

Please respond to: peter.just@rcslt.org

The Rt Hon Victoria Atkins MP
The Secretary of State for Health and Social Care
39 Victoria Street
London
SW1H 0EU

29 January 2024

Dear Secretary of State,

Fears for people with language-led dementias

We are writing to ask you to intervene to ensure the resumption of dedicated speech and language therapy services within the cognitive disorders clinic at the National Hospital for Neurology and Neurosurgery (NHNN).

As organisations representing people with Primary Progressive Aphasia (PPA) and the professionals who work with, and support, them and their families, we are very concerned about the loss of the only national specialist speech and language therapy service in England and Wales.

Given the rarity of these language-led dementias, we are particularly concerned about the significant risks people with them face if the only speech and language therapy service dedicated to supporting them is not restored as soon as possible.

These risks are detailed fully in the enclosed statement, but in summary, people face the risk of misdiagnosis. They face the risk of not receiving appropriate support, as do their families. They face the risk of having their human rights violated under the terms of the Mental Capacity Act 2005.

Given the significance of these risks, we would welcome an early opportunity to discuss these issues with you so that a way can be found for the speech and language therapy service to be reestablished.

We look forward to hearing from you and working with you to ensure the best possible level of diagnosis and support for people with language-led dementias and their families.

Yours sincerely,

Steve Jamieson MSc BSc (Hons) RN, Chief Executive, Royal College of Speech and Language Therapists

Professor Sebastian Crutch, Clinic Lead, Rare Dementia Support

Rosemary Townsend, Principal Speech and Language Therapist – PPA Service, Dyscover

cc: Amanda Pritchard, Chief Executive, NHS England

cc: David Probert, Chief Executive, University College London Hospitals

Enc: statement on fears for people with language-led dementias