COMMUNICATION & SWALLOW

Parkinson Society
British Columbia

Contents

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Canadian Guidelines on Parkinson's Disease

The Canadian Guidelines on Parkinson's disease are published by national Parkinson's specialists for healthcare professionals. If you are interested in obtaining the complete guidelines contact PSBC at 1-800-668-3330.

The focus on non-pharmacologic methods of treatment is emerging for Parkinson's disease (PD). Provision of education and valid information is essential to empower both patients and families in actively participating in disease management (Grimes et al., 2012).

Speech and language therapy is essential to the quality of life for people with Parkinson's (PwP) disease. Hypophonia, weak or soft voice, is a common problem resulting in social withdrawal and the misperception of cognitive decline for PwP. Speech-Language therapy can improve communication.

Assessment of swallowing safety is crucial. Speech-Language pathologists (SLPs) in conjunction with clinical nutritionists make important contributions to the patient healthcare team. Their involvement can result in identifying causes for weight loss, reduce the risk of aspiration* and help maintain weight.

According to the Canadian Guidelines on Parkinson's Disease, Speech-Language therapy should be available for PwP. Particular consideration should be given to:

- Improvement of vocal loudness, including speech therapy programs, such as the *Lee Silverman Voice Treatment*® (LSVT®).
- Ensuring an effective means of communication is maintained throughout the course of the disease, including use of assistive technologies.
- Review and management to support safety and efficiency of swallowing, and to minimize the risk of aspiration.

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Overview of the Communication and Swallow Booklet

This booklet focuses on communication and swallow challenges faced by people with Parkinson's disease (PwP)). This booklet is intended to complement Parkinson Society British Columbia's (PSBC) Communication and Swallow Workshops, which are interactive and participatory in format. It can also be referred to as a stand-alone resource. PwP at all stages are welcomed to use this resource, including those who currently do not experience communication and swallow symptoms but wish to be proactive with their treatment.

Those individuals seeking more information about communication and swallow challenges should consult a Registered Speech-Language pathologist (RSLP) in their community.

To find a Registered Speech Language Pathologist:

College of Speech and Hearing Health Professionals BC:
https://cshbc.ca.thentiacloud.net/webs/cshbc/register/#/

Speech and Hearing BC Find a Professional: https://speechandhearingbc.ca/#professional-map

To find a RSLP trained in LSVT® LOUD near you, contact PSBC at 1-800-668-3330 or visit the LSVT® Global website at www.lsvtglobal.com.

To find a RSLP trained in Speak Out! https://www.parkinsonvoiceproject.org/ProvidersInt.aspx

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Editorial Statement

The information in this booklet is not intended to take the place of professional consultation with a Registered Speech-Language Pathologist (RSLP) or your health care team. Information for this booklet was taken from the PSBC Communication and Swallow Workshops, the American Parkinson Disease Association (APDA; 2010) Speaking Effectively resource [http://www.apdaparkinson.org/resources-support/download-publications/], Lee Silverman Voice Treatment® resource, and the Parkinson Voice Project website.

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Communication and Swallowing Fast Facts

1. A Registered Speech-Language Pathologist (RSLP) is an important member of your healthcare team to help support and maintain quality of life in the areas of communication and swallowing.
2. Communication and swallow difficulties can occur at any phase of Parkinson's disease (PD) and can be early symptoms prior to diagnosis.
3. Up to 90% of PwP worldwide will have trouble with communication, at varying levels of severity, most typically characterized by low vocal volume.
4. The trouble communicating specific to PD is called *hypokinetic dysarthria* which can include low volume, decreased rate of speech, hoarseness, speech sound problems and voice tremor.
5. Lee Silverman Voice Treatment® has been the gold standard for speech therapy for PwP.
6. Most PwP will have difficulty with some aspect of swallowing, at varying levels of severity.
7. Up to 90% of PwP will have trouble swallowing which can impact health outcomes such as malnutrition, dehydration, and aspiration.
8. Those with PD should have a baseline swallow study, known as a Modified Barium Swallow (VFSS) study. This is a video X-ray of swallowing performed by a qualified RSLP and radiologist.
9. Safe swallowing recommendations including any changes to food texture, or any form of swallowing exercise, should be made by a RSLP *after* participating in a VFSS.
10. Behavioural treatment remains the most effective approach for managing dysphagia. There are no medications specifically for communication or swallowing difficulties but you may see improvement when your Parkinson's medication is optimized.
11. It is best to address communication and swallowing *early* to work on a plan to maintain quality of life.

Overview of Parkinson’s Disease

Parkinson's disease (PD) is the second most common neuro-degenerative disorder after Alzheimer's disease and affects both motor and non-motor functioning. PD is a progressive neurological disorder resulting from the loss of dopamine (chemical messenger) in a part of the brain called the substantia nigra. As dopamine continues to decrease, muscle movements become slower and more rigid, tremors can develop and reflexes become more impaired contributing to a loss of balance.

Common Symptoms

PD manifests itself through a wide spectrum of symptoms. While there are many potential challenges, keep in mind that the disease is unique to every individual.

Below is a list of the common motor and non-motor symptoms experienced by PwP. This list is not exhaustive.

Motor Symptoms

- Resting tremor
- Rigidity
- Slowness of movement (bradykinesia)
- Balance and postural impairment
- Softened voice (hypophonia)
- Difficulty swallowing (dysphagia)

Non-Motor Symptoms

- Reduced facial expression (hypomimia)
- Sleep disturbances
- Constipation
- Fatigue
- Changes in mood (depression and/or anxiety)

Neurological Basis for Communication and Swallow Difficulty

The symptoms of PD can affect respiration (breathing), phonation (voice production), resonation (richness of voice) and articulation (clarity of speech). Disruptions to breathing, voice, speech and swallowing characteristics are caused by movements of muscles, which are slower, less accurate, weaker or difficult to coordinate with other movements (Matsuo & Palmer, 2008). The muscles of the lips, tongue, throat, larynx* (voice box) and lungs may all be affected. The primary result of these changes in muscle performance includes imprecise articulation and rapid speech rate with progressive acceleration and short rushes of speech, reduced stress of syllables, reduced loudness and a hoarse, tremulous and monotone voice (Matsuo & Palmer, 2008).

Structure and Function of the Larynx

The structure of the larynx, or voice box, includes cartilage, bone, ligaments and muscle. Cartilage includes thyroid cartilage (commonly referred to as the Adam’s apple), cricoid cartilage, and the arytenoid complex (made up of 3 separate cartilages.) There is one bone in the larynx called the hyoid bone. The hyoid bone is our only floating bone and suspends the larynx between the base of the tongue and thyroid cartilage. It does not have another bone attachment, or joint, but rather is suspended by muscles from above and below.

We have two vocal folds which are made of layers of cells, ligaments, and muscles. They sit horizontally in the larynx from the thyroid cartilage in front to the arytenoid complex in the back. The vocal folds,

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move (open, close, and vibrate) via joints created by the cartilage and muscle attachments. The larynx is innervated (supplied with nerves for movement and sensation) by the superior laryngeal nerve and the recurrent laryngeal nerve branches of the Vagus nerve/cranial nerve X.).

The larynx has four primary functions: respiration (breathing), airway protection when swallowing or coughing, fixation (for lifting, pushing and pulling), and voice production.

Many of the same muscles that are used to produce voice and speech are also used for eating and swallowing. Most PwP will report problems in these areas.

It is best to address communication and swallowing *early* to work on a plan to maintain quality of life.

(Rosen & Simpson, 2008)

The Role of a Speech-Language Pathologist

Registered Speech-language pathologists (RSLPs) are healthcare professionals trained to evaluate and treat individuals with speech, voice, language, and swallowing problems. A RSLP has a graduate degree and has been registered by the College of Speech and Hearing Health Professionals of British Columbia (CSHHPBC).

The RSLP is the professional who will provide detailed information about the changes in communication and swallow as PD changes over time. The RSLP will be able to offer solutions and treatment for improving speech, voice and swallowing to help maintain quality of life.

Finding a Registered Speech-Language Pathologist

In BC, local hospitals, rehabilitation centres and movement disorder clinics employ RSLPs to provide both inpatient and outpatient services. In addition, many RSLPs work in private practice.

The CSHHPBC website will help you locate a RSLP in specific geographic areas [[http://www.cshhpbc.org/docs/directorybycity.pdf]. You can also contact the College at 604-568-1568.

Speech and Hearing BC, the provincial Speech and Hearing Association, also has a Find a Professional resource. [http://www.bcaslpa.ca/public/find-a-professional/].

To find a SLP trained in LSVT® LOUD near you, contact PSBC at 1-800-668-3330 or visit the LSVT® Global website at www.lsvtglobal.com.

A Registered Speech-Language Pathologist (RSLP) is an important member of your healthcare team to help support and maintain quality of life in the areas of communication and swallowing.

Communication and Swallowing

How Do I Know if My Communication and Swallowing is Changing?

The Radbound Oral Motor Inventory for Parkinson's disease (ROMP) is a self-evaluation tool to evaluate perceived problems with speech, swallowing and saliva control in patients with PD or atypical Parkinsonism. This can be used to identify initial concerns or monitor any changes. Share your results with your physician and health care team to help facilitate support in the areas identified as troublesome. You can complete the ROMP every 6 months to a year, or anytime you think you have experienced changes in communication or swallow abilities. We recommend keeping previously completed copies for comparison. You can find the ROMP questionnaire in Appendix A (reprinted with permission).

Communication and swallow difficulties can occur at any phase of Parkinson's disease (PD) can be early symptoms, prior to diagnosis.

Our ability to communicate allows us to express our emotions, socialize, work, and at a very basic level; have our wants and needs met. Wants and needs include expressions such as "I'm hungry, I'm tired, I need the doctor, I have pain, I love you." As many as 89% of PwP world-wide have disordered communication. Oftentimes PwP indicate that they cannot be heard or that they have a hard time speaking over crowd noise. Family members or a partner may complain that the PwP is not speaking loud enough. This can lead to frustration during communication interaction. The difficulties that PwP have with vocal loudness have been well studied. Low vocal loudness level means that the vocal output is softer than normal (see Appendix B – LSVT® Vocal Loudness Picture).

The diagnostic term used to describe difficulty with communication in PD is hypokinetic dysarthria*. Dysarthria* is a collective term used to refer to the impaired production of speech due to disturbances in the muscular control of the voice and speech mechanism. Hypokinetic means reduced movement. Therefore, hypokinetic dysarthria is reduced movement of the muscles used for voice and speech production. The structure that produces voice and speech, and allows for safe swallowing, is not broken in PwP. The message from the brain has been altered due to the breakdown in the motor cortex. When the message to the system is strong enough and "big" enough, the structure will respond in a more functional way.

Up to 90% of people with Parkinson's disease (PwP) worldwide will have trouble with communication most typically characterized by low vocal volume.

Symptoms of Hypokinetic Dysarthria May Include:

- Low vocal volume
- Hoarseness
- Changes in speech rate (faster or slower)
- Inaccurate articulation.

Less Obvious Symptoms That May Indicate Changes in Communication:

- Increased need to repeat

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- Decreased desire to socialize
- Decreased participation in conversation
- Not talking on the phone
- Less effective in the workplace for tasks requiring communication.

Please refer to your questions on the ROMP Questionnaire to help increase your awareness of any difficulties with communication and speech (see Appendix A).

Cognition and PD

Mild cognitive impairment occurs in 20-50% of PwP. Parkinson's dementia, much less common, has been estimated to occur in 0.2-0.5% of PwP (Goldman & Litvan, 2011). Cognition refers to mental abilities and processes which include attention, memory, judgment and evaluation, reasoning, problem solving and decision making, comprehension, and production of language.

Mild cognitive impairment has been described as notable changes in cognition but not severe enough to interfere with daily life or independent living (Goldman & Litvan, 2011). Dementia has been defined as a decline in cognition that significantly impairs the ability to perform everyday activities. PwP should report any cognitive concerns to their health care team. Medication and other health related issues should be addressed as possible contributors to changes in cognition. Several studies document the benefit of exercise on improving and maintaining cognitive function.

What is a Communication Evaluation?

A communication evaluation takes place with a Registered Speech-Language Pathologist. Information regarding your current concerns and medical history will be gathered and discussed. Baseline data on your communication abilities, speech and voice, will be collected and used to determine treatment plan and outcome measures. Cognitive screening or full cognitive evaluation may also be administered. Because the treatment for hypokinetic dysarthria is "voice" therapy (or Behavioural Therapy), it is important to also evaluate the vocal folds* prior to treatment. This can be done by an ear, nose and throat (ENT) specialist or qualified Registered Speech-Language Pathologist (RSLP).

Speech Therapy for Hypokinetic Dysarthria

The most widely used program shown to have positive outcomes for PwP is the *Lee Silverman Voice Treatment®* (LSVT®) program. SLPs, Lorraine O. Ramig, Ph.D., CCC-SLP and Carolyn Mead, M.A., CCC-SLP, developed this program in 1987. It was named for the patient who was the inspiration for this creative approach to speech therapy. LSVT® is an intensive behavioral treatment program that requires a PwP to engage in 16 60-minute therapy sessions in one month. The primary goal of the technique is to improve vocal loudness. In addition, because of the therapy, improvements in speech, fluency, breath support, lip movement and facial expression have also been well documented. There has been evidence that LSVT® has resulted in improvement of the oral phase of swallowing related to lip strength, drooling, chewing and manipulating food. Outcome studies have shown carryover of progress up to 2 years (Ramig et al., 2001; Ramig, Fox & Sapir, 2004). As everyone's experience with PD is different, outcomes may vary from researched outcomes. An established relationship with a RSLP will help extend the benefit of the LSVT® program.

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The trouble communicating specific to PD is called *hypokinetic dysarthria* which can include low volume, decreased rate of speech, hoarseness, speech sound problems and voice tremor.

The LSVT® Program Consists of Five Essential Concepts

Concept 1: Focuses on the VOICE. This concept works on helping the vocal folds close better, reinforces the idea of "THINKING LOUD/THINKING SHOUT" and attempts to train the speech to be as clear as possible.

Concept 2: Focuses on HIGH EFFORT with emphasis on vocal and physical effort. This focus on effort is thought to override the muscles' lack of movement and slowness of movement to new effort levels – particularly as the disease progresses. The clinician helps the person with PD scale the effort needed to perform the tasks during therapy.

Concept 3: Sixteen sessions are done on an individual basis for a period of one month. This provides daily opportunity to practice, and over the 16 sessions, allows the degree of vocal effort to be increased. It helps maintain a certain level of motivation and accountability. It also provides adequate time for the skill(s) to be learned and transferred to other environments such as home or work. Finally, it allows the speech pathologist to document any fluctuations in the patient's performance.

Concept 4: Focuses on defining what the patient "knows" and "accepts" about the amount of effort needed to consistently increase vocal loudness to a level that is within normal limits. The relationship between increased vocal effort and vocal output is then established. Those with PD often have problems knowing how loud their voice is.

Concept 5: Focuses on quantification. The key is to motivate the patient and provide feedback about the improvement or the need for more improvement. During this phase all five concepts are integrated and all focus on high effort voice used daily.

Voice exercises are introduced as part of the PSBC Communication and Swallow Workshop. While you will be able to perform these exercises, carryover of increased vocal loudness to all daily activities can be improved by participating in a formal LSVT® program with a certified LSVT® RSLP.

Technology

The LSVT Companion® is a commercial product designed to facilitate your treatment, increase treatment accessibility and encourage treatment maintenance with at home use. Use of the LSVT Companion® by the SLP can decrease the need for direct 1:1 therapy sessions by up to 50% with the same results as 16 individual sessions (Halpern et al., 2012). This was developed by LSVT® Global to increase access to LSVT® while decreasing the burden of intensive treatment. Ask your SLP if they have the LSVT® Companion.

Parkinson's Voice Project – Speak Out!

SPEAK OUT! and The LOUD Crowd is a standardized speech therapy program of 12 individual treatments combined with ongoing weekly group sessions for individuals with dysarthria due to Parkinson's disease

(PD). The premise of this program is that individuals with PD must rely on goal-directed basal ganglia–cortical circuits to compensate for deficits in habitual, automatic control.

SPEAK OUT! and The LOUD Crowd targets vocal effort by prompting patients to speak with “intent”, defined and modeled as a purposeful cognitive focus on increasing vocal loudness and intonation variability during speech.

Other options

Current technology allows for individuals to independently monitor loudness. There are several apps that can help the PwP work on voice and communication. Some apps are listed below. To find one that is right for you, work with your RSLP. The following is not a comprehensive list.

Voice Applications

- Speak Up for Parkinson’s
- Voice-O-Meter
- iParkinson’s
- Delayed Auditory Feedback
- Speech-Easy

Alternative Methods of Communication

There are other types of devices that are used when a person’s ability to communicate orally becomes very limited. These are augmentative or assistive devices. The devices can be used in addition to continued efforts at speech improvement or by themselves. Some systems are quite simple and inexpensive, while others are complex and more expensive.

Writing - This is the most common way to communicate without speech. Keep writing materials accessible at all times. These could include paper and pencil, clipboard, small chalkboard with chalk and eraser or a magic slate (found in toy departments). When writing or printing, concentrate on keeping the letters large and well-spaced.

Pointing Systems - This includes items such as a large board, notebook, binder or photo album with pictures of family, friends and commonly used items. Alphabet boards or notebooks with words for frequently needed items organized into categories are other helpful pointing systems.

Electronic/Computer Systems - These are the most sophisticated augmentative systems and may consist of a keyboard, display screen and printer. Many are portable. Size of keyboard and display/printer varies.

Before purchasing a device, consult with a RSLP. In British Columbia, you may be referred to CAYA. “Communication Assistance for Youth and Adults (CAYA) is a province-wide service program that supports **adults aged 19 years and older who require an augmentative/alternative communication (AAC) system** due to a severe communication disability, i.e. speech that is not functional for daily communication.” https://cayabc.net/ Some RSLPs are CAYA Partners which means they can fast-track loans and trial the equipment with clients directly in their outpatient/community sessions.

Other Options for Keeping Voice Strong

- Acting Lessons
- Community Choirs
- Community Theatre
- Group speech therapy opportunities (contact PSBC for a list of BC providers)
- Singing Lessons
- Song Shine Foundation - http://www.songshineforparkinsons.org
- Speak Out - http://www.parkinsonvoiceproject.org/index.html
- Toastmasters - http://www.vetc.ca/
- Tremble Clefs - www.trembleclefs.com

Exercises for Communication Practice

Voice exercises should be performed and supervised with a RSLP following communication evaluation. This is the only way to guarantee your best outcome and vocal health/safety.

The voice exercises introduced during the PSBC Communication and Swallow workshop serve the purpose of demonstration of a type of voice therapy for Parkinson Disease. Supervision of a RSLP is recommended for ongoing practice of voice and speech exercises.

Swallow

The term that is used to identify swallowing dysfunction is dysphagia*. It is common for PwP to report difficulty with chewing and swallowing. The physical changes in the muscles used for communication can also affect the ability to chew and swallow safely (Tjaden, 2008). Swallowing disorders can present themselves in many forms that may not be readily identified as a swallowing problem. The primary problems reported are:

- Food “sticking” in the throat
- Coughing or choking on food or liquid
- Difficulty in swallowing pills
- Difficulty initiating swallowing

Less obvious swallowing symptoms that can be encountered include:

- Slow rate of eating
- Fatigue during eating
- Unexplained weight loss
- Change in dietary habits
- Recurrent pneumonia
- Nasal regurgitation

Most PwP will have difficulty with some aspect of swallowing, at varying levels of severity. Symptoms can occur prior to formal diagnosis.

Please refer to your questions on the ROMP Questionnaire to help increase your awareness of any difficulties swallowing.

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Drooling

Poor control of saliva is known as sialorrhea. Problems encountered with drooling may be because swallowing is less frequent or there is a delay in the ability to trigger the swallowing reflex. There are both medical and behavioural management options for drooling. Close communication with a primary care physician or neurologist and RSLP is recommended. Drooling can be a sign of a swallowing disorder in PwP.

What is a Swallowing Evaluation?

A swallowing evaluation takes place with a qualified RSLP. Information regarding your current concerns and medical history will be gathered and discussed. The RSLP may ask you to eat and drink to make initial observations. The gold standard instrumental evaluation is a Videofluoroscopic Swallow Study* (VFSS). This exam includes a "video x-ray", or video-fluoroscopy, performed by a qualified RSLP and radiologist to detect the specific location and characteristics of problems in the swallowing mechanism.

During the VFSS, you will be asked to eat and drink various consistencies (pudding, water, milk, cookies, barium pill, or specific food items that give you difficulty when eating). The x-ray video will be taken during the chewing and swallowing process. The SLP and radiologist will assess the video and comment on the structure and function of the swallowing mechanism as well as any aspiration or risk for aspiration. All phases of swallowing, oral, pharyngeal and esophageal, can be assessed in the VFSS.

Fiberoptic Endoscopic Evaluation of Swallowing (FEES*) is another type of instrumental test that can be performed by a qualified RSLP. It is a procedure that allows for the direct viewing of the pharynx and larynx with the swallowing of liquids and solids. A very thin flexible fiberoptic tube will be passed through the nasal passage. It is connected to a camera and light source and allows for video and sound recording. The RSLP will evaluate the pharyngeal phase of swallowing and document evidence of aspiration or risk for aspiration. The FEES is an appropriate follow-up procedure to the VFSS.

The CSHHPBC requires Advanced Competency Certification in the following areas related to communication and swallowing: flexible endoscopic evaluation of voice, flexible endoscopic evaluation of swallowing and Videofluoroscopic Swallow Study (VFSS). Only a RSLP with the appropriate advanced competency may perform these evaluations.

Those with PD should have a baseline swallow study, also known as a Videofluoroscopic Swallow Study (VFSS) study, which is a video X-ray of swallowing performed by a qualified RSLP and radiologist.

Speech Therapy for Dysphagia

Following a complete swallowing evaluation, an intervention program is established for the PwP and family support members. Recommendations may include both compensatory* strategies and rehabilitative* strategies (Ashford et al., 2009; Tjaden, 2008).

Because severity and extent of swallowing difficulty vary significantly among PwP, compensatory or rehabilitative strategies should not be tried by individuals without the recommendation and training by a SLP following full instrumental evaluation.

Compensatory Strategies

- Airway protection maneuvers (effortful swallow, double swallow, supraglottic maneuver)
- Altering foods/fluids
- Dietary modifications (safest, least invasive diet consistencies)
- Feeding/eating modifications (adaptive utensils, bolus size, eating rate, order of liquid and solid boluses*, eating environment)
- Increasing bolus sensory input
- Oral health
- Saliva/drooling management
- Supervised/assisted feeding
- Verbal prompting to swallow/re-swallow

Rehabilitative Strategies towards strengthening and improvement

- Active Range of Motion (ROM) for jaw, lips, tongue
- Effortful swallow for PwP with reduced posterior movement of the tongue base
- Airway protection techniques:
  - Double swallow followed by a cough
  - Supraglottic swallow for PwP that aspirate during the swallow
- Shaker or head lift exercise to maximize upper esophageal opening
- Effortful pitch glide
- LSVT®
- Respiratory muscle strength training
  - Respiratory muscle training may be an effective addition to a rehabilitative program for improving respiratory muscle strength, swallowing function, cough, decreasing drooling, and vocal strength in people with Parkinson’s disease. Devices can be used under the direction of a RSLP.

Technology

iSwallow™($3.99USD) is a personal rehabilitation assistant (PRA) that was developed to assist patients who are undergoing rehabilitation for swallowing disorders (dysphagia). *The application was designed to be used only under the supervision of a RSLP.*

Swallow Prompt 2.99USD
“Swallow Prompt helps people who have difficulty in managing excess buildup of saliva. It helps those with neurological conditions such as Parkinson’s Disease, Stroke, MND, ALS, Multiple Sclerosis and Cerebral Palsy. It will vibrate or beep at a set interval to prompt the user to swallow and prevent excess saliva buildup.”

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Additional Information

Nutritional Risk Factors

When a person is sick or suffering from a debilitating disease process it changes his/her ability to accomplish tasks, which appear easy to a healthy person. PwP are often sedentary, their activity levels drop and the energy for eating can diminish. The drop in energy can lead to a lack of desire to prepare foods, thus reducing the amount of food eaten and the nutritional value. This, along with difficulty chewing foods and swallowing them, can lead to a substantial reduction in weight. Coupled with possible dietary restrictions due to medication use and/or other drug side effects such as nausea, vomiting and constipation, this can place the PwP at high-risk for malnutrition.

Nutritional Suggestions

- Eat a balanced diet, including all food groups.
- Consume sufficient calories to maintain weight.
- Consume adequate fiber and fluids to avoid constipation.
- Take vitamin D and calcium to prevent osteoporosis.
- Reduce protein to minimum daily allowance and eat during the evening meal.

A registered Dietician can help you identify individual risk factors. Find a registered Dietician on the Dietitians of Canada Website [http://www.dietitians.ca/].

Hearing

Hearing problems are not directly caused by PD but certainly are associated with aging. Hearing loss can be experienced by the PwP and/or affect the spouse or caregiver. Statistics Canada reported that 47% of adults aged 60-79 years were more likely to experience hearing loss compared to younger adults (Statistics Canada, *Hearing Loss of Canadians*, 2012-2013). Projections indicate that this number and percentage will grow as baby boomers age and increasing noise pollution continues to take its toll. Hearing loss affects everyone that needs to interact with the hearing impaired individual. Poor hearing seriously interferes with communications and when compounded with the difficulties that a PwP already has with their speaking, it can significantly diminish the quality of communication interaction.

The most common type of hearing loss that occurs with age is called a sensorineural hearing loss. A sensorineural hearing loss is caused by damage to the inner ear and/or the auditory nerve. Noise, certain medications, as well as age can contribute to this permanent hearing loss. Most sensorineural hearing losses can be treated effectively with hearing aids. If you suspect a hearing loss or are the spouse or caregiver of a PwP, seek a professional consultation with a Registered Audiologist (RAud)*. An RAud is a professional who specializes in hearing evaluation and treatment. Registered Hearing Instrument Practitioners (RHIP) are qualified to fit hearing aids.

The techniques below will be helpful when communicating with someone who has difficulty hearing:

- Always let the listener see the face of the speaker. Keep your communication at about arm's length.
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- Be sure you are in the same room with the person with whom you are communicating
- Get their attention before you start to speak by saying their name.
- Turn off the radio or the TV or go to a quiet place for conversation.
- Never talk directly into a hearing impaired person's ear.
- Keep your rate of speech slower.
- Repeat the message if needed. If the person with hearing impairment does not appear to understand what is being said, rephrase the statement rather than simply repeating the misunderstood words.
- Above all, treat the person with hearing impairment with respect.

Body Language

Not all communication takes place with speech and words. People also communicate with each other by their body language and gestures. Facial masking, or lack of facial expression that is common in those with PD, has been attributed to muscular rigidity and reduced range of movement in the muscles of the face. Some friends and family members report that the listener who displays no facial expression does not seem interested in their conversation. Facial expressions, as well as other nonverbal gestures, contribute to and enhance the communication process. We can use facial expressions, head movements, hand and arm gestures, and body posture and body position to clarify or add to what we are saying.

Using body language in communication can be a special challenge to PwP because of facial masking, slowness of body movements and rigidity of muscles. Practice body language and gestures and then make a point of using them when you are talking.

Practice and remember the following:

- Eye contact is an important type of non-spoken communication. Always make eye contact when you are talking. Making eye contact shows that you are interested in communicating and in the listener.
- Practice exaggerating facial expressions. What does the face feel and look like when expressing emotions such as happiness, sadness, worry or concern? Practice these facial expressions: raise the eyebrows, wrinkle the forehead, open the eyes widely, squint the eyes, smile broadly, purse the lips. Use these movements of facial muscles when talking.
- Keep the lips closed when listening. Having lips closed indicates concentration and attention.
- Use body posture to show feelings when talking. Leaning slightly forward in the chair shows interest; leaning back in the chair may show a state of relaxation and comfort. Leaning back and breaking eye contact can show a lack of interest in communicating or that the communication should stop.
- Use gestures to add to the spoken message. Shrug the shoulders, clasp the hands, turn the head, raise the arms.
- Simply pointing to what is being talked about can be an effective way to add to the spoken message.

Medication Effects on Communication and Swallow

While medications are the primary tool for management of PD, the effects of these pharmacological agents on speech, voice and swallowing deficits have been difficult to measure. Additionally, there are some side effects of PD medications that may negatively impact voice, speech and swallowing functions. It is of extreme importance that a PwP recognize the cycle of their medication in terms of "on" and "off" time effects that accompany the cycles of medication regimen.

There are no medications specifically for communication or swallowing difficulties but you may see improvement when your medication is optimized.

Helpful Strategies

- Be aware of the 'on' cycle of PD medications as the voice, speech and swallowing will be at its peak performance.
- Avoid too much vocal communication when tired or fatigued, or during the 'off' cycle of the PD medications.
- Schedule important phone calls and other conversational interaction during the 'on' cycle of the medication regimen.
- Take time to rest between multiple phone calls and important communication interactions.

Although PD medications do not directly improve communication or swallowing difficulties, it is generally understood that when your medications is optimized, voice, speech and swallowing will be better.

Deep Brain Stimulation

Deep brain stimulation (DBS) is a surgical treatment option for PD that has been shown to ease motor symptoms and decrease medication. DBS has involved unilateral or bilateral surgical implantation of electrodes that generate electrical impulses in brain regions, most commonly the subthalamic nucleus (STN) or globus pallidus internus (GBi). Neither STN or GBi DBS have resulted in improved swallow safety, with some patients even worsening after stimulation was activated. Evidence has shown a DBS benefit bias towards swallow efficiency, but not safety. Emerging stimulation-based treatments for PD-associated dysphagia include DBS for non-STN regions, high frequency STN-DBS, and transcranial magnetic stimulation. (Krasko et al 2023) A comprehensive evaluation with a RSLP to establish baseline function of communication and swallowing has been recommended prior to DBS.

Appendix A

Radbound Oral Motor Inventory for Parkinson Disease

PART A

Speech

My voice nowadays:

a) My voice sounds normal.
b) My voice sounds a bit softer or hoarser than it used to be.
c) My voice is clearly softer or hoarser.
d) My voice is very soft or hoarse.
e) My voice can hardly be heard.

My ability to speak to familiar people:

a) Familiar people find me intelligible as normal; I do not have to repeat.
b) For familiar people, I am sometimes less intelligible when I am tired or do not pay attention.
c) For familiar people, I am frequently less intelligible; I have to repeat multiple times.
d) For familiar people, I am very often unintelligible, especially when I am tired.
e) For familiar people, I am usually unintelligible, also when I repeat.

My ability to speak to strange people:

a) Strange people find me intelligible as normal; I do not have to repeat.
b) For strange people, I am sometimes less intelligible when I am tired or do not pay attention.
c) For strange people, I am frequently less intelligible; I have to repeat multiple times.
d) For strange people, I am very often unintelligible, especially when I am tired.
e) For strange people, I am usually unintelligible, also when I repeat.

The use of my telephone:

a) Using the telephone is no problem for me at all.
b) I use my telephone as I used to do, but I need to pay more attention than before.
c) I have to repeat regularly when I am on the telephone.
d) I am reluctant to use the telephone because people do not understand me.
e) Using the telephone is impossible for me because my speech is inadequate.

When I start to talk:

a) I can say what I want to say as easy as I used to.
b) I sometimes have to think a bit longer than I used to.
c) I need more time or easily forget what I wanted to say.
d) I need help to formulate my thoughts.
e) I usually do not know what to say and prefer to stay silent.

Having a conversation in a group:

a) I can take part in conversations as always.
b) I can take part in a conversation, but I need to pay more attention.
c) I can take part in a conversation only when others take into account that I need more time.

Note: words with an asterisk (*) are defined in the Glossary.

d) I can take part in a conversation only when familiar people assist me.
e) I feel left out because I cannot take part.

How bothered are you as a result of your difficulty speaking?

a) I have no difficulty speaking.
b) My difficulty speaking bothers me a little.
c) I am bothered by my difficulty speaking, but it is not my priority concern.
d) My difficulty speaking bothers me a lot because it is very limiting.
e) Difficulty speaking is the worst aspect of my disease.

PART B

Swallowing

How many times do you choke when eating or drinking?

a) I do not choke at all or not more than I used to.
b) I choke about once a week.
c) I choke almost daily.
d) I choke about 3 times a day or during every meal.
e) I choke more than 3 times a day or multiple times during meals.

Are you limited during drinking?

a) I can drink liquids as easily as I used to.
b) I can easily drink liquids, but I choke a little easier than I used to.
c) I can drink safely only when I concentrate on it.
d) To drink safely, I need to use a special cup or technique.
e) I can drink safely only when I take thickened liquids.

Are you limited during eating?

a) I can eat as easily as I used to.
b) I can eat everything, but it takes me longer than before.
c) I have to avoid tough or hard solid foods (meat, peanuts, etc.).
d) I can eat only soft or easy chewable food.
e) I have to use supplemental or non-oral feeding.

Do you have difficulty swallowing pills?

a) I take my pills just like I used to.
b) I have a little more difficulty swallowing my pills than I used to.
c) I can take my pills only with applesauce or using a specific technique.
d) Swallowing my pills is a struggle nowadays.
e) I cannot swallow pills anymore and need another way of taking medication.

Does your swallowing difficulty limit your dining with others?

a) Eating with others is no problem for me at all.

b) I dine and drink with others, but I have to take my swallowing difficulty into account.
c) I prefer eating in the presence of familiar people in familiar places.
d) I eat only at home and in the presence of familiar people.
e) I can eat only at home and with the assistance of a skillful caregiver.

Are you concerned about your difficulty swallowing?

a) I do not experience difficulty.
b) I have some difficulty swallowing, but I am not concerned about it.
c) I am a little concerned about my difficulty swallowing.
d) I am becoming more concerned about my difficulty swallowing.
e) I am very much concerned about my difficulty swallowing.

How bothered are you as a result of your difficulty swallowing?

a) I have no difficulty swallowing.
b) My difficulty swallowing bothers me a little.
c) I am bothered by my difficulty swallowing, but it is not my priority concern.
d) My difficulty swallowing bothers me a lot because it is very limiting.
e) My difficulty swallowing is the worst aspect of my disease.

PART C

Saliva

Do you experience loss of saliva from your mouth **during the day?**

a) I do not lose saliva during the day and do not feel accumulation of saliva in my mouth.
b) I do not lose saliva, but I feel accumulation of saliva in my mouth.
c) I lose some saliva in the corners of my mouth or on my chin.
d) I lose saliva on my clothes.
e) I lose saliva on my clothes, but also on books or on the floor.

How often do you experience increased amounts or loss of saliva?

a) Less than once a day.
b) Occasionally: on average, once or twice a day.
c) Frequently: 2 to 5 times a day.
d) Very often: 6 to 10 times a day.
e) Almost constantly.

Do you experience loss of saliva during the night?

a) I do not experience loss of saliva during the night at all.
b) My pillow sometimes gets wet during the night.
c) My pillow regularly gets wet during the night.
d) My pillow always gets wet during the night.
e) Every night my pillow and other bedclothes get wet.

Does your (loss of) saliva impair your eating and drinking?

a) No, my (loss of) saliva does not impair my eating or drinking.
b) Yes, my (loss of) saliva occasionally impairs my eating or drinking.
c) Yes, my (loss of) saliva frequently impairs my eating or drinking.
d) Yes, my (loss of) saliva very often impairs my eating or drinking.
e) Yes, my (loss of) saliva always impairs my eating or drinking.

Does your (loss of) saliva impair your speech?

a) No, my (loss of) saliva does not impair my speech.
b) Yes, my (loss of) saliva occasionally impairs my speech.
c) Yes, my (loss of) saliva frequently impairs my speech.
d) Yes, my (loss of) saliva very often impairs my speech.
e) Yes, my (loss of) saliva always impairs my speech.

What do you have to do to remove saliva?

a) I do not have to remove saliva.
b) I always carry a handkerchief to remove possible saliva.
c) I use 1 or 2 handkerchiefs to remove some saliva daily
d) I need more than 2 handkerchiefs to remove saliva daily.
e) I need to remove saliva so frequently that I always keep tissues near me or use a towel to protect my clothes.

Does the loss of saliva limit you in contacts with others?

a) My loss of saliva does not limit me in contacts with others.
b) I have to pay attention, but that does not bother me.
c) I have to pay more attention because I know that others could see me losing saliva.
d) I try to avoid contact when I know that I lose saliva.
e) I notice that others avoid having contact with me because I lose saliva.

Does your loss of saliva limit you in doing activities inside or outside your home (work, hobbies)?

a) My (loss of) saliva does not limit me in activities.
b) I have to pay attention when I am busy, but that does not bother me.
c) I have to pay more attention, which is rather effortful.
d) My loss of saliva limits me in being active.

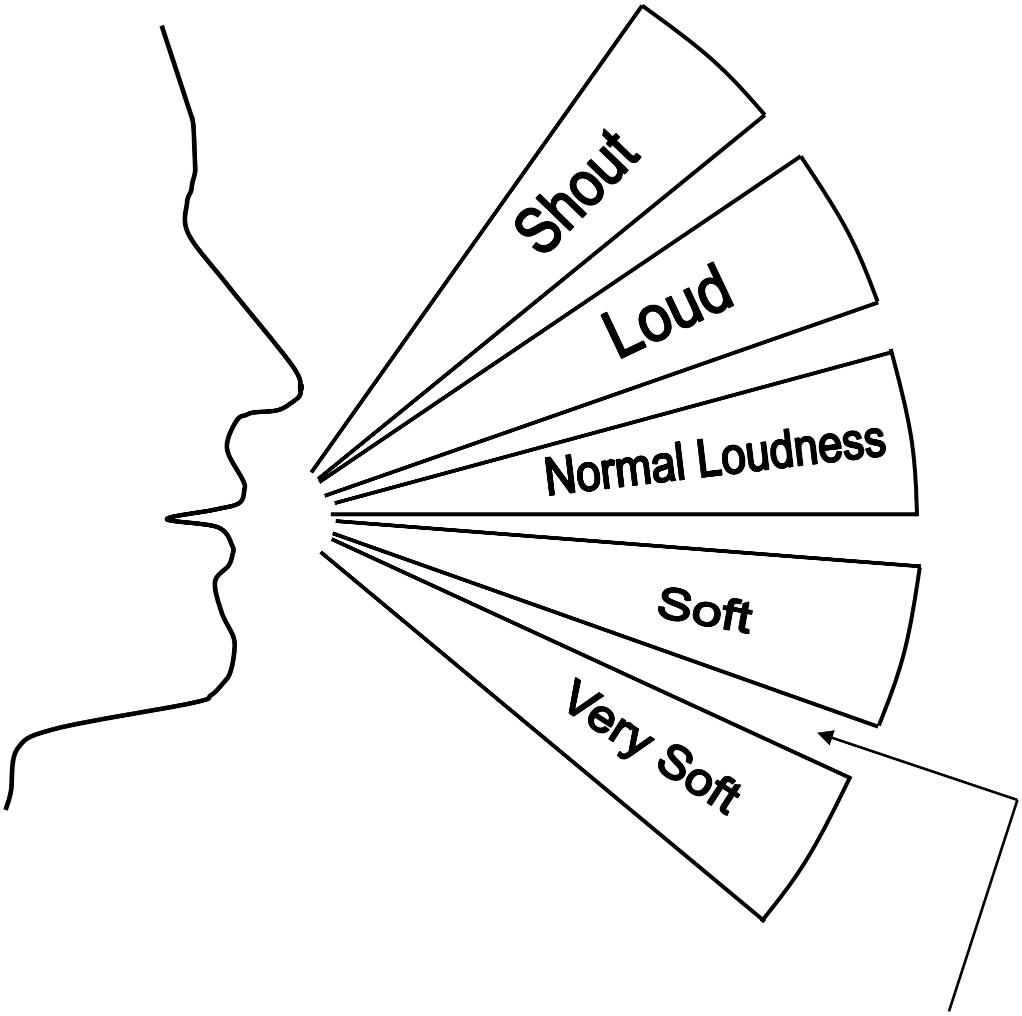
How bothered are you as a result of your (loss of) saliva?

a) I hardly notice loss of saliva.
b) Feeling more saliva or losing it bothers me a little.
c) I am bothered by my loss of saliva, but it is not my priority concern.
d) My loss of saliva bothers me a lot because it is very limiting.
e) Due to my loss of saliva, important activities are no longer possible for me.
f) Losing saliva is the worst aspect of my disease.

(Kalf et al., 2011)

Appendix B

RELATIVE VOCAL LOUDNESS LEVEL OF AN INDIVIDUAL WITH PARKINSON DISEASE



(Adapted from Carolyn Mead Bonitati, 1987)

Vocal loudness level of an individual with Parkinson disease

As a result of Parkinson disease you will need to use more **vocal effort** to have a voice within normal loudness limits.

Note: words with an asterisk (*) are defined in the Glossary.

Glossary

1. **Aspiration**: food or liquid goes through the vocal folds and into the trachea to the lungs.
2. **Audiologist**: allied health professional trained to evaluate and treat the hearing and balance systems.
3. **Basal ganglia**: a group of structures linked to the thalamus in the base of the brain and involved in coordination of movement.
4. **Communication**: the act or process of using words, sounds, signs or behaviors to express or exchange information, or to express your ideas, thoughts, feelings, etc., to someone else. (Merriam Webster).
5. **Compensatory**: reduce or offset the unpleasant effects of something, to provide or be an equivalent for.
6. **Drooling**: a problem keeping saliva in the mouth which, in PwP, can be due to decreased awareness of accumulation of saliva (decreased sensory proprioception. Drooling may also be an indicator of problems with the oral phase of swallowing. Medical terminology for drooling is sialorrhea.
7. **Dysarthria**: speech disorders resulting from disturbances in muscular control-weakness, slowness or incoordination of the speech mechanism due to damage to the central or peripheral nervous system or both. The term encompasses coexisting neurogenic disorders of several or all the basic processes of speech: respiration, phonation, resonance, articulation and prosody (Darley, 1969).
8. **Dysphagia**: medical term for symptoms of difficulty swallowing.
9. **Epiglottis:** A leaf-like piece of cartilage extending upwards from the larynx, which can close like a lid over the trachea to prevent the airway from receiving any food or liquid being swallowed.
10. **Esophagram**: A series of X-ray images of the esophagus. The X-ray pictures are taken after the patient drinks a barium solution that coats and outlines the walls of the esophagus. Also called a barium swallow.
11. **Fiberoptic endoscopic evaluation of swallowing** (**FEES)**: A procedure that allows assessment of areas surrounding the voice box and opening of the esophagus, through the use of a small flexible telescope. The telescope is passed through the nose after anesthetizing this area to minimize pain or discomfort. Once the telescope is in position, various foods are provided to eat. The speech pathologist observes and evaluates the swallowing process and makes safe swallowing recommendations.
12. **Hypokinetic dysarthria**: characterized by reduced vocal loudness, hoarseness, abnormal speaking rates, impaired intelligibility. Site of lesion – subcortical structures involving basal ganglia. Specific to Parkinson's disease and Parkinsonism.
13. **Larynx**: A tube-shaped organ in the neck that contains the vocal folds. The larynx is about 5 cm (2 in) long. It is part of the respiratory system and is located between the pharynx and the trachea. Humans use the larynx to breathe, talk and swallow.
14. **Liquid bolus**: a volume of fluid.
15. **Lee Silverman Voice Treatment (LSVT®)**: The gold standard voice therapy for communication disorders associated with Parkinson disease.
16. **Videofluroscopic Swallow Study/video-fluoroscopic evaluation of swallowing**: Gold standard evaluation of swallowing. It is a radiologic examination of swallowing function that uses a special movie-type X-ray called fluoroscopy. The patient is observed swallowing various types of

substances that can be seen by fluoroscopy (usually liquid barium and/or foods coated with barium) in order to evaluate his or her ability to swallow safely and effectively. Patients are often observed swallowing various consistencies and textures, ranging from thin barium to barium-coated cookies to barium pills. This exam is performed with a speech-language pathologist present.

17. **Palate:** the roof of the mouth, separating the cavities of the nose and the mouth in vertebrates.
18. **Penetration**: food or liquid goes into the airway and stays on or above the vocal folds.
19. **Penetration-Aspiration Scale**: An 8 point interval scale used to describe penetration and aspiration events resulting from impaired swallowing as a result of a change in the structures or movements necessary for normal swallowing.
20. **Rehabilitative**: to restore to a condition of good health, ability to work or the like.
21. **Sensory proprioception**: controlled by the central nervous system, a means to keep track of and control the different parts of the body – how your brain knows what your body is doing.
22. **Silent aspiration**: food or liquid goes into the airway and through the vocal folds to the lungs *without* your awareness or a sensory response (coughing).
23. **Solid bolus**: a mass of food that has been chewed and is ready to swallow.
24. **Speech-language pathologist (SLP)**: An allied health professional trained to evaluate and treat communication and swallowing disorders across the lifespan.
25. **Videostroboscopy**: (or stroboscopy) is a specialised examination of the vocal folds using an endoscope placed through the nose or mouth to examine the larynx (voice box) with a strobe light. This special light source allows slow motion assessment of the vibration of the vocal folds.
26. **Vocal folds:** layer structure of epithelium, gelatinous material and muscle used to produce voice. Also muscles of respiration and 3rd level of airway protection when swallowing.
27. **Xerostomia:** *the condition of not having enough saliva to keep the mouth wet and well hydrated.*

References

Ashford, J., McCabe, D., Wheeler-Hegland, K., Frymark, T., Mullen, R., Musson, N., . . . & Smith Hammond, C. (2009). Evidence-based systematic review: Oropharyngeal dysphagia behavioral treatments. Part III-Impact of dysphagia treatments on populations with neurological disorders. *Journal of Rehabilitation Research and Development, 46*(2), 195-204.

American Parkinson Disease Association. (2010). *Speaking Effectively: A Strategic Guide for Speaking and Swallowing*. American Parkinson Disease Association, Inc.

Behrman, A., Cody, J., Elandary, S., Flom, P., & Chitnis, S. (2020). The Effect of SPEAK OUT! and The LOUD Crowd on Dysarthria Due to Parkinson's Disease. American Journal of Speech-Language Pathology, https://doi.org/10.1044/2020_AJSLP-19-00024.

Goldman, J. G., & Litvan, I. (2011). Mild cognitive impairment in Parkinson's disease. *Minerva medica, 102*(6), 441.

Grimes, D., Gordon, J., Snelgrove, B., Lim-Carter, I., Fon, E., Martin, W., & Canadian, N. S. F. (2012). Canadian Guidelines on Parkinson's Disease. T*he Canadian journal of neurological sciences, 39*(4 Suppl 4), S1.

Halpern, A., Ramig, L., Matos, C., Petska-Cable, J., Spielman, J., Pogoda, J., . . . & McFarland, D. (2012). Innovative Technology for the Assisted Delivery of Intensive Voice Treatment (LSVT®LOUD) for Parkinson Disease. *American Journal of Speech-Language Pathology, 21*(4), 354-367.

Kalf, J.G., Borm, G.F., de Swart, B.J.M., Bloem, B.R., Zwarts, M.J., & Munneke, M. (2011). Reproducibility and validity of patients-rated assessment of speech, swallowing and saliva control in Parkinson's disease. *Archives of Physical Medicine and Rehabilitation, 92*(7), 1152-1158.

Krasko, M.N., Rudisch, D.M., Burdick, R.J. *et al.* Dysphagia in Parkinson Disease: Part II—Current Treatment Options and Insights from Animal Research. *Curr Phys Med Rehabil Rep* (2023). https://doi.org/10.1007/s40141-023-00393-8

Matsuo, K., & Palmer, J. B. (2008). Anatomy and physiology of feeding and swallowing: normal and abnormal. *Physical medicine and rehabilitation clinics of North America, 19*(4), 691-707.

Ramig L.O., Fox C., & Sapir S. (2004). Parkinson's disease: speech and voice disorders and their treatment with the Lee Silverman Voice Treatment. In *Seminars in Speech and Language, 25*(2), 169-180.

Ramig, L.O., Sapir S., Countryman, S., Pawlas A.A., O'Brien, C., Hoehn, M., & Thompson, L.L. (2001). Intensive voice treatment® (LSVT®) for patients with Parkinson's disease: a 2 year follow up. *Journal of Neurology, Neurosurgery and Psychiatry, 71*(4), 493-498.

Rosen, C. A., & Simpson, B. (2008). *Operative techniques in laryngology*. Springer Science & Business Media.

Tjaden, K. (2008). Speech and swallowing in Parkinson's disease. T*opics in geriatric rehabilitation, 24*(2), 115.

Watts, C.R. (2016). A Retrospective Study of Long-term Treatment Outcomes for Reduced Vocal Intensity in Hypokinetic Dysarthria. *BMC Ear, Nose and Throat Disorders, 16(2). doi:10.1186/s12901-016-0022-8*

Notes

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