

CAD Brent - Ethnographic Research Project

Executive Summary

Community Action on Dementia (CAD) Brent has the ambition to create a dementia-friendly community where those with dementia are empowered to live well. To do this, CAD has adopted a systems leadership approach to facilitate transformation of public services to address the complex social issue of dementia.

This paper summarises the main findings from a research project carried out throughout June and July 2015, which aimed to obtain an in-depth understanding of what day-to-day life looks like for people with dementia. This consisted of sixteen ethnographies undertaken by professional and community researchers, providing unique insights into the lives of people with dementia and those who care for them. In addition, the project also looked at examples of best practice from around the world where community initiatives have been used to help deal with health problems.

Thematic analysis revealed findings under seven themes which afford challenges and opportunities for CAD. These include: awareness and understanding; isolation and loneliness; cultural and religious issues; balancing risk; maintaining abilities; best practice in Brent; and improving services.

The findings have been synthesised and six key actionable recommendations are prioritised. Each recommendation is supported by examples of innovative international best practise. These include:

1. Wide-reaching community dementia training to increase awareness and acceptance
2. Creation of a holistic care co-ordinator care role
3. Peer support service available to all at time of and after diagnosis
4. Creation of accessible information to help overcome stigma and cultural misunderstanding
5. Establishing a network by which statutory services and community groups work together to extend the care and support provided to people living with dementia
6. Use cultural hubs or faith communities to advocate and support people with dementia and facilitate education

Main conclusions from the research

This research primarily sought to produce insightful in-depth stories of those living with dementia in Brent; to understand their challenges and to highlight opportunities which could solve these challenges and help those with dementia live better in Brent. Through the ethnographies produced by both the community researchers and the professional researchers, the key findings can be synthesised.

1. Unmet needs of those with dementia

Those with dementia have needs which are currently not being met by the services they access and the care they receive. Emotional support is typically lacking for participants in the study, some are depressed and fearful of the condition, yet are desperate to express their feelings to someone who understands and will not judge them.

Participants expressed frustration at their lack of independence as they have to rely on others for simple day-to-day tasks, reducing their sense of self-efficacy. This in turn has negative effects on participants' perceived ability to retain and share skills and abilities.

Participants with dementia want to remain independent and to be able to contribute to society in order to help them maintain a sense of purpose. However, opportunities to do so are perceived to be limited.

2. Challenges for living well with dementia

The neurological and behavioural changes associated with dementia cause participants to face challenges in almost every aspect of their daily lives. Understanding of dementia is low and stigma exists across UK society but particularly among some minority ethnic cultures or religions. This can mean that people with dementia or their families are reluctant to access services, which could help them live well with dementia.

The fear of becoming confused, getting lost or being a problem to their families or other people caused some participants not to trust themselves. Instead they often limit their own autonomy while still able, albeit needing some simple help. In a similar vein, some families have become over-protective which negatively impacts upon the freedom and ability of the person with dementia to make choices. Striking a balance which protects the person with dementia whilst still nurturing their existing abilities is a challenge in a risk averse society. It is evident that participants are not passive recipients of the condition and the majority are actively coping and negotiating ways to live better.

3. Opportunities to stimulate societal change

There are a wealth of opportunities available in Brent to help people with dementia live well within an inclusive supportive community. However there is considerable scope to enhance what already exists and how it is provided. Building upon existing initiatives which already add considerable value to participants lives is crucial. Key examples of this include peer support programmes, community groups such as the Raunchy Rockers, dementia cafes and initiatives offered by various faith groups and minority ethnic organisations.

Understanding the challenges faced by people with dementia when they are out and about enables us to identify aspects of service which would most benefit users if improved. There are examples of individual businesses ensuring people with dementia can still do the things they enjoy – such as barmen monitoring someone with dementia's spending and booking a taxi to ensure they get home safely.

Such initiatives are successful because they are based on a user-focussed approach. By considering the needs of people with dementia, services can tailor their offerings and stimulate positive change in peoples' lives.

Understanding the challenges faced by people with dementia within the health care system enables us identify how the maximum benefit could be achieved by service improvements. There is a need for dementia awareness at community level to address fear and stigma, understand symptoms and to create social spaces where dementia is understood and accepted. Families would appreciate information about the condition, what to expect and how to support a person with dementia. Existing services need to be publicised and through a network, work collaboratively to support carers. Health and social care providers, business and service industries should consider how their systems disadvantage people with dementia and train staff to be dementia friendly.

Recommendations for Brent

1. Facilitate community wide dementia awareness to enhance knowledge and understanding: This is imperative to improve understanding of the condition and should be especially targeted at the public, businesses and services. Training for staff in public services, health and social care could be provided at differing levels depending on their role. Children and youth should also be targeted to eliminate stigma from the bottom up.

2. Create the role within the care system of 'holistic care co-ordinator':

The professional care received by those with dementia is fragmented and only adequate enough to meet their most basic needs.

For individuals to live well with dementia, they need access to a professional who can co-ordinate their care and ensure that their social, emotional and cultural needs are met. This person will liaise with and capture the expertise of local community organisations to ensure person centred, culturally appropriate care and support.

3. Peer support available to all at the time of and after diagnosis:

It is imperative that those who receive a diagnosis have the opportunity to come to terms with it. Through peer support people recently diagnosed with dementia can meet others with the condition, express their emotional distress in a confidential environment and learn about their diagnosis from people who really understand dementia. Peer support provides a sense of purpose for those already diagnosed and further along the dementia journey.

4. Create accessible information to help overcome stigma and cultural misunderstanding about dementia:

Creating an informed community will help to reduce fear associated with dementia and in turn, equip the public with skills, knowledge and confidence to support people with living with dementia. Information needs to reach out to the wider community and take account of culture, literacy, language and sensory impairments whilst utilising a range of media to convey the message.

5. Establish a network by which statutory services and community groups work together to extend the care and support provided to people living with dementia:

Busy statutory providers are often unaware of what voluntary and community services, dementia friendly environments and businesses can do to enable those with dementia to live independently and comfortably for as long as possible. Fostering collaborative links between health services, community organisations, public and private services can lead would ensure a holistic and cost effective approach to care.

6. Use cultural hubs or faith communities to advocate and support people with dementia and facilitate education:

Cultural groups, community organisations and faith communities are best suited to support people with early stage dementia (as well as families who care for them), and educate their respective constituencies. Commissioners should support existing groups to develop their capacity to promote understanding of dementia, encourage early diagnosis and help those with dementia remain active and independent within their culturally appropriate service of choice. This offers a sustainable solution.

A full version of the report can be found at: www.brent.gov.uk/dementia