



Clinical Commissioning Group

Brent Health and Wellbeing Board

10 November 2015

Report from Danny Maher - Community Action on Dementia (CAD) Brent

For information / discussion

Wards affected:
ALL

Living with dementia in today's community

1.0 Summary

- 1.1 The paper provides a summary of a programme of work carried out by CAD Brent, including a summary of findings from an ethnographic research project looking into the lives of people in Brent living with dementia.

2.0 Recommendations

- 2.1 The Health and Wellbeing Board endorse and support the work of CAD in helping to make Brent a dementia friendly borough. The Board acknowledge the important contribution of the community researchers and the research participants.
- 2.2 The Health and Wellbeing Board consider how it might use similar approaches to tackling other complex issues relating to health and wellbeing in the Borough.
- 2.3 The Health and Wellbeing Board recognise the benefits of co-production and consider what the necessary changes to culture, systems and processes to support this approach might be.

3.0 Detail

- 3.1 Community Action on Dementia (CAD) Brent has the ambition to create a dementia-friendly community where those with dementia are empowered to live well.
- 3.2 As of March 2015, there were 1,771 people in Brent with a dementia diagnosis, with an expected overall prevalence of 2,513 (a dementia diagnosis rate of 70.4%). The majority of those diagnosed live in the community (84%). Over half (55.1%) of cases were classified as having mild dementia, with 32.7% classified as having moderate dementia, and 12.2% classified as having severe dementia.
- 3.3 The team recognised that the path to a dementia-friendly Brent was not certain; nor was there broad agreement between people living with dementia, their families and carers or local stakeholders, as to the nature of the issues that needed to be addressed. Consequently the CAD Brent steering group sought to adopt a systems leadership approach which is committed to experimenting with new ideas, prototyping new products, connecting the system to more of itself and addressing power differentials by focussing on partnerships.
- 3.4 This project is the start of CAD's overarching journey to create a dementia-friendly borough. To date, there have been four main phases of the project:
1. Ethnographic research carried out with people living with dementia and their carers. Both professional researchers and community researchers carried out this research
 2. A data mapping exercise to help provide greater context to the issue of dementia in Brent
 3. A horizon scan of ideas from across the world where community initiatives have been used to help tackle complex social issues
 4. A prototype design conference on 23rd October involving 100 delegates, whereby findings from the research were reported to a wide audience, including people with dementia and their carers, commissioners, NHS, local authority and voluntary sector representatives, minority ethnic groups and faith communities, sports clubs, peer supporters, volunteers and interested individuals. During the conference, delegates came up with a number of community initiatives to prototype.
- 3.5 The research into the lives of people with dementia has highlighted the lack of awareness about dementia in the community. It was clear that people with memory problems, struggled with everyday life as they actively tried to maintain normality and independence. They identified that greater understanding of dementia was needed to ensure that the public were confident to help with simple tasks if they looked confused or appeared lost. People with dementia were conscious of feeling a burden to their families and others and felt guilty about their dependence. However, while they understood their families desire to protect them, this could be claustrophobic and limiting

to their independence. They often restricted their own activities because of fear of getting lost, being a nuisance or embarrassing their families.

- 3.6 People with dementia were critical of the absence of support following a diagnosis of dementia. A number were grateful for the support of voluntary groups or faith communities and described them as a lifeline. However, they were not well publicised or able to do more than they already did. Although people needed professional help, health services were largely unaware of community groups and what they could offer and there was little communication between them. However there was a very clear call for a space where people with dementia could share anxieties, seek advice from those further along the dementia journey. A young person with dementia, who is also a peer supporter spoke about the value of peer support and others reiterated the importance of befrienders, dementia cafes and their faith groups in improving their quality of life.
- 3.7 The delegates were then guided through a series of exercises to identify how the social movement which is CAD Brent could begin to meet the needs of people with dementia and their carers by making Brent more dementia friendly. They developed 12 initial prototype ideas for community-led initiatives, and CAD are now in the stage of prioritising these, and helping to assist the community in making some of these ideas come to fruition.

Appendices

A summary of the research findings, including executive summary, key findings and recommendations is provided with this pack.

Background Papers

Weblink to the full report: www.brent.gov.uk/dementia

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