

Alzheimer's Society Centre of Excellence at Newcastle University



PriDem Dementia Care Community

Summary of Initial Meeting, 16th October 2018

The PriDem programme & Dementia Care Community (DCC)

Louise Robinson (Programme Lead) gave a short introduction to the PriDem project, and Claire Bamford talked about why we are creating a DCC. These talks are summarised in the attached slides.

Experiences of post diagnosis support

We then invited people to share their experiences of post diagnosis dementia services.

Key themes from people with dementia and family members were:

- Accepting help can be hard
- The importance of services fitting around the person's needs
- Continuity of care is important but often does not happen

Key themes from professionals were:

- Reducing stigma and increasing awareness around dementia is important, and more of this needs to be done
- People with dementia and their families are often not followed up enough, which can lead to situations where they need help urgently
- Communication and links between services are poor

Shared themes across the groups were:

- There is a lack of support for people and their families following a dementia diagnosis
- People often do not know where to turn
- Giving clear information about dementia and connecting families to services are important

How the Dementia Care Community will work

Possible ways to keep people updated about PriDem are:

- A newsletter
- Written summaries of meetings of the DCC including slides used
- Setting up a Twitter account

We agreed to:

- Hold face to face meetings when needed
- Use e-mail, short meetings or home visits for briefer discussions
- Include ideas and views that members bring from other groups or meetings they are part of, such as team meetings or support groups
- Send information before face to face meetings to help people prepare

Next steps

- The e-survey of commissioners of dementia services is planned for November
- Telephone interviews with service managers and commissioners are due to begin in November
- Involve the DCC in developing our first PriDem newsletter

We would value your thoughts on this summary and any suggestions to make it better. Please share any comments with Greta Brunskill by email greta.brunskill@newcastle.ac.uk or telephone 0191 208 7963

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