

Alzheimer's Society Centre of Excellence at Newcastle University



PriDem Dementia Care Community

Summary of meetings, October 2019

Feedback from last meeting

We thanked the DCC for their views about the practical aspects of post diagnostic support. Including who should provide it, where should it be based and how should people access it. These views will inform our new intervention.

Update on the programme

- Journal articles reviewing the effectiveness of primary care models of post diagnostic support and a survey of UK commissioners have been accepted for publication
- Interviews with service managers and commissioners of dementia services are now complete
- We have successfully recruited six services to look at in depth—data collection will be complete by the end of November
- After a review of progress, funding for the second half of PriDem has been confirmed
- Greta will be going on maternity leave in early December

Main discussion

We focused on what post diagnostic support should include. To inform the discussion, Louise presented a summary of the national dementia guideline published by NICE in 2018 (see attached slides). Louise also shared that a new multi-national programme of research she is involved in that will build on the work of PriDem—'Co-designing Dementia Diagnosis and Post Diagnostic Care' (COGNISANCE).

Claire then introduced the idea of **outcomes** as one way of thinking about what post diagnostic support should cover. Outcomes are what we want to achieve from an intervention or service.

We asked the DCC to prioritise 7 key outcomes identified as important to people with dementia and their carers by previous research. Presented on cards, these outcomes were:



- Feeling well informed and knowing where you can get help & advice
- Maintaining memory and thinking skills
- Doing enjoyable activities & feeling connected to people
- Supporting psychological wellbeing
- Optimising physical health
- Living in a safe & supportive environment
- Supporting carer wellbeing

Discussion suggested that DCC members found this task difficult for a number of reasons. Most of the group felt that all areas were relevant, and also that they were interlinked so it was difficult to separate them. Others in the group felt that priorities would depend on whether they were considering the person with dementia, family members or professionals working with people with dementia and their families. Group members also emphasised that priorities would vary according to individual needs and circumstances, and the stage in the illness.

We then split into three smaller groups to explore selected outcomes in more detail. Each of the broad outcomes above were broken into more specific outcomes, and members were asked to consider whether each specific outcome needed:

- ◇ A health or social care professional?
- ◇ Someone with dementia expertise?
- ◇ Someone who knows what help / services are available locally?
- ◇ Someone who knows you well?

The discussions highlighted that there were no simple answers! The type of individual delivering the service depended on: the stage of dementia; the specific outcome area; and the nature of the problems. Skilled professionals were not needed for every visit and it was suggested that using a mixture of qualified and unqualified staff could be more affordable & appropriate. Local knowledge was key for some outcomes (but not all) and professionals highlighted the difficulties in keeping up to date with local services.

Next steps

- The next DCC meetings and visits will be in November to continue to develop ideas about how best to provide post diagnostic support.
- This work will directly feed into the research team workshop being held in late November

If you have any questions or comments about this summary, please contact Greta Brunskill (Researcher and DCC Facilitator) on 0191 208 7963 or greta.brunskill@ncl.ac.uk

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