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# Saturday

## How do the activities of daily living change longitudinally in people living with frontotemporal dementia and other rarer dementias? A systematic review.

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State of the art
Frontotemporal dementia is one of the rarer dementias, all of which are characterised by atypical symptoms and younger onset which lead to higher carer burden. To facilitate personalised care we need to understand the sequence and rate at which activities of daily living (ADLs) decline. We conducted a systematic review to synthesise current literature on this topic.

Methodology
'Rarer dementia' was defined as variants that account for less than 10% of neurological dementias in the UK.

The review was preregistered and followed PRISMA guidelines. We searched five databases (Embase, Medline, Emcare, PsycINFO and Cinahl), resulting in 579 studies after removing duplicates. Twenty studies were ultimately considered relevant, and therefore assessed for quality and included in the review

Results

- Nineteen of the 20 studies focussed on patients with a diagnosis in the frontotemporal dementia/ primary progressive aphasia spectrum. One study focussed on posterior cortical atrophy.
- Activities of daily living decline was largely measured using staging scales developed for typical Alzheimer's disease.
- Studies ranged in length from one to 10 years. Longer studies described more detailed sequences of decline in ADLs.

Conclusion
Despite many years of research into FTD and other rarer dementias, our understanding of the decline in ADLs remains minimal, which results in poor outcomes for patients and carers. We make three key recommendations for addressing this: develop dementia-specific ADL scales; investigate objective measures such as from wearable technologies; use computational analyses to characterise ADL decline and account for heterogeneity.

## Conflicts of interest

Nothing to declare