



Supporting people affected by Parkinson's

People affected by Parkinson's can develop problems with communication and with eating, drinking and swallowing (dysphagia)ⁱ. As well as the more obvious motor changes, people with Parkinson's may also experience non-motor changes that can impact on communication and more general quality of life, including depression, anxiety, apathy, fatigue, pain, sleep disturbance and cognitive changes^{ii iii}. Speech and language therapists (SLTs) are a crucial part of the multidisciplinary team that helps people affected by Parkinson's, and their families and carers, to manage their condition and maintain their quality of life.



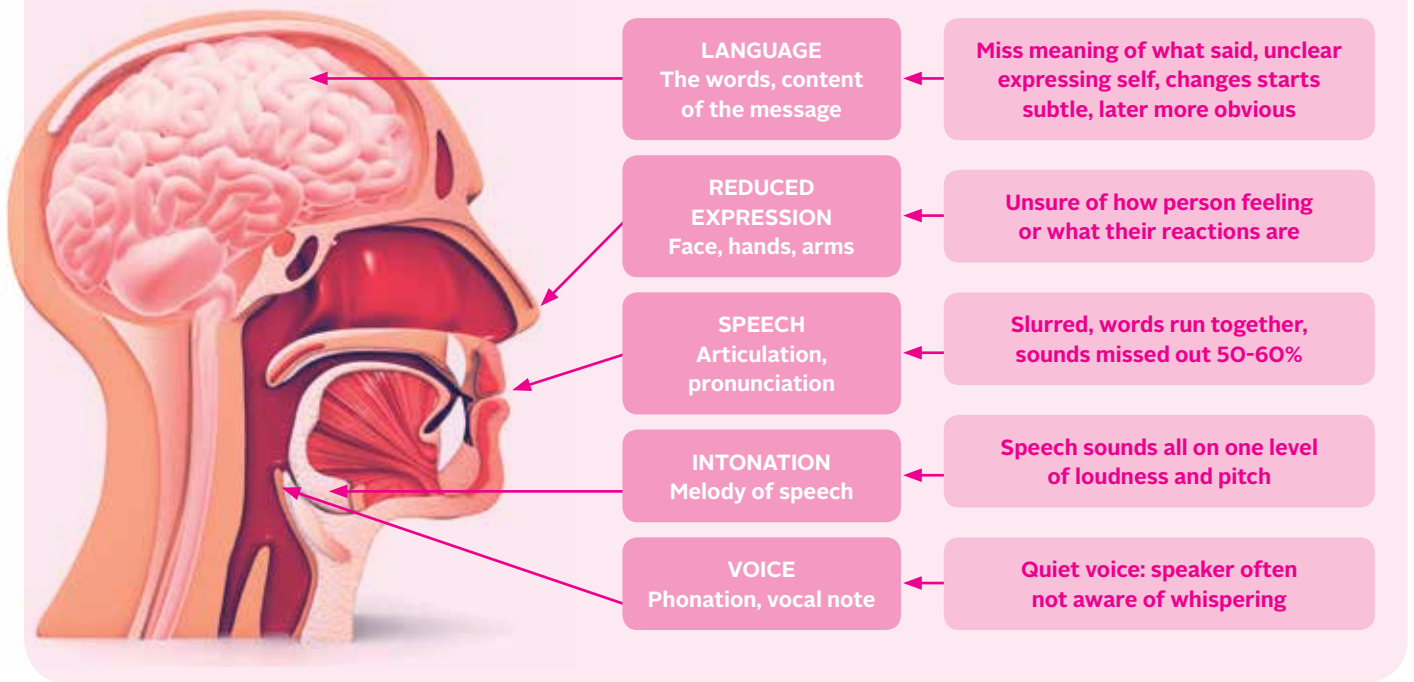
The size of the problem

- ▶ There are about **127,000** people in the UK with Parkinson's.
- ▶ About **90%** of people with Parkinson's report changes to their voiceⁱⁱⁱ.
- ▶ **Up to half** of people with Parkinson's are affected by unclear speech sufficient to cause strangers to have difficulty understanding all they say, even in the early phases of the condition^{iv}.
- ▶ Changes to swallowing affect eating and drinking for up to **80%** of people with Parkinson's and become a major issue as the condition progresses^{v vi vii}.
- ▶ Dysphagia is a significant factor that contributes to drooling in Parkinson's. Over the course of Parkinson's up to **75-80%** of people may be troubled by drooling^{viii ix x}.

A serious issue

Communication: Parkinson's affects all aspects of communication. This includes language (words and content), facial expression (and hand and arm gestures), speech (articulation and pronunciation), intonation (melody of speech), and voice (phonation and vocal note). These changes to the way people affected by Parkinson's usually communicate can affect them in their employment, social activities and day-to-day situations. This can lead to less confidence, and difficulty with getting into conversations, keeping their place in conversations, keeping up with and perceiving what others are saying, and conveying information. This can lead to

What will listeners notice?

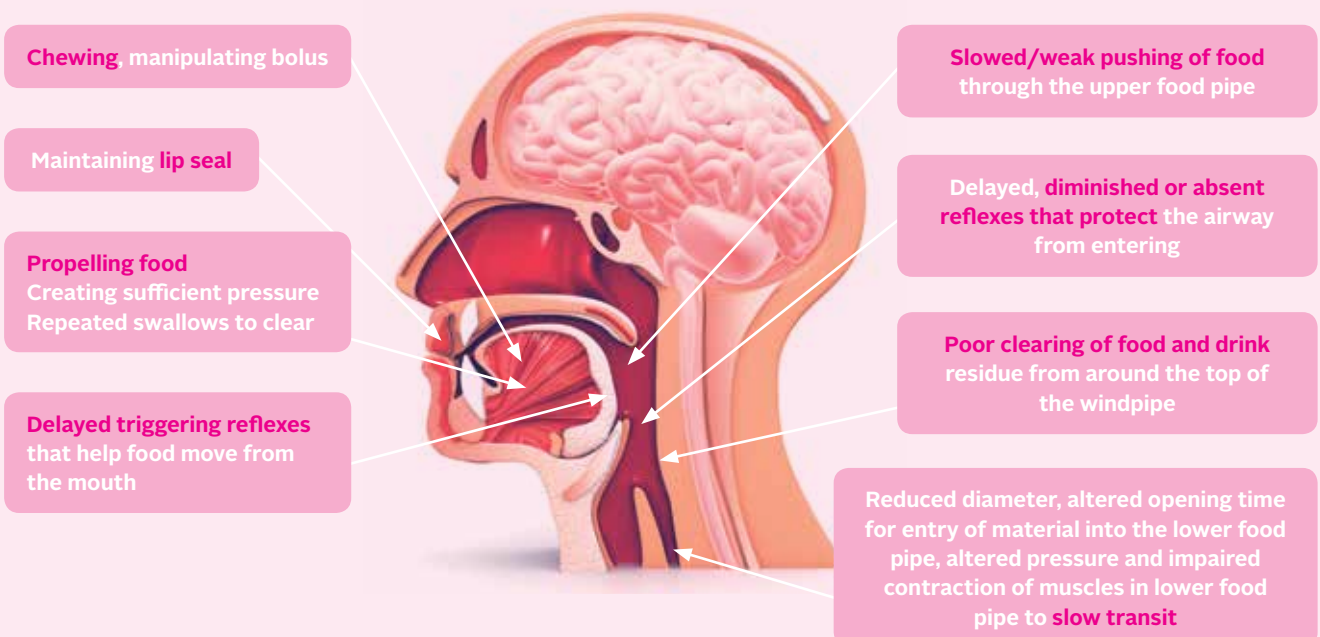


feelings of loss of independence and inadequacy¹. It can also have significant consequences, such as the development of negative perceptions of the individual, the misdiagnosis of depression,ⁱⁱⁱ and an impact on a person's mental health.

Swallowing: Parkinson's affects all aspects of swallowing. People affected by Parkinson's can have difficulties chewing food, propelling food down their throat and clearing their throat. In the early stages, patients or carers may not always recognise

the changes and symptoms of swallowing difficulties. In later stages, these difficulties pose significant risks to hydration and to nutritional and respiratory health. They can lead to fatigue and confusion, and also put the person at risk for a poorer quality of life.ⁱⁱ Eating and mealtimes can become less enjoyable, which can have a significant impact on socialisation and on families and carers, and can lead to depression. Unsafe eating and drinking can also lead to an increased risk of choking and aspiration pneumonia, requiring hospital admission and in some cases resulting in death.

How is swallowing affected in Parkinson's?





SLTs can also work directly with people affected by Parkinson's on their voice and speech. This can include providing personalised strategies and exercises to help with volume of speech, pace, speed of talking and facial expression. SLTs may also recommend attention-to-effort therapies, self-monitoring and dedicated exercises to ensure gains made in clinic can be transferred to other environments. In the later stages of Parkinson's, SLTs can help with tools and technology to support communication, such as Augmentative and Alternative Communication.

...with swallowing

SLTs have a unique role in the assessment, diagnosis and management of swallowing difficulties. SLTs help people affected by Parkinson's to maintain a safe swallow through exercises (for example, expiratory muscle strength training), techniques and positioning and promote safety through modifying the texture of food and fluids. This reduces the risks associated with malnutrition, dehydration and choking, and helps prevent secondary infection. SLTs can also train and advise families and the wider health and care workforce to help ensure that mealtimes are as safe and enjoyable as possible. They will also liaise with pharmacies or GPs regarding medication reviews to ensure that medication is in a form which is safe and easy to swallow.

Drooling: Parkinson's affects the control of saliva, which can lead to drooling. Drooling is associated with reduced swallowing abilityⁱⁱ and this is exacerbated by poor lip seal^{xi}. Drooling affects everyday life, impacting on hydration levels,^{xii} quality of life and social participationⁱⁱ.

Mental health: Parkinson's can affect mental health and wellbeing due to the difficulties of living with the condition; for example experiencing a fear of choking^{xiii} or the increased social challenges that come with drooling^{xiii} ^{xiv}. People in the later stages of Parkinson's may also be vulnerable to hallucinations, psychosis and depression.

How speech and language therapy can help....

The National Institute for Health and Care Excellence (NICE) Parkinson's guideline^{xv} highlights that referral to speech and language therapy is essential for problems with communication, swallowing and saliva, in order to maintain people's independence and avoid hospital admission.

...with communication

With their clinical expertise in speech, language and communication, SLTs have a unique role to play in the assessment, education and support of people affected by Parkinson's and their families and carers, helping them to anticipate and adjust to changes in communication.

SLTs can help create a supportive communication environment by advising on how to remove barriers to successful communication and boost support and understanding of how best to communicate. They can also provide advice on how to manage conversations, including on how to recognise and repair breakdowns in understanding.

Case study

Mr K was diagnosed with Parkinson's in 1995 at the age of 54 and was later referred to an SLT when he was concerned that people kept asking him to repeat himself. He threw out a telephone because he thought it was broken, as people kept saying they couldn't hear him, but eventually he realised his reduced vocal loudness was at fault. He was a driving instructor at the time and his clients were at risk of turning their heads to look at him when he was talking because his speech was so quiet. In June 2004 he attended an intensive voice treatment programme called LSVT. By the end of treatment he had built up vocal stamina and was achieving the necessary vocal loudness in reading, conversation and telephone calls to be clearly heard and understood by all.

Review appointments have since been carried out at 6-12 month intervals over the past 13 years and interventions, including videofluoroscopy, made to help address complications as they arose. Extra sessions were given when optimum voice levels dropped. Saliva management became a concern in 2009. Patient education was given for this and a programme of purposeful saliva swallows was introduced, initially using a swallow reminder buzzer and more recently revisited using the 'Swallow Now' smartphone application.

Mr K now maintains speech and voice function through singing and has been part of an expert patient group at his local hospital who have been instrumental in setting up a singing group/Parkinson's choir with support from SLTs. He liaises with venues within the community and encourages other people with Parkinson's to keep their voices healthy through singing.

...with drooling

SLTs help develop strategies to improve the safety and efficiency of swallowing and to minimise the risk of aspiration^{xvi}. SLTs help develop exercises to promote a good lip seal, a favourable posture and ways to encourage force and frequency of swallowing. Devices that give the person an auditory or vibratory prompt to swallow can help to increase swallow frequency. Attention-to-effort instructions, similar to control of voice loudness therapies, can help deliver a more forceful swallow. SLTs also work with carers to advise on how to help prevent drooling.

...with mental health

Given the links between mental health, communication needs, dysphagia and Parkinson's, SLTs have a crucial role to play in ensuring that people affected by Parkinson's who have mental health problems can access and engage with mental health referrals, assessments and interventions. SLTs can support and train mental health teams to recognise and respond to communication needs and dysphagia so barriers to access and engagement are removed. Better communication, safer swallowing and reduced drooling are associated with better mood and increased motivation.



REFERENCES AND RESOURCES

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- ^{xv} www.nice.org.uk/guidance/qs164/resources/parkinsons-disease-pdf-75545600441029
- ^{xvi} NICE: Parkinson's disease in adults, 2017

Resources

RCSLT and UK Parkinson's Excellence Network webinar

For more on how Parkinson's affects communication and swallowing, the role of speech and language therapy, and the work of the UK Parkinson's Excellence Network, see the RCSLT and UK Parkinson's Excellence Network webinar and associated resources. Accessible via: www.rcslt.org/news/webinars/gvpparkinsons

Relevant guidelines

Parkinson's NICE guideline

www.nice.org.uk/guidance/qs164/resources/parkinsons-disease-pdf-75545600441029

Department of Health. National Service Framework for Long Term Neurological Conditions. (2005) www.gov.uk/government/publications/quality-standards-for-supporting-people-with-long-term-conditions

► For more information, contact: info@rcslt.org