

# Shouting from far away: three poems about living with speechlessness

Rory JQ Barnes,<sup>1</sup> Jason D Warren<sup>2</sup>

<sup>1</sup>Specialist Cognitive Disorders Clinic, National Hospital for Neurology and Neurosurgery, Queen Square, London, UK  
<sup>2</sup>Dementia Research Centre, UCL Queen Square Institute of Neurology, London, UK

## Correspondence to

Dr Jason D Warren, Dementia Research Centre, UCL Queen Square Institute of Neurology, London, WC1N 3BG, UK; [jason.warren@ucl.ac.uk](mailto:jason.warren@ucl.ac.uk)

Accepted 30 November 2022  
Published Online First  
26 December 2022

## ABSTRACT

We present three poems written from personal experience of living with primary progressive non-fluent aphasia (primary progressive apraxia of speech). The poems provide a window on this illness ‘from the inside’, and vividly illustrate how intellect and inner life may survive strikingly intact, even after speech is lost.

RJQB turned to writing after a long career as a solicitor. In 2016, at the age of 74, he began to experience difficulty articulating words when conversing. This deteriorated insidiously, and 3 years later, he was diagnosed with primary progressive non-fluent aphasia. His illness has been characterised chiefly by severe speech apraxia, which has largely destroyed his ability to talk. His speech is now limited to sparse, barely intelligible words produced only with considerable effort and there is an accompanying apraxia of other orofacial movements. He currently uses an iPad with a voice-synthesising app to communicate in person. His typing is clumsier, and he now makes some spelling mistakes, as well as occasional binary reversals (‘yes’/‘no’ confusions).<sup>1</sup> However, since his diagnosis, he has continued to produce poems describing his experience of living with the condition, three of which are below.

‘Primary progressive apraxia of speech’ can be remarkably pure, leaving many aspects of language and general intellect unscathed. Rory’s case is a particularly striking illustration of this syndrome, which presents something of a nosological dilemma.<sup>2,3</sup> A neurologist may see it as the harbinger of atypical parkinsonism on the corticobasal degeneration—progressive supranuclear palsy spectrum.<sup>3</sup> A neuropsychologist might wonder if it qualifies as an aphasia at all.<sup>3,4</sup> A neuropathologist will generally characterise it as a primary tauopathy.<sup>5</sup> But to convey the bane of speechlessness after a life’s work trading in words requires a poet.

## The last sweet

Do you remember sucking the last sweet,  
Long in the past, making it last  
As long as possible?  
Now is the time to suck away  
To savour the juice of life  
To run your tongue over the texture  
To tease out the flavour  
To let the sweetness slide down your  
throat without swallowing.  
Cheating time to let the seconds chime  
Concentrating on what you’ve got  
Not what you’ve lost:  
The less you have  
The more precious it is.

## An evening out

Around the table  
I clear my throat  
And everyone is silent  
To hear my words.  
I must take care  
To say something worth their effort  
And not to make noises  
That silence the conversation  
When I have nothing to say.  
And pray they will understand my  
speech  
And not pretend they have  
When they have not.

## Fifi

Fifi is my granddaughter  
Aged nine and clever  
She called her favourite teacher  
Long tempered.  
I was looking forward  
To arguing with her  
When she was grown and beautiful  
And accomplished.  
Now I cannot talk  
I have missed the boat  
And must find another role  
But I am still her grandpa  
And I can write her poems  
She can read instead.

Rory Barnes  
August – November, 2021



© Author(s) (or their employer(s)) 2023. No commercial re-use. See rights and permissions. Published by BMJ.

**To cite:** Barnes RJQ, Warren JD. *Pract Neurol* 2023;**23**:176–177.

**Acknowledgements** The authors thank Dr Anna Volkmer for helpful insights.

**Contributors** The authors have jointly drafted and revised the paper.

**Funding** The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

**Competing interests** None declared.

**Patient consent for publication** Consent obtained directly from patient(s).

**Ethics approval** This study involves human participants and was approved by UCL/UCLH Joint Research Ethics Committee. Participants gave informed consent to participate in the study before taking part.

**Provenance and peer review** Not commissioned; internally peer reviewed.

**Data availability statement** No data are available.

## REFERENCES

- 1 Warren JD, Hardy CJ, Fletcher PD, *et al.* Binary reversals in primary progressive aphasia. *Cortex* 2016;82:287–9.
- 2 Marshall CR, Hardy CJD, Volkmer A, *et al.* Primary progressive aphasia: a clinical approach. *J Neurol* 2018;265:1474–90.
- 3 Duffy JR, Utianski RL, Josephs KA. Primary progressive apraxia of speech: from recognition to diagnosis and care. *Aphasiology* 2021;35:560–91.
- 4 Josephs KA, Duffy JR, Strand EA, *et al.* Characterizing a neurodegenerative syndrome: primary progressive apraxia of speech. *Brain* 2012;135:1522–36.
- 5 Olfati N, Shoeibi A, Litvan I. Clinical spectrum of tauopathies. *Front Neurol* 2022;13:944806.