

## Non-memory led dementias, risk of infection and care in the time of COVID-19

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Non-memory-led dementias account for ~15% of all dementia cases (1). They are relatively more common in younger individuals (<65 years), who do not fit with societal perceptions of dementia, making their disability and support needs less noticeable. Dementias such as behavioural variant frontotemporal dementia (bvFTD), posterior cortical atrophy (PCA) and primary progressive aphasia (PPA) have phenotype-specific symptoms that increase the challenges of keeping safe from COVID-19 and exacerbate pressures on care. We wish to highlight the particular needs of this population and their carers.

Changes in behaviour typically seen in bvFTD, such as lack of insight, behavioural disinhibition (e.g. approaching and touching strangers) and compulsive behaviours (e.g. repeatedly walking the same route) make managing in lockdown extremely difficult. Tailored advice is required in these cases, as for example, persuading one of our bvFTD patients with a “hyper-religious” compulsion to attending mass daily, to attend online religious services instead. People with PCA live with progressive cortically-based visual impairments that lead to greater reliance on touch (e.g. holding handrails to reduce the risk of falling) which may increase the risk of COVID-19 infection. For people living with PPA, condition-specific communication challenges also increase vulnerability (e.g. semantic breakdown in semantic variant PPA limits understanding of concepts like “virus”, “mask”, or “soap”).

The past months have seen a doubling of calls to the UCL-led Rare Dementia Support (RDS) service (<https://www.raredementiasupport.org/>) concerning issues such as loss of day care services, adjustment to isolation, hygiene maintenance and hospital admission. In response, RDS launched a COVID-19 emergency kit, increased phone and email support, established information-based (e.g. care planning) and experience-based (e.g. loss of independence) small online discussions, and facilitated member-to-member virtual buddying via videoconference.

The provision of informed support in current times is required to sustain care and carers and protect those with non-memory-led dementias from COVID-19.

### References

1. Harvey, R.J., Rossor MN, Skelton-Robinson M, Garralda E. Young onset dementia: epidemiology, clinical Symptoms, family burden, support, and outcome. London: Dementia Research Group; 1998.

**Authors contributions:**

ASG conceived this letter and wrote the first draft. NZ, CW, OW, EH, EB, SJC and NCF reviewed and contributed to its final version.

**Conflict of interests' statements:**

NZ, CW, OL, EH, EB and SJC report no competing interests. NCF has served as scientific advisory board member for Roche and Biogen and received non-financial support from Eli Lilly. ASG reports fees from MedAvante Pro-Phase. All reported financial activities are unrelated to this correspondence.

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