft palate, located in the back of the roof of the mouth, closes off the nasal cavity while speaking, except when producing nasal sounds such as "m...", "n...", or "ing...". In Parkinson's disease, the soft palate may not move adequately, which allows air to leak into the nose, creating a nasal quality in the voice.

Articulation

The articulatory system is comprised of the muscles of the face, lips, tongue, and jaw. While speaking, these muscles move at rapid speeds as well as in a coordinated manner. This allows for clear and precise speech. Often individuals with PD notice that their words are not formed or enunciated as clearly as they once were. Some people report "slurred" or mumbled speech. These changes are not usually the result of muscle weakness or paralysis (as in individuals who have suffered a stroke).

Imprecise articulation in PD is attributed to reduced movement and reduced range of motion, tremor, dyskinesias (involuntary movements), or lack of coordination of the face, jaw, lip and /or tongue muscles.

The following is an example of how articulation is affected by reduced movement in 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.

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Medication Effects on Speech and Voice

With the recent advances in anti-Parkinson medications, many individuals are moving and functioning better than ever before. While medications are the primary tool for management of PD, the effects of those agents on speech and voice deficits are harder to measure.

Even anecdotal accounts from persons with PD are inconsistent. A majority of individuals with PD state that they notice little change (either positive or negative) in speech and voice ability related to changes in medication regime. Yet some patients insist that their voices *are* stronger when the anti-Parkinson drugs are at peak levels to control motor deficits.

These comments coincide with research reports that drugs used to treat Parkinson's disease may have some benefit for speech and voice problems, but the results are not as significant as those observed in motor function.

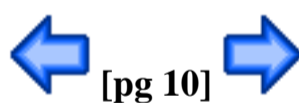
Recognizing Speech and Voice Changes

Difficulty within the respiratory, phonatory and articulatory systems together may create other speech deficits in PD. Changes in speech rate may occur, but vary from one person to another. Some individuals speak with short rushes of speech (fast speech), while others have slow, labored speech.

There are many ways that Parkinson's disease may affect speech and voice ability, thus affecting overall communication skills. The most common complaints are soft or weak voice, hoarse voice, monotone voice, and slurred or mumbled speech.

While mild to moderate changes in the speech and voice systems may be noted early in PD, more deficits are observed later in the disease process. As changes within the speech production system progress, an individual with PD might report, "My spouse needs a hearing aid!", rather than realizing that his or her own voice has become softer and more difficult to understand. It is not uncommon to experience increasing frustration, reducing efforts to converse with others, or limiting social contacts because of these changes.

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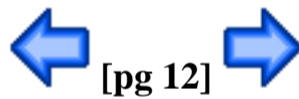


This section is to be completed by a care partner, family member or friend who has regular contact with the person with PD. (The text refers to the person with PD as "Parkinson partner".) The respondent should carefully read each statement, thoughtfully consider if it applies to the person with Parkinson's disease, and check the box if it does:

- 1) I have difficulty hearing my Parkinson partner when s/he speaks.**
- 2) I have difficulty understanding his or her speech.**
- 3) My Parkinson partner does not talk as much as in the past.**
- 4) My Parkinson partner does not attend social functions as frequently as in the past.**
- 5) He or she often asks me to make phone calls or order from a menu for him or her.**
- 6) My Parkinson partner clears his or her throat often.**
- 7) My Parkinson partner often sounds as if s/he is running out of breath when speaking.**
- 8) My Parkinson partner suspects that I need a hearing aid.**
- 9) My Parkinson partner thinks I ignore what s/he has to say.**

Multiple "yes" answers, or a "yes" answer to even one issue that truly interferes with daily communication between the individual with PD and others is sufficient basis to request referral for a complete speech and voice evaluation.

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CHAPTER 3

Personal Assessment Tools

There are several signs or symptoms in addition to the speech and voice changes noted in prior sections of this handbook that may help an individual with PD to recognize changes in communication abilities.

The following self-assessment questionnaire is to be completed by the individual with Parkinson's disease. Carefully consider the following statements, honestly decide if it applies to you, then check the box if it does:

1) People often ask me to repeat a statement.

(It is important to notice if you are having to repeat information when speaking to others. Are you asked to repeat on the phone -- in restaurants -- by family -- or in groups?)

2) People look slightly confused or as if they are trying hard to listen to me when I speak.

3) My care partner comments that I sometimes slur or mumble words.

4) My care partner comments that I do not speak loud enough.

5) I feel that my care partner is ignoring me or may need a hearing aid.

6) I do not attend social functions as often as in the past because I feel like people do not listen to what I have to say.

7) I notice that I often "give up" when trying to communicate in a group or that others seem to "talk over me".

8) I feel like people do not listen to me anymore.

9) I feel like people do not think I have anything interesting to say.

10) I avoid speaking on the phone when possible.

11) I often feel a need to clear my throat.

12) When finishing a conversation, I feel frustrated at being unable to communicate what I had to say.

An individual who answers "yes" to any of these statements may be experiencing changes in communication ability related to the PD influence on speech and voice.

Many of the areas of difficulty reflected by this survey can be improved by short-term speech therapy. Anyone experiencing such changes is advised to discuss them with the neurologist or other physician, and request an evaluation by a qualified speech therapist.



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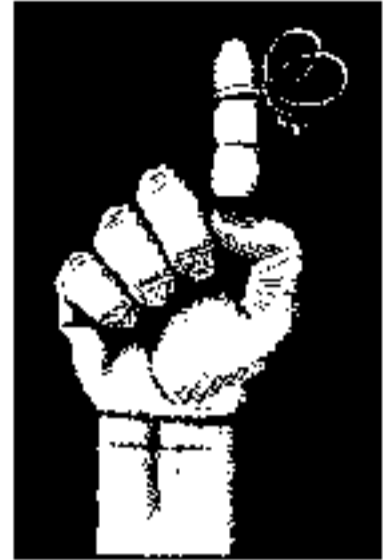
CHAPTER 4

Memory and Concentration

*"Eggs, milk, bread...
what else was on that grocery list?"*

Sound familiar?

Most of us have experienced this sort of memory lapse. As we age, we begin to notice subtle changes in memory. Memory changes of normal aging include difficulty with short term memory; for example: remembering new information such as the reason you went into a room, what you did last night, or items on a grocery list.



Conversely, older people experience little difficulty remembering events that happened 30 years ago, or long term memory. People with Parkinson's disease experience these challenges, but report that their problems seem more severe or happen more often than would be expected due to normal aging.

It is important to note that many persons with Parkinson's disease do not notice or report *any* significant changes in their ability to think clearly, process information, make decisions, etc.

Within the onset of even subtle changes in memory and concentration, however, some people with Parkinson's disease are afraid that they have Alzheimer's disease in addition to PD. awhile it is possible to have both Parkinson's disease and Alzheimer's disease, research has shown that the memory problems experienced by people who have only PD are different from those problems experienced in Alzheimer's disease.

Memory problems with Alzheimer's disease include reduction in the amount of speech, inability to process complex information, difficulty recalling information even when given clues, and forgetting friends and family members, possibly even one's own identity.

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In Parkinson's disease, memory and cognitive changes *can* appear at any stage in the progression of the disease, but are more often reported by individuals who have had the disease for many years. In those individuals who do experience cognitive changes, the observations may include:

- Reduced ability to concentrate or "think through" an activity
- Additional time required to think of what one wants to say
- Difficulty thinking of a specific word one wants to use
- Loss of one's train of thought while speaking
- Being easily distracted
- Increased time required to process information

If you are concerned about changes in your memory or concentration, ask your physician for an evaluation. Some medications for Parkinson's disease can adversely affect memory and concentration. Adjusting the dose or discontinuing a particular medication can often correct the problem. The physician can also rule out other potential causes of cognitive problems, such as undetected depression or underlying infection.

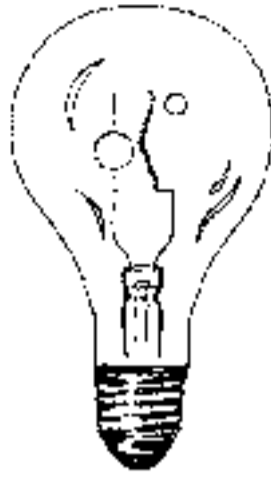
When medications are optimally adjusted, your physician may elect to refer you to a speech-language pathologist (SLP), who can further evaluate memory and concentration skills. A certified speech-language pathologist has extensive educational preparation to recognize and assess changes that occur within the brain that affect use of language and memory. He or she also has knowledge of strategies and therapy procedures to address any deficits and can recommend recall strategies to aid in carrying out everyday activities.

A SLP may be able to help you regain more control over planning and preparing for daily routines and events, which can lead to greater independence and self-confidence.

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More good news for people with Parkinson's disease is that there are many daily activities that provide opportunities to stimulate "brain power"!



Brain Power Boosters



Reading and discussing articles in the newspaper or in magazines.



Working crossword puzzles and "seek and find" puzzles.



Becoming a bird watcher with birdhouses and feeders to be taken care of on a daily basis.



Doing flower pot gardening. Decide which flowers to purchase, make a list of all materials needed, and make a plan for maintaining the plants and follow through with daily care.



Going through old photos and making memory books for your children and grandchildren.



Exercising daily with some outside activity such as short walks in the neighborhood, sweeping sidewalks, outside gardening, etc.



Planning a household job to do everyday.

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Memory Joggers

- **Keep a detailed diary** of daily events and review it every day.
- **Keep a calendar of appointments** and engagements and review it daily.
- **Keep paper and pen handy** to write down information to be remembered, such as phone numbers, lists, etc.
- **Organize lists in categories** to stimulate memories.
- **Focus on remembering main points**, not trying to recall every detail.

Tips for Family and Friends

- **Allow individuals with Parkinson's disease ample time** to process what has been said and to respond.
- **Be concise when speaking of specific people and events.** Use proper names rather than pronouns ("Sally" vs. "she").
- **When asking someone with PD to make a choice, offer limited options.**
For example, when choosing food for dinner, say "Would you like chicken or beef?"
not, "What would you like for dinner?"
- **Review upcoming activities for the day every morning.**
- **Perform activities of daily living (ADL's) 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.



While many persons with Parkinson's disease never develop memory and cognitive changes, the recommendations presented in this chapter can help individuals who *do* experience difficulties in this area to better cope with and compensate for the changes. By incorporating some of these memory aids and suggestions into your daily schedule, you can greatly enhance your functional level and self-esteem.

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CHAPTER 5

Improving Swallow Function

Individuals with Parkinson's disease may notice changes or difficulty with chewing, eating, or swallowing. These changes can occur at anytime throughout the disease process, and are usually in the mild to moderate range. Common complaints from individuals with PD are drooling, slowness in eating, a sensation that food is caught in the throat, and difficulty swallowing pills.

There are many techniques and strategies to improve or compensate for these difficulties. To understand and utilize these techniques, it is important to understand the swallow system and how it changes in Parkinson's disease. There are three stages of a swallow: *oral, pharyngeal, and esophageal*. All three stages may be affected in PD.

Oral Stage

The first stage, or oral stage, begins when food is placed into the mouth, chewed, formed into a ball (bolus) on top of the tongue, and moved to the back of the mouth.

Because the tongue, jaw, and face are all composed of muscles, the oral stage of swallowing can be affected by rigidity, reduced movement, tremors, or dyskinesias in the same way limb mobility can be affected.

In this stage of a swallow, the tongue, lips and cheeks are primarily responsible for difficulty observed in PD. This is a result of the reduced movement, rigidity or range of motion, rather than from actual muscle weakness. Changes noticed in this stage of swallowing can include a feeling of excess saliva in the mouth, dry mouth, food trapped around the gumline and teeth, difficulty moving food to the back of the mouth, and difficulty actually swallowing the chewed food.

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Transition Phase

The second stage of a swallow starts the moment the food is propelled from the tongue into the throat. It ends once the food enters the esophagus or food tube. This is the part of the swallow where the food is going down the throat into the esophagus, by-passing the windpipe (trachea). Correct or adequate movement of food and liquid during this stage of swallowing is important because of the proximity of the trachea to the esophagus. Difficulty can arise at this stage due to a reduced swallow trigger, reduced contraction of the throat muscles, reduced elevation of the voice box, or vocal folds that do not close. *The act of swallowing is not a simple maneuver!*

Symptoms that can occur during this stage are coughing or choking before, during or after the swallow, or aspiration (foreign material entering the lungs by way of the trachea). There can also be a delay in the swallow, with the resulting sensation of food stuck in the throat.

Esophageal Phase

The third stage of a swallow starts once food enters the esophagus. Often, difficulty in this stage of swallowing is not felt or noticed. One symptom that may be noticed is the sensation of food "stuck" in the food tube or going down slowly. Heartburn or gastroesophageal reflux caused by this phenomenon may occur more often in persons with PD. A physician, such as a gastroenterologist, should be consulted when difficulty with this stage of a swallow is suspected.

Medications Effects on Eating, Chewing, Swallowing

Again, the effects of anti-Parkinson medications on these functions are not well- documented in research literature. Anecdotal reports from individuals with PD vary. Some persons report that the PD medications improve ability to swallow, while some observe no difference in swallow function related to peak dose of medications.

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Several signs and symptoms that indicate changes in eating, chewing and swallowing ability can be identified through a detailed self-assessment process. The following exercises are to be completed by the individual with PD and his or her care partner who wish to pinpoint the exact nature of any functional problems in this area.

Swallowing Self-Assessment Survey

Carefully consider each statement below in regard to your own level of swallow function, and check the box if it applies:

- 1) I have recently experienced an unintentional loss of weight.**
- 2) I have a tendency to avoid liquids.**
- 3) I occasionally run a fever for unexplained reasons.**
- 4) I have a tendency to drool.**
- 5) I notice an excess pocketing of food around my gumline.**
- 6) I have increased occurrence of coughing or choking before, during, or after eating or drinking.**
- 7) I have frequent heartburn or persistent sore throat.**
- 8) I have difficulty moving food to the back of my mouth.**
- 9) I have difficulty keeping food or liquid in my mouth.**
- 10) It takes me a long time to eat a meal.**
- 11) I get the sensation of food being stuck in my throat.**
- 12) I sometimes have difficulty swallowing pills.**
- 13) I have had recent changes in my eating habits or loss of appetite.**
- 14) I notice changes in my voice quality after eating or drinking.**

"Yes" answers to any of these questions may indicate a need to see a SLP for a swallow assessment. Your physician can facilitate such a referral.

Make a note of any other swallowing difficulties you experience to report to your physician or therapist:

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Care Partner Swallowing Assessment Survey

This form is to be completed by the care partner regarding the person with Parkinson's disease. Consider each statement thoughtfully as it applies to that individual, and check the box if it does:

- 1) My Parkinson partner seems uninterested in food.
- 2) S/he coughs or gets "strangled" during meals.
- 3) S/he often coughs following a meal when we are engaged in other activities such as watching TV or reading.
- 4) It takes my Parkinson partner longer to eat a meal than in the past.
- 5) My Parkinson partner's voice sounds "wet" or "gurgly" when s/he speaks.

"Yes" answers to any of these responses is indicative of possible problems with chewing, swallowing or eating functions. Encourage the person with Parkinson's disease to seek referral for a swallow evaluation by a qualified speech-language pathologist.

Improving Swallow Function

The following guidelines and tips are provided for improving eating, chewing and swallow abilities:

"Think swallow" - Remember to swallow saliva before speaking and otherwise frequently to compensate for the reduction of the natural reflex.

Swallow twice after every bite. Take small bites.

Take small sips. Alternate bites and sips. This helps clear food from the mouth and throat.

Be wary of straws. Straws are useful when someone has severe tremors or dyskinesias. But do not put the straw too far back in the mouth.



Keep your chin down or parallel to the table. There is a tendency to lift the chin when drinking the last little bit of liquid in a cup or bottle. When the chin is raised, the esophagus is partially closed off and the trachea (windpipe into the lungs) is more open. This position increases the risk of aspiration.

Take only small sips (not consecutively).

Do not talk with food in your mouth!

There are also dietary modifications that can improve chewing and swallowing efficiency. Some foods such as raw vegetables, nuts, and peanut butter may be more difficult to chew or swallow. A speech-language pathologist or registered dietitian can recommend food textures and beverage consistencies that are easiest to swallow. A SLP, dietitian, or occupational therapist can also recommend various types of adaptive equipment that can make eating a more pleasant experience.

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CHAPTER 6

Getting The Help You Need

Speech-language pathologists (SLP) are healthcare professionals trained to evaluate and treat individuals with speech, voice, language, and swallowing problems. A SLP has a graduate degree and is certified by the American Speech- language and Hearing Association (ASHA).

Developing and improving effective communication skills and swallow election are the primary roles of a SLP when treating an individual with PD. Many SLPs are trained specifically in treating the Parkinson population.

Finding a Speech-Language Pathologist

Local hospitals and rehabilitation centers often employ SLPs to provide both inpatient and outpatient services. In addition, many speech-language pathologists have private practices that accept new patients with referral from a physician.

It is important to inquire if the SLP to which you are referred has experience treating individuals with Parkinson's disease. Several resources exist to locate experienced therapists. In some states, the National Parkinson Foundation (NPF) sponsors a comprehensive rehabilitation program (including speech therapy services) known as the Parkinson Outreach Program (POP). Individuals may call **(800) 243-3333** for more information and referral to the nearest Parkinson Outreach Program.

Patient Service Coordinators at NPF Centers of Excellence throughout the U.S. and Canada can also recommend qualified speech therapists. To contact the national headquarters for NPF and request referral to an SLP, call **(800) 327-4545**.

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The American Speech-language and Hearing Association (ASHA) may also help identify SLP's in specific geographic regions. ASHA can be contacted at:

American Speech-Language and Hearing Association
10801 Rockville Pike
Rockville, Maryland 20852
Phone: (800) 638-8255

The Ellis Neurological Voice Treatment Foundation is dedicated to the education, research and training of speech-language pathologists in the treatment of: neurological speech and voice disorders. This foundation maintains a roster of certified SLPs specifically trained in LSVT for Parkinson's disease and can recommend educational resources for families living with PD. Contact information is:

Ellis Neurological Voice Treatment Foundation
P. O. Box 642
Louisville, Colorado 80027
Phone: (303) 604-3280

Finally, neurologists and primary care physicians can often recommend and refer patients to a SLP who is familiar with Parkinson's disease treatment methods.

The Therapy Process

Once a referral is made and an initial appointment scheduled, the speech-language pathologist will evaluate the speech, voice, and swallow characteristics of the individual with PD.

If indicated, he or she will then recommend a specific course of treatment. Treatment focuses on improving the overall effectiveness of communication, and in some cases, swallow function.

Ongoing research regarding a speech therapy program known as the Lee Silverman Voice Treatment (LSVT) method is funded by the National Institutes of Health (NIH) and the U.S. Office of Education. Due to the straightforward nature of: LSVT methodology and its demonstrated effectiveness in improving voice and speech in persons with PD, it is highly regarded within the medical community.

LSVT was pioneered by Dr. Lorraine Ramig of the University of Colorado at Boulder and the Wilbur James Gould Voice Research Center in Denver; it is heralded as the first speech treatment for Parkinson's disease documented to significantly improve speech after only one month of treatment.

Exercises taught in the LSVT method are easy to learn and have an immediate impact on functional communication. The gains have been shown to last up to two years following treatment. LSVT methods have also been used successfully in treating speech and voice problems in individuals with atypical Parkinson syndromes such as Shy-Drager syndrome, progressive supranuclear palsy (PSP), and multi-system atrophy (MSA).

Continuing research studies are evaluating the effects of LSVT on improving swallow function as well as speech production. More information on the LSVT method is available from the Ellis Neurological Foundation.

Early Intervention

As with any progressive neurological condition, *early* intervention is the key to maintaining or increasing communicative effectiveness and swallow function.

As soon as an individual with PD or a care partner notices changes in speech or swallowing, it is time to seek referral to a SLP. It is much *easier* to learn effective strategies and techniques to keep the speech mechanism highly functional than it is to rebuild what may have already been lost.



However, it must be stressed that it is *never too late* to see a SLP and get help to restore functions regarding speech and swallowing. Individual gains following comprehensive therapy are often surprising and most rewarding.

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Medical Procedures

Some alternative treatments for voice problems associated with PD are available, but many are experimental and not totally supported by research literature.

Collagen injections have recently gained attention in the Parkinson community. The purpose of collagen injections is to "beef up" vocal folds that do not close completely while talking. The procedure involves injecting collagen directly into the vocal folds via a needle inserted into the neck.

Individuals who have undergone this procedure report some improvement in voice, specifically loudness and voice quality. However, the injection does not improve respiratory or articulatory function. The collagen effect typically lasts for about 6 months, and must be re-injected. For the duration of its effect, collagen is slowly being absorbed by the body. Over time a gradual decline in voice function may occur.

This procedure is not effective for everyone, but more information can be obtained by consulting an otolaryngologist (ear, nose and throat specialist).

Surgical Procedures

In addition to pharmacologic (drug) therapy for Parkinson's disease, several surgical options are available to treat the patient who no longer benefits from medication alone.

Thalamotomy and deep brain stimulation (DBS) are available for persons with severe tremor. Pallidotomy and fetal transplantation are thought to offer benefit to patients with severe dyskinesias or those seeking an overall improvement in their motor abilities.

Some individuals do report improved motor function following these surgeries, although the majority continue to take anti-Parkinson medications. However, *there have been no consistent reports of improved speech and voice function following these procedures.*

In fact, some individuals have reported a decline in communication skills after surgery for Parkinson's disease. Those undergoing bilateral procedures (performed

on both sides of the brain simultaneously) are at higher risk for speech and voice impairment following surgery. Prior to signing a consent form, persons considering surgery for Parkinson's disease are encouraged to ask the neurologist and neurosurgeon *specifically* about changes that can occur in the speech and voice mechanism as a result of the operation.

Augmentative Communication Devices

In a few individuals, speech and voice become so impaired that it is difficult to communicate even basic needs and thoughts. In this case, it may be wise to consider what is known as an augmentative or assistive communication device.

These devices are designed to help an individual communicate. They come in all shapes and sizes. The assistive device most often used by persons with PD is called an amplification system. This is most effective for people who have a weakening or softening of the voice volume.

The device amplifies any speech an individual produces through a microphone and speaker system. The microphone can be hand-held, worn on the head like a pair of glasses, or attached to a shirt pocket or collar. The amplifiers are *not* effective for improving breath support, articulation or rate of speech.

A relatively new augmentative communication system on the market is called the *Speech Enhancer*[™]. This system not only amplifies the voice, but improves speech clarity through a filtering system. It has received positive reviews and can be beneficial for individuals with poor speech intelligibility due to severe dysarthria that has not improved with therapy. A significant drawback of this device is that it is cost-prohibitive for many people.

Other augmentative communication devices are available. These range from hand-made communication books or tablets to sophisticated computerized equipment. People sometimes comment that such devices are distracting and bulky. These can also be costly, ranging from \$100 to \$5,000. However, for some individuals, this is an acceptable and necessary solution for increasing functional communication.

If it seems like any of the devices or systems described in this section could be of help in enhancing your ability to communicate, a speech-language pathologist can recommend the most appropriate selection.

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CHAPTER 7

Communication Practice Sets

Clues for Friends and Family

Family members are usually the best ongoing support system for individuals living with Parkinson's disease. There are several things care partners, family members, and friends can do to assist the person with Parkinsonian dysarthria to communicate more effectively.

The first and most important thing is to encourage the individual to agree to speech therapy when changes in voice and speech production are noticed. In addition, simple yet effective environmental and behavioral modifications can be implemented to greatly improve communication.

Communication Boosters

Establish the habit of looking at one another while having a conversation. The element of lip reading greatly enhances comprehension.

Eliminate background noise while speaking. Turn off radio or TV, close car windows, doors to noisy areas, etc.

Be aware that facial masking is a feature of the Parkinson's disease. Individuals with PD may feel emotions that do not show fully because of rigid facial muscles. Don't assume that the individual does not understand your message. "Blank" expressions may be due to facial rigidity. Avoid depending on facial cues to determine if the message was "transmitted".

Encourage and practice the use of shorter sentences when speaking. The individual with PD can put more breath support behind shorter statements. Ask questions that can be answered in short sentences. Choose questions that give the person a limited choice of answer i.e., "Do you want eggs or pancakes for breakfast?"

Be patient. Don't rush or force conversational responses. Allow ample time for the person with Parkinson's disease to communicate. Patience encourages an accepting climate in which the individual who is slow or soft of speech can respond and feel more comfortable.

Encourage your Parkinson partner to regularly practice a home exercise regimen that can be tailored to his or her needs by a speech-language pathologist. Some components of such a program are included in the exercises that follow...



Vocal Strategies*

It is important to develop a homework routine that can be completed consistently. Choose a time of day to practice these maneuvers for 10-15 minutes daily without interruptions.

1) **Take a deep breath and say the "ah" sound in a loud voice.** Try projecting your voice across the room; hold the "ah" for as long as you can.



2) **Sing musical scales on "la" both going up and coming down.** Make sure to take a deep breath before starting, and sing in a loud voice.

3) **Try talking in a voice that feels/sounds really loud.** This increases overall function of your voice and speech.

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* Exercises outlined are part of the Lee Silverman Voice Treatment (LSVT). referenced below:

Ramig, L., Bonitati, C., and Winholtz, W., (1994) "The Lee Silverman Voice Treatment: A Videotape of Speech and Voice Exercises"; produced by Wintronix, Inc., P.O. Box 514, Blue Springs, MO 64015. Phone: (816) 229-0193

Ramig, L., Countryman, S., O'Brien, C., Hoehn, M., and Thompson, L., (1996) Intensive speech treatment for patients with Parkinson disease: short and long-term comparison of two techniques. *Neurology* 47: 1496-1504.

Ramig, L., Countryman, S., Thompson, L., Horii, Y., (1995) A comparison of two forms of intensive speech treatment for Parkinson disease. Journal of Speech and Hearing Research 38: 1232-1251.


Ramig, L., Pawlas, A., and Countryman, S., (1995) "The Lee Silverman Voice Treatment (LSVT): A Practical Guide for Treating the Voice and Speech Disorders in Parkinson Disease", published by the National Center for Voice and Speech, Bldg. 125-SHC, Iowa City, IA 52242. Phone: (319) 335-6602.

The professional advice and instructions provided in this manual are not intended to replace the guidance of one's personal physician or speech-language pathologist.

But many of the tips are applicable to a majority of persons with Parkinson's disease, and can be immensely helpful in improving voice quality, and thus, quality of life.

It is the hope of the NPF Speech Team that this booklet will provide help for effective communication skills that will last a lifetime!

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Conversational Challenges



The best way to practice talking is to **keep talking!** Do not limit your speaking because you feel self-conscious or have difficulty. The motto, "*use it or lose it*" certainly applies in this instance.

Here is a list of possible conversation topics. If you don't have a companion with whom to converse, *talk to yourself!*

Talk about your family - who's who, where they're from, etc.

Describe a favorite hobby or pastime in detail.

Give a travelogue about a trip or vacation you've enjoyed.

Discuss a period of time or particular event you recall from childhood.

Talk about your favorite food or restaurant.

Verbalize opinions and thoughts about your favorite state in the U.S.

Talk about three things you hope to accomplish in the next year.

Talk about three things you appreciate most about a spouse or friend.

Talk about the most beautiful place in the world.

Facial Exercises

Many individuals with PD request facial and oral exercises, hoping to reduce the effects of rigidity of muscles in the face and hypomimia (reduced facial expression). Choose the exercises that seem most difficult to execute; this is an indicator that the muscles involved in that motion may need to be worked.

It is suggested that you start with 10 repetitions of each of the facial movements described. Each exercise should be completed with deliberate 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 to gauge success:

1) **Smile - hold - relax - repeat.**

2) **Pucker your lips - hold - relax - repeat.**

3) **Alternate puckering, then smiling.** Pucker as tightly and smile as hard as you can. (To increase the effectiveness of this combined 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, both corners. Movements should be deliberate, not "darting".

5) **Open your mouth and move the tongue around the gumline...** i.e. back of top and bottom teeth, front of top and bottom teeth, each side of both top and bottom teeth.

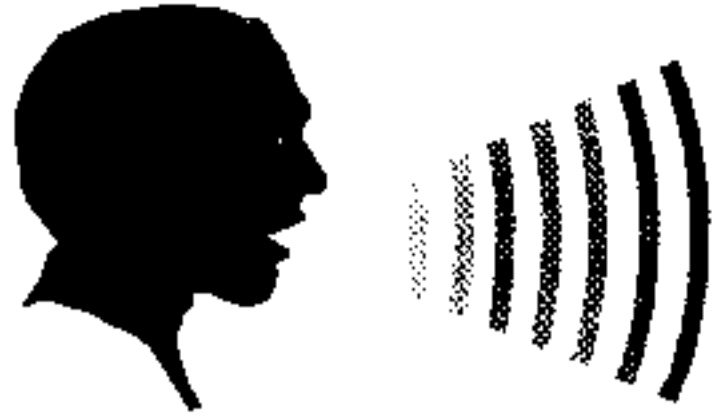
6) **Open your mouth as wide as you can - hold - relax - repeat.**

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.**

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4) **Practice using a loud voice ...** First in short phrases, then sentences and reading paragraphs, finally in conversation. Although your voice sounds loud to you, it is probably just right for the listener.



5) **When speaking on the phone or engaged in conversation, count the number of times you are asked to repeat.** Now try again in a loud voice, and count the requests to repeat. Doing this helps increase awareness of how you actually sound to others.

6) **While driving or riding in the car, practice saying aloud the street signs or places you pass.** Use a loud voice (and considerable caution if you are the driver!)

7) **Read short newspaper articles out loud.** Read each article as if you were reading to a large group.

8) **Read children's books to your children or grandchildren in a loud voice.** Practice putting extra expression into your voice as you read.

9) **Tape record yourself while doing any of the above exercises.** It helps increase awareness of how you sound when using a strong voice.

Practice Maneuvers*

Practice the following phrases in a loud, expressive voice:

"Shut the door."	"Good night, honey?"
"Pass the food, please."	"Answer the phone."
"How are you ?"	"I'm fine, thank you."
"I love you."	"Who is this?"
"I need help ?"	"Please sit down."

Practice saying the following sentences in a loud, strong voice. Use proper breathing techniques as indicated to enhance vocal strength:

- 1) (inhale) **"Did I take my medication yet?"** (exhale)
- 2) (inhale) **"I would love a cup of coffee."** (exhale)
- 3) (inhale) **"Where are you going?"** (exhale)
- 4) (inhale) **"I need to go to the bathroom."** (exhale)
- 5) (inhale) **"It's a beautiful day!"** (exhale)
- 6) (inhale) **"Where is the remote control?"** (exhale)
- 7) (inhale) **"Would you like to go out to eat?"** (exhale)
- 8) (inhale) **"It's good to see you!"** (exhale)
- 9) (inhale) **"Wow are you today?"** (exhale)
- 10) (inhale) **"I went to the doctor's last week."** (exhale)



Paragraphs are easy to find...

Try reading out loud anything that you are currently reading: from the newspaper, a favorite book, magazines, or reading aloud to children from their books. Remember to "think loud" and *breathe*.

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