

PriDem project:

Improving **Pri**mary care support for people with **Dem**entia

The challenge



More than 900,000 people in the UK have dementia. Many do not receive the support they need.

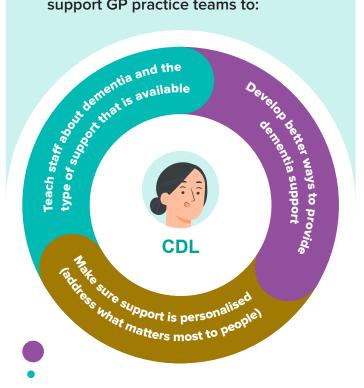
More than 900,000

The PriDem project

aimed to meet the needs of people with dementia and carers. A new approach was created by a group of researchers, NHS professionals, people with dementia and carers.

In the PriDem approach:

- Primary care staff (GPs and GP practice staff) provide day-to-day dementia support, rather than specialists based in hospitals, who can be hard to access.
- Clinical Dementia Leads (or CDLs) with expertise in dementia work with and support GP practice teams to:





To test the approach

- Two Clinical Dementia Leads worked with seven GP practices in the Southeast and Northeast of England for 12 months.
- We interviewed healthcare professionals, people with dementia and carers to find out about their experiences of the PriDem approach.



The rocky ground of primary care

Introducing the PriDem approach was challenging for GP practices, due to stretched services, lack of funding, and difficulties retaining staff. This 'rocky ground' made it difficult to introduce a new approach that would thrive.

People with dementia and carers should have their support needs reviewed annually, and a personalised care plan created. This was not happening, even though GPs are funded to carry out this process.

The power of people

People were key to success:

- Clinical Dementia Leads worked hard to build relationships with and engage staff teams. Staff members greatly appreciated their work.
- It was not always easy for Clinical Dementia Leads to gain access to people who had the most power and influence to change things, such as lead GPs.
- Motivated staff members, who were interested in dementia already acted as 'practice champions,' spreading the word and encouraging others to get involved.

Flexibility of the PriDem approach: advantages and disadvantages

Advantages

The PriDem approach is flexible. Practice staff can develop their own ways of improving dementia care with support from the Clinical Dementia Lead.

Staff found this motivating.

Example: staff created 'dementia care alerts' on patient records, so that staff would know immediately that a person has dementia and might need extra support.

The Clinical Dementia Leads aimed to help teams develop better ways of supporting people with dementia and carers that would last after the Clinical Dementia Leads had finished their involvement.

Disadvantages

BUT the flexibility of the approach led to some teams using Clinical Dementia Leads as an extra pair of hands, to help with staffing problems.

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...the surgeries were expecting a clinical dementia lead to come in and do all their dementia care <u>for them.</u> (*Clinical Dementia Lead*)

This did not help to create longer lasting change.



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New approaches to care planning

The Clinical Dementia Leads helped some practices develop new ways of doing care planning.



The research team provided resources that staff adapted to use for dementia reviews.

One of these was a leaflet that people with dementia and carers could use to help them think about their priorities before the review.

Two practices ran 'One Stop Shop' dementia review clinics.

Several people with dementia and carers attended on the same day and had opportunities to speak with the GP and Clinical Dementia Lead, and others (e.g., practice nurses, dementia advisors, care coordinators, social prescribers, people from a relevant local charity or voluntary organisation). Everyone worked together to create personalised care plans. The 'One Stop Shops' were well received by patients, carers and staff, especially in the post-Covid restrictions era:

A lot of patients have felt neglected in the last two years. Proactively reaching them and offering them such a comprehensive review has regained some of their trust in us.

Clinical Dementia Leads helped staff improve their knowledge of local and national dementia services and how to refer to them. This helped practice staff to make timely and tailored referrals to sources of support.

(GP)

In some practices, people who were housebound missed out on new care planning opportunities. In others, they were offered a review in their own homes for the first time.

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One size does not fit all

People with dementia and carers valued personalised care and support. For them it meant:

 Offering separate annual review appointments for people with dementia and carers. Their needs and preferences are very different.



- Offering home visits.
- Staff taking time to listen and sensitively get to know a person's circumstances.
- Offering services tailored to peoples' interests and needs: ->
- Providing information about the diagnosis and support services available. Some people with dementia and carers said that they had received better information during the project.

The music they play is suited for people in their late seventies, so he kept saying, "Oh, *I'm going to see* the old people" (laughs). (Carer, talking about day centre activities)

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6 Positive and longer-lasting effects of the PriDem approach

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Most of the professionals felt more confident and knowledgeable about supporting people with dementia and their carers.

The majority of people with dementia and carers who attended annual dementia reviews found the experience helpful: I went away very well satisfied from this thing that I'd never been to before. I thought it was a great success. I hope they'll do it every year from now. (Person with dementia)



Some people noticed the practices had become more dementia inclusive:

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...the receptionist or whoever it is who's answering the phone. They seem to have improved to what they were before. (Carer) Some changes that came about, especially to care planning, lasted after the project.

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In the Southeast, professionals can now access the Clinical Dementia Lead's directory of local and national dementia services online. This gives them easy access to information on support that will match people's individual needs.

Going forwards...

A Clinical Dementia Lead (CDL) supporting GP practice teams can lead to meaningful and lasting improvements in dementia support. Dementia service commissioners should consider this approach.

We recommend:

- Funding to support already stretched services.
- Identifying and supporting motivated and engaged staff who can champion the approach and bring others on board.
- Making sure everyone understands the aims of the PriDem approach, so that the Clinical Dementia Lead does not simply become an extra pair of hands.

Future research should investigate how improvements in support can become long-lasting.



This leaflet was written by the PriDem team at UCL, in partnership with a lived experience group of people with dementia and carers.