Parkinson’s overview

Introduction

The following information is a guide to evaluating and treating the difficulties with communication, eating, drinking and swallowing that can arise from Parkinson’s and atypical Parkinson’s. Parkinson’s UK and the Royal College of Speech and Language Therapists developed it.

Parkinson’s UK
Excellence Network

Parkinson’s UK has a vast library of information about Parkinson’s and provides support for people with Parkinson’s, as well as their friends and family and healthcare professionals. Another useful source of information is **the International Parkinson and Movement Disorder Society**.

Role of the speech and language therapist

The speech and language therapist's role when working with people with Parkinson's and related conditions is to promote safety and enjoyment of communication and eating, drinking and swallowing activities. This will include help with managing sialorrhea (excessive production of saliva).

These guidelines are intended to give clinicians and people with Parkinson's the information they need to provide or receive the best treatment available

Motivation for change

Factors such as nutrition, walking, physical exercise, mood, fatigue, sleep and timing of medication can impact communication and eating, drinking and swallowing. People with Parkinson’s may find out for themselves what works well, or they may ask professionals. Balancing what works for the individual with the advice being given is a challenging but rewarding way to manage the symptoms.

Exercise

However successful and effective a treatment is, it needs to be supported by regular and appropriate exercise. Ideally, people with Parkinson’s should exercise for at least two and a half hours per week. Any type of exercise can be helpful.

Below are some activities that people with Parkinson’s can do to help maintain the gains from therapy:

- Walking can help clear secretions and keep the lungs working. Studies show that people who continue walking have fewer episodes of aspiration pneumonia than those who don’t walk.
- People with Parkinson’s who have already seen an SLT should continue with their daily voice exercises.
- Chewing gum can help with clearing saliva from the mouth and swallowing it more often.
- Singing groups or choirs can help improve communication. They can be in-person or online.
- People with Parkinson’s should continue their social, work and family roles as much as they can. Social events and other communication can be tiring but they are the best way to maintain a loud, strong voice.

When to visit a speech and language therapist

Speech and language therapists (SLTs) provide advice and therapy to people with Parkinson's through all stages of their condition. Therapy aims to stabilise and treat speech, swallowing and saliva problems and reduce the impact of them on everyday life.

Most services offer self-referrals, so a person with Parkinson's can seek advice and therapy directly without a referral from a healthcare professional.

We recommend people with Parkinson's see an SLT in the following situations:

- as soon as possible after diagnosis, for support with self-management
- when they find it difficult to maintain social, work and family roles due to communication issues, for example, when family or friends ask them to repeat themselves or they don't understand them
- when they experience difficulties with swallowing, such as coughing more often during and after meals, or chest infections
- when they feel that saliva or phlegm is stuck in their throat and they cannot clear it
- if they feel they need to 'boost' their voice to recover the volume they may have had during therapy.

Getting the most out of a visit to an SLT

Many people find it helpful before a visit to any health care professional to write down the problems they need advice for.

We recommend that when visiting an SLT, people with Parkinson's should:

- explain how they're feeling
- ask the SLT to explain anything they don't understand, such as a medical term or a piece of advice
- consider bringing a friend, partner or caregiver for support
- explain how problems in communicating or swallowing affect their daily life and what they would like to change
- describe the ways they have already tried to reduce the problem and what has or hasn't helped.

The therapy with most evidence for voice and speech is called Lee Silverman Voice Treatment (LSVT LOUD). You can find more information on **the LSVT Global website**. The therapy with most evidence for the management of swallowing difficulties is the use of the Expiratory Muscle Strength Training Device (EMST150). Both interventions are not suitable for everyone. Talk to the SLT to decide which interventions are best suited to the individual and how to apply them.

If the SLT cannot help with a specific issue they should suggest treatment options provided by other health professionals.

People with Parkinson’s and SLTs are partners in care and it is beneficial to work together. We recommend that together, you:

- decide on the goals. How long will they take to achieve and what will the approach be?
- agree upon a realistic plan. Think about how much time and effort the person with Parkinson’s can put in and if there are other things that could impact this.
- plan follow-up visits. This allows for feedback and any adjustments to exercises.
- discuss any challenges with keeping to the exercise plan and agree upon changes to make it easier.
- agree what information the SLT will share with the referring clinician and other health professionals.
- bear in mind that most of the speech treatments can be provided via telehealth, to minimise travelling costs and fatigue.

Atypical Parkinson's

Atypical parkinsonism, also called Parkinson-plus syndrome, is when the person has symptoms of Parkinson's plus other features. These can include early balance problems/falling, poor reaction to the drug levodopa, early cognitive problems and impaired control of blood pressure/bowel/bladder.

The most common types of atypical Parkinson's are progressive supranuclear palsy (PSP), multi-system atrophy (MSA) and corticobasal syndrome (CBS).

Speech and swallowing difficulties are common in atypical Parkinson's. Seeing an SLT with experience with these complex diagnoses is essential. If someone has been diagnosed with Parkinson's but as the condition progresses the diagnosis doesn't seem to fit, we recommend talking to your neurologist and SLT.

Progressive supranuclear palsy (PSP)

PSP is the most common type of atypical parkinsonism. It is due to a build-up of a protein in the brain called tau that clumps up in all cell types. The cause of this clumping is unknown.

Some symptoms of PSP that could impact communication include the following:

- Many people with PSP experience difficulty with eye movements. This makes reading difficult and may cause double vision. They can also have involuntary blinking or eye closing and difficulty opening the eyes ('blepharospasm'). This might interfere with communication and reading.
- People with PSP may experience stiffness, especially in the neck.
- Facial expressions may change due to increased or decreased facial muscle activation. This is often characterised by staring ahead with raised eyebrows and a frown on the forehead.
- People with PSP can experience a hoarse, slurred, groaning voice or very fast rate with palilalia and echolalia (repetitions of whole words or some syllables).
- Some people with PSP may experience loss of motivation and inhibition and/or emotional variability (pseudobulbar palsy).

The condition varies from person to person.

For further information on PSP please see **the PSP Association website**.

PSP communication characteristics

Many people with PSP experience a difficulty with speech sounds called dysarthria, often within the first two years of diagnosis. Dysarthria affects speech and can make it sound like the person's voice is harsh or strained. They may sound quiet or slur their words. They may have difficulty finding the right words or may speak quickly. Some people may repeat sounds or words; this may sound similar to a stammer.

Treatments used for people with Parkinson's may not be suitable for people with PSP. It is important to discuss the person's goals with their SLT. Early referral to an SLT is crucial. **The Lee Silverman Voice Treatment** may be suitable for some people with PSP but not all. Using a delayed auditory feedback (DAF) device may slow down the rate at which someone talks and increase the loudness. 'Speech Vive' is a recent treatment which uses the same principle of feedback.

Each person with PSP can present differently, so any treatment needs to be tailored to the individual. People with PSP should have regular reviews to help prevent loss of their voice and to introduce other methods of communicating such as augmentative and alternative communication (AAC). Voice banking is a way to store the person's voice to be used later in AAC devices. Voice banking should be done as early as possible. There is an urgent need for more research on communication treatments for people with PSP.

PSP eating, drinking and swallowing characteristics

People with PSP often have good awareness of their difficulties with eating, drinking and swallowing. The SLT should work with the person and other professionals such as occupational therapists, physiotherapists and dietitians to help support these difficulties.

In the early stages, people with PSP often have more difficulty with drinks than with food. Food or drink may enter the airway when trying to swallow. This can cause long-lasting coughing episodes. The cough can sound severe even if only a small amount of food or drink enters the airway. Due to this severe coughing the SLT may think the person's swallowing difficulties are more severe than they are. Specialist swallowing assessments such as videofluoroscopy or FEES can help with understanding how swallowing is affected.

The SLT will carry out a swallowing assessment. They should then discuss the results with the person with PSP and their family and carers. Strategies that are useful for some people with PSP include a chin tuck, an effortful swallow or changing the consistency of drinks and food. It is important to consider benefits and pitfalls of changing how and what a person eats or drinks holistically and with a dietitian. See **RCSLT's guidance on thickened fluids** for more information.

There has been some early research on using sensorimotor training for airway protection (smTAP). This showed that patients with PSP are able to train their cough to protect their airway. Further research is needed into this area, but it is promising for the future. SLTs may consider whether it is appropriate for a person with PSP to trial this approach.

Multiple system atrophy (MSA)

Multiple system atrophy (MSA) is a rare disorder that affects multiple bodily functions such as balance, blood pressure, bladder and bowel control, sexual function and coordination of movement.

The symptoms of MSA that may influence communication are:

- slowness of movement, muscle stiffness and/or shaking/jerky movements
- problems with balance and coordination
- feelings of light-headedness or dizziness on standing
- problems controlling bladder function and constipation.

Patients with MSA often need to be seen by SLTs more often and more quickly because of the condition's complexity and the rate at which it progresses.

For more information, please see **the MSA Trust website**.

MSA speech characteristics

Speech problems can be common in people with MSA, particularly in the early stages. Some people find it is their first symptom. The voice may sound weaker in volume and tremulous. There may be a wheezing sound from the voice box as they breathe in, due to problems with the muscles in their throat.

'Clear Speech' or intensive voice therapy programmes such as **the LSVT** have been shown to help some people with MSA. Joint education programmes for people with MSA and their carers may improve communication.

Alternative and augmentative communication (AAC) may be useful for some people with MSA. People with MSA often experience fatigue. Any treatment needs to consider this and work with the person at a rate that is achievable for them. More research is needed into communication treatments for people with MSA.

MSA eating, drinking and swallowing characteristics

Research has shown that people with MSA mostly struggle with holding and moving food and drinks around their mouths.

Another difficulty can be oesophageal regurgitation, where the food comes back into the mouth after it has been swallowed. Patients need to report this to their physician and get advice on the best position to sleep.

People with difficulty swallowing pills should consult their GP or pharmacist before crushing/splitting tablets or considering other formats.

The SLT and dietitian will work closely together with the patient and the caregiver throughout the disease process to enhance the eating, drinking and swallowing experience.

Corticobasal syndrome (CBS)

Corticobasal degeneration (CBD), also known as corticobasal syndrome (CBS), is a rare, progressive neurodegenerative disease with a wide variety of symptoms and signs. It typically starts between the ages of 60 and 70 and usually affects one side of the body much more than the other.

Common symptoms of CBS that could impact communication include:

- slowing of movement and stiffness of the neck, arms and legs
- balance and walking problems, which may cause falls
- muscle twitches and jerks
- difficulties with forming the sounds for speaking
- behavioural changes such as loss of motivation or increased irritability, or personality changes
- difficulties manipulating food in the mouth.

CBS signs may be similar to other conditions, such as Parkinson’s. This makes it difficult to diagnose in the early stages. Scans such as MRIs are often useful and may rule out other conditions that are similar to CBS.

Please note that although there is some information on the speech and EDS difficulties of people with CBS, there is no specific research on successful treatments for speech and EDS difficulties. SLTs should be careful when trying treatments with people with CBS. Research into this area is needed.

More information about CBS is available from **the PSP Association**.

CBS speech characteristics

Communication difficulties are common in people with CBS and sometimes they are the first symptom. Dysarthria, a difficulty with speech sounds, is the most common. Speech may sound slurred or strained. Some people will have difficulty coordinating the movements needed for speech. This is called apraxia of speech.

People with CBS may have difficulty with yes–no reversals, ie they say or gesture ‘yes’ to questions when they mean ‘no’ and vice versa.

CBS eating, drinking and swallowing characteristics

People with CBS may find it difficult to move food or drinks around their mouths. Swallowing problems tend to be seen early in the disease. Prompting/cueing a person with CBS to swallow, eg by saying ‘swallow’, may make it harder for them; they may just repeat the word ‘swallow’. Instead, caregivers can encourage modelling of the swallowing action (mirroring) and should keep the swallowing environment as natural as possible.