

Parkinson's public information

DRAFT FOR CONSULTATION

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The information in this document is currently in development and has been shared as part of a consultation. If you are seeking guidance or information on this topic, please ensure you refer to final published content which can be found on rcslt.org.

We appreciate any comments provided to us during the consultation, all of which will be reviewed by the working group within the context and scope of the project. We ask that, where possible and relevant, you accompany any counter arguments to statements made in the document with supporting evidence e.g. a research reference.

Members of the working group should not be contacted directly, and all feedback should be made through the assigned route e.g. via survey or project manager. Feedback made through unassigned routes or after the closing date will not be accepted or responded to.

Thank you for your support with this project.

Public guidance

Introduction

The information below 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. It has been developed by Parkinson's UK and the Royal College of Speech and Language Therapists.

[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 Disorders 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.

Self-management

Factors such as timing of medication, nutrition, walking, physical exercise, mood, fatigue and sleep 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 can sometimes be difficult.

Exercise

However successful and effective a treatment is, it needs to be supported by regular and appropriate exercise. Below are some activities that people with Parkinson's can do to help maintain the gains from therapy.

- Exercise: Ideally, people with Parkinson's should exercise for at least 2½ hours per week. Any type of exercise can be helpful. Dancing has been shown to be particularly good.
- Walking: It can help with swallowing safely.
- Voice exercises: People with Parkinson's who have already seen an SLT should continue with the daily voice exercises they were given.

- Singing groups or choirs: These can be in person or online and can help improve communication.
- Social, work and family roles: People with Parkinson's should continue with social, work and family roles as much as they can. Social events and other communication can be tiring but it is the best way to maintain a loud and 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.

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, such as people not understanding them or asking them to repeat themselves
- 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.

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

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

- 88 • Decide on the goals. How long will they take to achieve and what will the approach
89 be?
- 90 • Agree upon a realistic plan. Think about how much time and effort the person with
91 Parkinson's can put in, and if there are other things that could impact this.
- 92 • Plan follow-up visits. This allows for feedback and any adjustments to exercises.
- 93 • Discuss any challenges with keeping to the exercise plan and agree upon changes to
94 make it easier.
- 95 • Agree what information the SLT will share with the referring clinician and other health
96 professionals.

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