

Enabling people to live and die well with dementia: a new primary care intervention

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Currently, the support available following a dementia diagnosis in the UK is inconsistent and individual experiences are highly variable. It has been suggested that primary care should take a more central role in the care of people living with dementia, similar to other long term conditions. The PriDem project aims to develop and test a new intervention based in primary care to improve the support of people living with dementia and their families from the point of diagnosis to end of life care.

We conducted literature reviews, interviews with commissioners and service managers, and in depth qualitative studies of six different service models in England. We also explored views on a primary care based approach with professionals, people living with dementia and their carers. Using these findings, ideas for intervention were refined through a co-development process involving our programme management board, stakeholder involvement panel (the Dementia Care Community), and a series of virtual task groups with representation of all stakeholders.

The new intervention will be led and facilitated by a clinical dementia expert, a specialist nurse or similar professional with dementia expertise, based within a primary care network. The intervention will focus on three interlinked areas designed to address key concerns identified by the research: developing systems; building capacity and capability; and delivering tailored care and support. Developing systems will address the lack of shared knowledge about the services available, and establish systems to support how services and transitions between them are navigated. Building capacity and capability will focus on enhancing the skills, knowledge and confidence of primary care practitioners in caring for people with dementia. Delivering tailored support will focus on improving the consistency and quality of dementia reviews and care planning, and ensuring the right level of support is provided at the right time to meet the needs of each person living with dementia. Implementation of the intervention will be flexible to the local context, with an emphasis on developing a local dementia pathway of support, and enhancing the ability of primary care to deliver evidence-based, person-centred dementia care for the long-term.

With the right systems and resources in place, primary care could offer the optimum setting for providing good quality post diagnostic support to people living with dementia and their families. The feasibility and implementation of the new intervention will be now tested in a small number of primary care sites.