

## **Fears for people with language-led dementias: call for urgent action from the UK Government and NHS England**

**January 2024**

The Royal College of Speech and Language Therapists, Rare Dementia Support, and Dyscover have come together to express deep concern about the ending of the speech and language therapy service within the cognitive disorders clinic at the National Hospital for Neurology and Neurosurgery (NHNN).

The loss of the only national specialist speech and language therapy service for people with Primary Progressive Aphasia (PPA) in England and Wales poses significant risks to those with a range of language-led dementias. They risk being misdiagnosed. They risk not receiving appropriate support. They risk having their human rights violated under the terms of the Mental Capacity Act 2005.

Given this, we are calling on the UK Government and NHS England to urgently step in to ensure the speech and language therapy service is reinstated so the hundreds of people who were accessing it each year can continue to do so.

### **What is Primary Progressive Aphasia (PPA)?**

PPA describes a group of progressive neurological disorders starting with language difficulties. These are types of dementia, associated with Alzheimer's disease and frontotemporal dementia.<sup>i</sup> There is currently no curative treatment for PPA, and the disease progresses inexorably over time. Speech and language therapy is the only available option for treatment and management of speech, language and communication difficulties in PPA.<sup>ii</sup> Moreover, speech and language therapy is key to making an accurate diagnosis of these complex language-led dementias.

### **What did the speech and language therapy service do at the National Hospital for Neurology and Neurosurgery?**

The speech and language therapy service within the cognitive disorders clinic at the National Hospital for Neurology and Neurosurgery (NHNN) has supported the diagnosis process for around 300 patients and delivered therapy to around 500 patients per annum, from around England and Wales, for the last four and half years. This service was discontinued in April 2023. This, in turn, means that the estimated 6,000 people living with this rare language-led dementia in England and Wales no longer have access to what was the only national specialist speech and language therapy service for PPA.

### **What risks do people face not being able to access speech and language therapy?**

People with PPA are at risk of misdiagnosis as well as being unable to access relevant treatment and support, due to the loss of the speech and language therapy service in the cognitive disorders service at NHNN. Assessment of speech and language difficulties is essential to diagnosis of PPA. Without an accurate diagnosis it is often difficult to access support and treatment and in the past people have reported being offered unsuitable and expensive treatments for misdiagnoses such as depression, stroke, and deafness. Furthermore, the delay in diagnosis, will delay access to interventions that have been shown to maintain language function and quality of life for longer.<sup>iii</sup> This is likely to result in significant negative mental health outcomes for both the person with PPA and their families and carers.<sup>iv</sup> These negative mental health consequences are likely, in turn, to lead to increased care needs and dependency at an earlier stage of the disease.

### **What wider risks are people at risk of?**

In addition to what is outlined above, it is important to note that people with PPA will not have access to all practicable supports (as outlined as a key principle of the Mental Capacity Act 2005) in decision-making in relation to issues that may be discussed in their medical appointments. Thus, not having speech and language therapy services in the cognitive disorders clinic at NHNN might be considered as a violation of the rights of people with PPA, in line with the Mental Capacity legislation.

There is also a risk of impacts on onward referrals to local speech and language therapy services, such as those provided by the NHS and third sector organisations. The valuable professional network that exists between specialist clinicians in the field is also at risk, to the potential detriment of the people they support.

### **What benefits would re-establishing the speech and language therapy service bring?**

Funding a speech and language therapy service at NHNN would provide accurate and timely diagnosis for people with PPA in England and Wales. A centre of clinical and research excellence such as this will also provide access to support and interventions that can help people with PPA and their family members live better, for longer.

### **What needs to be done?**

The Department of Health and Social Care and NHS England must urgently find a way of ensuring the speech and language therapy service at NHNN's cognitive disorders clinic can be reestablished. We stand ready to discuss that with them, and with NHNN, to find a way forward for everyone living with PPA in England and Wales and their families and carers.

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<sup>i</sup> Belder, C. R., Marshall, C. R., Jiang, J., Mazzeo, S., Chokesuwattanaskul, A., Rohrer, J. D., & Warren, J. D. (2023). Primary progressive aphasia: six questions in search of an answer. *Journal of Neurology*, 1-19.

<sup>ii</sup> Volkmer, A., Rogalski, E., Henry, M., Taylor-Rubin, C., Ruggero, L., Khayum, R., & Rohrer, J. D. (2020). Speech and language therapy approaches to managing primary progressive aphasia. *Practical neurology*, 20(2), 154-161.

<sup>iii</sup> Wauters, L. D., Croot, K., Dial, H. R., Duffy, J. R., Grasso, S. M., Kim, E., & Henry, M. L. (2023). Behavioral Treatment for Speech and Language in Primary Progressive Aphasia and Primary Progressive Apraxia of Speech: A Systematic Review. *Neuropsychology Review*, 1-42.

<sup>iv</sup> Pozzebon, M., Douglas, J., & Ames, D. (2018). Facing the challenges of primary progressive aphasia: The spousal perspective. *Journal of Speech, Language, and Hearing Research*, 61(9), 2292-2312.