

# **Challenge Demcare: management of challenging behaviour in dementia at home and in care homes – development, evaluation and implementation of an online individualised intervention for care homes; and a cohort study of specialist community mental health care for families**

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## Plain English summary

### Challenge Demcare

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## Plain English summary

**D**ementia brings behavioural changes in a person that families and staff in care homes can find challenging. Causes of these 'challenging behaviours' (CBs) are complex and not always attributable to the dementia condition itself. Simple responses, such as 'reasoning' with the person or giving 'calming' drugs, have limited use. Instead, a skilled 'detective-like' approach to understand the sometimes hidden need(s) of each person with dementia is required.

We developed an online system with comprehensive training and individually tailored care plans to assist care home staff and community practitioners to use this detective-like approach to find solutions for common CBs.

This was tested for people with dementia and significant CBs in care homes. The intervention was not effective in reducing CBs, compared with those who did not receive it. Care staff did not readily access worksite-based online training, despite significant provision for back-fill time and information technology resources. Off-worksite training facilitated by an experienced dementia practitioner, with opportunity for discussion and practice in tailoring care plans, received positive feedback.

The intervention with home-dwelling people with dementia and CBs was not tested because of insufficient referrals. An observational study was conducted in home-dwelling people with dementia and CB. Over 60% of these had mild dementia. An average of nine clinical contacts over 6 months did not have an overall impact on CB. The changing landscape of NHS practices may have undermined timely responses to dementia with CB. Furthermore, families found it hard to know when they were deserving of specialist support from the NHS. Families bear the majority of the care costs for dementia with CB. A care gap in the delivery of post-diagnostic help for families supporting relatives with dementia and significant CB at home has emerged.

Our evidence suggests that priorities for a skilled NHS-led dementia workforce should shift from early diagnosis to early recognition and clinical support of family and staff carers who are challenged by dementia-related behaviours. Our programme has produced clinical protocols and resources for the recognition of significant CBs and manualised guidance for practitioners to deliver interventions. These require dissemination and further evaluation.



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