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Better Living with Non-memory-led Dementia (BELIDE):

Recruitment and Baseline Characteristics

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P1-01

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Background

Non-memory-led dementias, including posterior cortical atrophy (PCA), primary progressive aphasia (PPA), and behavioural variant frontotemporal dementia (bvFTD), present unique cognitive, functional, and behavioural challenges placing complex demands on family caregivers.

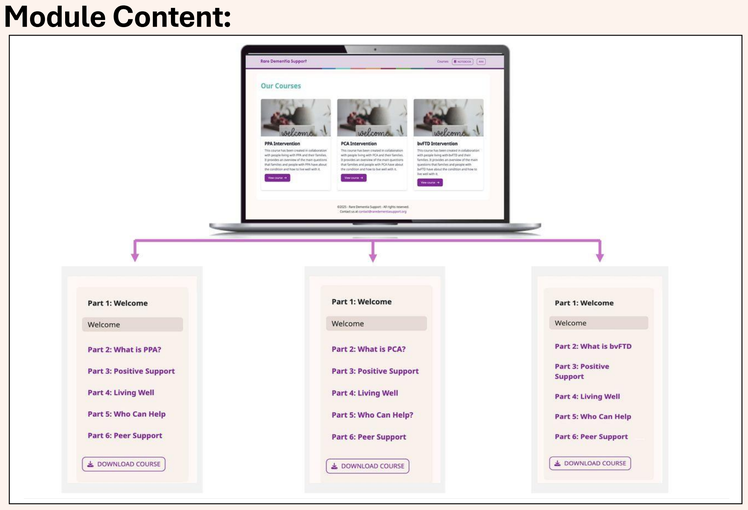
However, evidence-based, phenotype-specific educational resources remain limited worldwide. Better living with non-memory-led dementia (BELIDE) is a co-designed, web-based educational programme developed to support caregivers of people with these phenotypes.

Following an initial feasibility study, it is currently being tested in the largest randomised controlled trial on non-memory-led dementias (NCT06241287). This poster reports recruitment outcomes and baseline characteristics of the BELIDE trial.

BELIDE Intervention

Duration: 8 weeks
Digital Modules: 6
Facilitator Videoconferencing sessions: 2
Delivery: Online
Underpinning Framework: BELIDE is informed by a logic model based on theories of self-efficacy, behaviour change, coping theory and social learning and modelled according to the COM-B (Capability, Opportunity, Motivation, and Behaviour) model of behaviour change.

Module Content:



The programme includes six educational modules providing **psychoeducation**, **positive support strategies** and **self-care techniques** to caregivers of people with PCA, PPA, and bvFTD and includes real-life 'put your knowledge into practice' tasks to reinforce engagement and skill development.

Methods

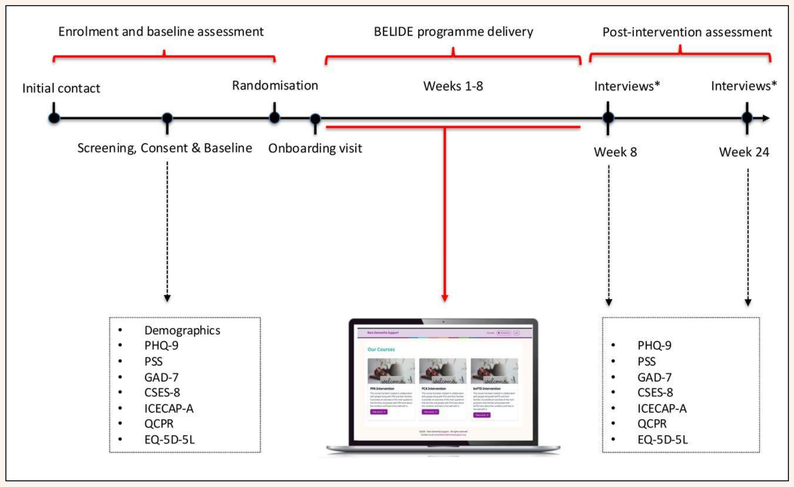
The BELIDE trial is a parallel-group, single-blind, randomised waitlist-controlled trial enrolling family caregivers of individuals diagnosed with PCA, PPA, or bvFTD.

Participants are recruited internationally via Rare Dementia Support (RDS). Eligible caregivers are aged ≥18 years, supporting someone not in full-time care, and have internet access.

Participants are randomised 1:1 to the BELIDE programme or treatment-as-usual (TAU) using dynamic adaptive allocation stratified by diagnosis and gender.

Baseline assessments included: **depression (PHQ-9; primary outcome)**, anxiety (GAD-7), perceived stress (PSS), caregiver self-efficacy (CSES-8), health-related quality of life (EQ-5D-5L), capability (ICECAP-A), relationship quality (QCPR), and demographic and caregiving context variables.

Participant timeline:



Results

We report recruitment to December 2025 and baseline characteristics for 85% of the sample recruited.

The presented statistics are derived from data that has not been fully cleaned so may be subject to change.

206 caregivers were recruited between March 2024 and December 2025.

Questionnaire completion (demographics, outcome measures, health economics) at baseline was **100%**

Data completeness across measures ranged from **99%** to **100%**

Core Demographics

Age Range	22 – 81 (59.6 ± 12.1; mean ± SD)
Gender	73.8% Female, 26.2% Male
Diagnosis	45.6% PPA, 31.6% PCA, 22.8% bvFTD
Relationship to person living with dementia (PLWD)	81.6% Spouse/Partner, 12.6% Child, 3.4% Parent, 1.5% Friend, 1% Other
Living with PLWD?	83.5% Yes, 16.5% No
Ethnicity	85.4% British, 7.3% Any other white background, 1.9% Irish, 1.5% Indian, 3.9% other*

* 0.5% Chinese, 0.5% Arab, 0.5% Caribbean, 0.5% White and Asian, 0.5% White and Black Caribbean, 0.5% any other mixed/multiple ethnic background, 0.5% other Asian background (unspecified), 0.5% other (unspecified)

Baseline Scores

Measure	Mean ± SD	Interpretation
PHQ-9	5.1 ± 4.4	Mild depression
GAD-7	5.3 ± 3.9	Mild anxiety
PSS	16.9 ± 6.7	Moderate perceived stress
CSES-8	45.4 ± 14.1	Middling self-efficacy
EQ-5D-5L	0.872 ± 0.125	Good health related QoL
ICECAP-A	0.773 ± 0.152	Relatively high capability wellbeing
QCPR	52.9 ± 10.5	Standard relationship

Discussion

Recruitment goals: The BELIDE study has successfully recruited and retained, with excellent measure completion rate, a large cohort of caregivers supporting individuals with PCA, PPA, bvFTD. This underlines that undertaking large scale research with this population is feasible.

Baseline characteristics reflect high psychological variability in response to care demands: The large variability observed across outcome measures suggests substantial heterogeneity in the psychological profile of caregivers entering the trial. This supports the need for interventions that are flexible to accommodate diverse support needs among families affected by PCA, PPA, and bvFTD