It's time to stop saying “the mind is unaffected” in ALS

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When Professor Stephen Hawking died in March 2018 after living with amyotrophic lateral sclerosis (ALS) for 55 years, the obituaries rightly celebrated a brilliant mind trapped in a failing body. Unfortunately, this shorthand description of ALS (found throughout the medical and lay literature alike) is firmly contradicted by a research base that finds frontotemporal dementia in 10% to 15% of cases and subtle cognitive deficits in 33% to 50%.¹ In this issue of Neurology®, Crockford et al.² report a large and carefully controlled study of 161 patients with ALS across 3 centers with 80 matched healthy controls to address a question that has puzzled the field for 40 years: are the cognitive and behavioral symptoms in ALS more prevalent at more advanced stages of disease?

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