



Royal College of Speech and Language Therapists response to the APPG on Parkinson's inquiry – "Mental health matters too"

1. Executive Summary

- Eating, drinking and swallowing difficulties (dysphagia) affect most people with Parkinson's¹ and many people with Parkinson's experience communication problems (which include difficulties with speech, language and voice)².
- People with Parkinson's may experience mental health problems including difficulties with mood³, depression and anxiety^{4 5}.
- Input from speech and language therapy is directed at improving verbal and written communication and maintaining a safe swallow, and through this adequate hydration and nutrition and prevention of secondary infection. Better communication, safer swallowing and reduced drooling are associated with better mood and increased motivation. Better communication also assures access for people with Parkinson's to talking therapies and generally supports them to express their wishes and concerns.

2. Parkinson's

There are about 127,000 people in the UK with Parkinson's. Communication abilities change even in the pre-diagnosis stage and these changes progress over the years.

Communication

- 80-90% of people with Parkinson's report changes to their voice⁶
- Up to half of people with Parkinson's are affected by unclear speech, even in the early phases of the condition⁷

Swallowing

- 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^{8 9 10}
- 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^{11 12 13}

3. Parkinson's and mental health

There are clear links between mental health problems and Parkinson's. People with Parkinson's can experience an impact on their mental health and mood due to the difficulties of living with the condition for example due to a fear of choking¹⁴ or increased social challenges of drooling^{15 16}. Individuals report a loss of control in communication, less confidence, difficulty getting into conversations, keeping place in conversations and conveying information which leads to feelings of loss of independence and inadequacy^{17 18}.

People in the later stages of Parkinson's are also vulnerable to hallucinations, psychosis and depression¹⁹. This may arise partly due to the underlying damage caused by the condition or the psychological consequences for the person, for example, finding it difficult to communicate, walk or socialise.

4. Mental health and the link with speech, language and communication and eating, drinking and swallowing needs

Communication needs and dysphagia affect people with Parkinson's and people with mental health problems.

Communication

Being able to communicate is essential in explaining concerns around mental health, and accessing and benefitting from therapies for mental health issues. People with Parkinson's already have to manage the presence of communication needs. These place them at a greater risk of developing mental health problems. Evidence shows that people with a primary communication problem are at greater risk of experiencing mental health problems, commonly anxiety or depression than their peers²⁰.

Swallowing

Difficulties with swallowing can lead to unsafe eating and drinking. In turn this puts people at risk of malnutrition, dehydration, chest infections, and choking.

Even when safe swallowing is largely maintained, anxiety about choking may affect swallowing or mealtime enjoyment.²¹ Dysphagia and depression have been strongly linked.^{22 23 24}

5. Why is it a problem?

Left unidentified and unmet communication needs and dysphagia can put people at risk of worse outcomes.

Communication

Communication problems can hinder people's ability to access and benefit from verbally mediated interventions, such as psychotherapy, anger management, or individual or group based talking therapies, which require significant understanding and expressive language skills²⁵. These intervention approaches will be unsuccessful if the person does not currently have sufficient communication skills. It is therefore essential that communication needs are identified and supported as a priority.

In addition, people with Parkinson's can have difficulties with non-verbal communication for example reduced facial expression (masked face/hypomimia) or flattened intonation in speech. These symptoms can have significant consequences including others developing negative perceptions of the individual to misdiagnosis of depression.²⁶

Swallowing

Dysphagia represents a significant risk factor for chest infections²⁷. Unsafe eating and drinking can lead to an increased risk of malnutrition, choking, aspiration pneumonia requiring hospital admission and in some cases death.

There is a greater prevalence of dysphagia in acute and community mental health settings compared to the general population²⁸. There is also evidence for an elevated rate of death due to asphyxia in acute mental health settings²⁹ due to the effects of medication and the neurological condition³⁰.

6. Supporting people with Parkinson's with mental health problems

Given the links between mental health, Parkinson's and communication and dysphagia, speech and language therapists have a crucial role to play in the identification and response to need. Speech and language therapists support access to verbally mediated interventions to ensure that treatment resources are not wasted, promote patient safety by reducing the risk of swallowing problems and support communication changes as the condition progresses.

7. The RCSLT recommends

1. On entry to mental health services, all people should be screened to identify the presence of communication changes/challenges or dysphagia. Furthermore due to the potential side effects of some medical and surgical interventions on communication and dysphagia these needs should be regularly monitored.
2. People with Parkinson's with mental health problems and communication needs or dysphagia are referred to speech and language therapy as early as possible to assess and support these needs.
3. Ensure adequate training for all professionals and support staff working with mental health teams to help staff recognise and understand how to respond to communication needs and dysphagia.
4. All staff carrying out mental health assessments should be competent in: relevant verbal and non-verbal communication skills, including the ability to tailor information, support participation in decision-making and discussing treatment options.

Submitted by the Royal College of Speech and Language Therapists. For more information please contact Claire Moser, Claire.moser@rcslt.org

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