

Delivering tailored, holistic support to people living with dementia and their families: a new primary care intervention

Greta Brunskill, Claire Bamford, Jane Wilcock, Alison Wheatley, Louise Robinson on behalf of the PriDem team

Background: Currently, post-diagnostic dementia care and support in England and Wales is highly variable, and often insufficient in meeting the needs of people living with dementia and their families.

Objective: To develop and deliver a new primary care based intervention to enable people living with dementia and their carers to live as well as possible from the point of diagnosis to end of life.

Method: We conducted a survey and interviews with managers and commissioners of dementia services, and in-depth qualitative studies of six different existing service models to understand current post-diagnostic support in England and Wales. We also reviewed relevant literature on the management of long-term conditions and models of post-diagnostic support. Using the findings, a new intervention has been produced through a co-development process involving stakeholder task groups, our patient and public involvement group (the Dementia Care Community), and the multidisciplinary programme management board.

Results: Our findings highlighted key priorities from the perspective of people living with dementia, their carers, and professionals which focus on the need for personalised, proactive and holistic care. We also identified a number of challenges in the provision of good quality post-diagnostic support, and examples of how these could be overcome to deliver best practice. Importantly, we found that no one service model delivered all aspects of post-diagnostic dementia support well.

The new intervention will focus on three main areas: developing systems for delivering evidence-based support; delivering tailored care and support; and building capacity and capability. A clinical dementia expert, a specialist nurse or similar professional with dementia expertise, will be based in primary care to lead and facilitate change across these three interlinked areas to develop systems and services that meet the needs of all older people living with dementia.

Conclusion: Our new intervention will now be tested in practice in a feasibility and implementation study.