

Shouting from far away: three poems about living with speechlessness

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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).¹ 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.^{2,3} A neurologist may see it as the harbinger of atypical parkinsonism on the corticobasal degeneration—progressive supranuclear palsy spectrum.³ A neuropsychologist might wonder if it qualifies as an aphasia at all.^{3,4} A neuropathologist will generally characterise it as a primary tauopathy.⁵ 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
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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.