

One Thousand Minds

A Dementia Awareness Project with Black, Asian and Minority Ethnic Communities in Redbridge

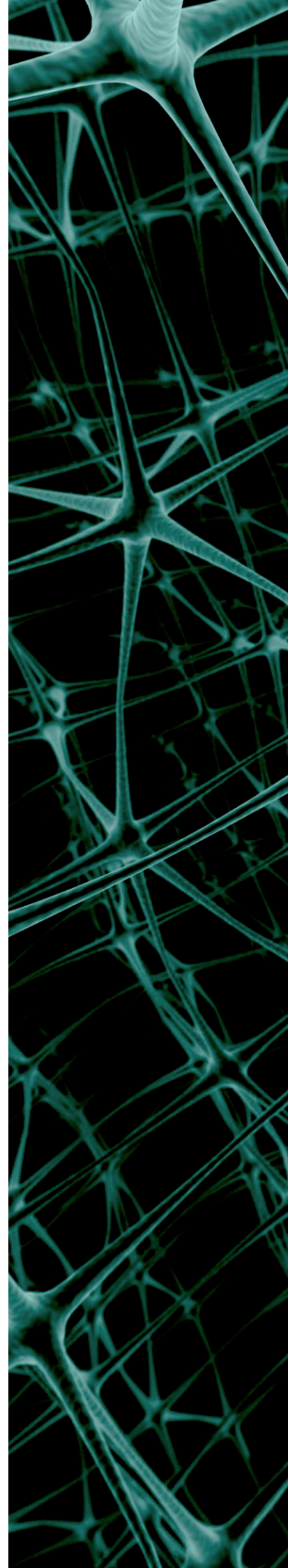
April 2013



1. Introduction

As part of a project commissioned by NHS North East London and the City, Nisema Patel (RedbridgeCVS's Psychological Health Community Development Worker) and colleagues from the Living Well Resource Centre spoke to over one thousand local people from Black, Asian and Minority Ethnic communities about dementia. Films and discussions were used to give information about dementia symptoms and care pathways in the London Borough of Redbridge in eighteen community settings on twenty occasions and in a range of different languages.

As a result of this programme many more Redbridge residents have the knowledge to decide when it is the right time to approach their GP if they have concerns about this condition affecting themselves or a loved one, as well as now having information about healthy lifestyles that may help to delay the onset of dementia and a greater awareness of the negative impacts of stigma and discrimination that can surround the subject.



A vertical strip on the left side of the page features a microscopic image of neurons, showing their cell bodies and branching dendrites and axons in shades of teal and black.

2. Context

Dementia is a term that describes a non-specific syndrome associated with symptoms such as issues with memory loss, problems with reasoning and communication, and a decline in the ability of an individual to carry out daily activities such as washing, dressing and cooking. The most common types of dementia are: Alzheimer's disease, vascular dementia, mixed dementia and dementia with Lewy Bodies¹. It is currently estimated that very few² (around 1%) 'true dementias' are reversible (though around 10% of cases of 'dementia-like illnesses' are due to causes that can be reversed with treatment³).

Dementia is usually a progressive condition, where the symptoms gradually get worse; however the progression varies from individual to individual with each person experiencing dementia symptoms differently. According to the figures from the Alzheimer's Society (May, 2013), around 800,000 people in the UK have a form of dementia, and one in three people after the age of 65 will go on to develop the condition.

Progression of the disease without diagnosis can greatly diminish the quality of life of the patient and their family, and leads to increased costs to the National Health Service and the welfare system, including as a result of stressors that may lead to mental health problems and unemployment for patients and carers.

In March 2012 Prime Minister David Cameron expressed concern about the fact that around half of all dementia sufferers in this country are unaware that they may have the condition, and that because of this they and their families will not get the help they need.

More recently the Health Secretary, Jeremy Hunt, said that it can be a "total nightmare getting a diagnosis" and suggested that only 46.0% of dementia sufferers in the UK have been identified. Diagnostic rates for Redbridge are found to be one of the lowest in the country - averaging at just 39.5% of the predicted levels of dementia. The neighbouring borough of Newham, by contrast, has an average diagnosis rate of 62.2%. There are also great variations within Redbridge - with some GP practices diagnosing at 5.2% of the predicted levels whilst others are at 100%. (Source: NHS Dementia Calculator, 2013.)

Early diagnosis is important since it will allow those affected to access information, support and treatment at the earliest possible stage, plan for any future needs and consider other medical conditions that may have similar symptoms. Most importantly if an individual is at an early stage of dementia they may be able to get access to medication that may, in some forms of dementia, prevent symptoms getting worse for a period of time.

1 National Institute for Health Care Excellence (April 2013)

2 How Reversible are 'Reversible Dementias?': European Neurological Review (2011, 6 (4),230-233)

3 Not All Dementia is Alzheimer's Disease: Arizona Center on Ageing (Jan 2013)

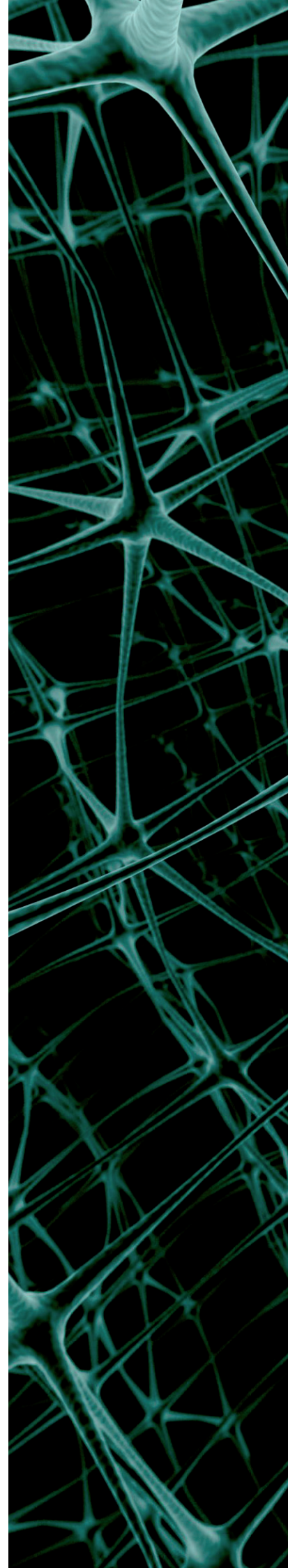
3. Target participants

Black, Asian and Minority Ethnic (BAME) communities across Redbridge were targeted for this work, since Redbridge has an aging population that includes significant numbers of first-generation settlers, many of whom have not previously come across the term 'dementia' - meaning they are even more likely than other communities to be under-diagnosed. Over 1,000 residents were engaged, of which 90% were from the South Asian community.

The 2011 census gave the population of Redbridge as 279,000 residents, of which 118,600 (42.5%) were White. However if only the English, Welsh, Scottish and Irish population were included in the 'White' population of Redbridge, then the figure would be 100,290 (35.9%) and 160,400 were non-White (57.5%).

The greatest number of non-White residents in Redbridge were Asian/Asian British (41.8% of the total population). The Asian population in Redbridge is significantly higher than the figure for the total population for London (18.5%) and England as whole (7.8%)⁴.

4 2011 Census, Office of National Statistics, April 2013 update.







A detailed microscopic image of neurons, showing their cell bodies and branching processes, rendered in a teal color against a black background.

4. Intervention

A specialist programme was developed by RedbridgeCVS's Psychological Health Community Development Worker to engage Black, Asian and Minority Ethnic (BAME) residents in order to increase awareness of dementia and the pathways to services in Redbridge. The programme was funded by NHS North East London and the City and developed and delivered by RedbridgeCVS, working in partnership with the Living Well Resource Centre.

The programme was delivered twenty times in eighteen different community settings (see Appendix for details), with some tailoring to meet the needs of each group (including, in some cases, communicating in a range of different languages). The community and faith organisations were visited at times and places of their choosing. Discussions were then led, and a number of short films, which were available in a choice of languages, and which included powerful imagery and sound in order to get the key messages across in memorable and effective ways, were shown. Groups benefited from the programme being delivered within surroundings in which they felt secure (such as community centres, a polyclinic, mosques, gurudwaras, temples etc.) and those present were able to collectively share empathy and use language and behaviour in support of those affected by dementia.

Brief outline of the programme

-  **Booklets** were handed out in English and in preferred languages. These covered:
 - What is dementia?
 - Losing your memory
-  A 5-minute DVD explaining the **nature of dementia** was shown. This was offered in Bengali, Gujarati, Hindi, Punjabi and Urdu. (The Bengali version was not requested.)
-  Nisema then talked through some slides, giving **more information on dementia**, followed by a recap looking what dementia is – and what it is not. This was partly done to address the issue of potentially stigmatising people with symptoms. It also ensured that people understood the differences between normal cognitive lapses and significant memory loss that might indicate dementia
-  A 13-minute DVD was then shown. This film was selected because of its strong visual and audio imagery, which enabled the audience to **understand the impact of dementia**. It was a powerful short film that showed how three generations of an extended family were affected by the impact of the grandmother having dementia. The emotional storyline brought about empathy and the idea that dementia can impact on any family, even though it may be well organised, educated and financially secure. The

video was paused on a number of occasions to explain and explore facets of the film

An interactive discussion was then encouraged – with the **impact of dementia on the whole family** as a key focus

A third DVD was shown. This was 3.5 minutes long and examined the **fear of discrimination within communities**. This was offered in English, Hindi, Bengali, Panjabi, Gujarati and Urdu. (The Bengali version was not requested.)

Further slides were presented and discussed, including **information about healthy lifestyles** that may help to delay the onset of dementia

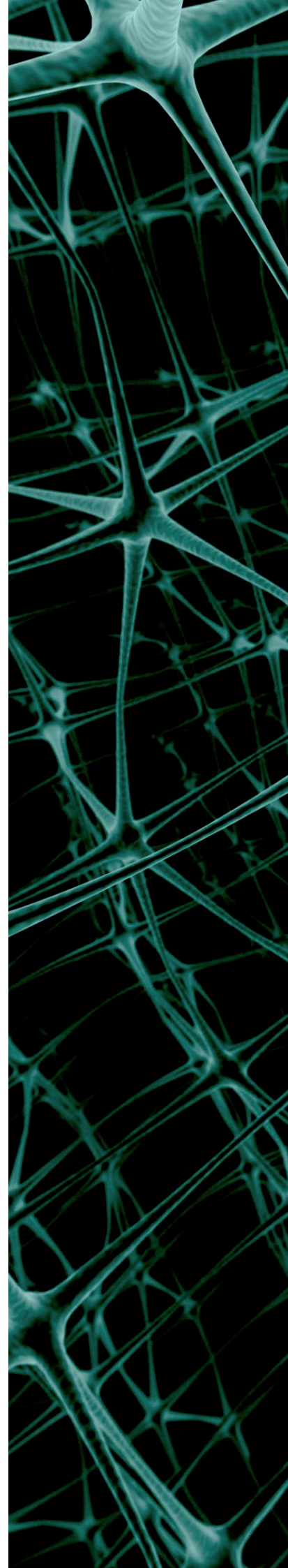
Local pathways to support and care were explained and discussed

There was an **open question and answer session**

Finally, **pamphlets from the local Living Well Resource Centre** were circulated

Gatherings ranged from 8-190 participants, and the ages of those taking part ranged from 20-90 years old. However, a significant majority of the participants were over the age of 55.

The films were carefully selected to bring about increased understanding of dementia and to help viewers develop empathy towards the individuals suffering from the condition, and their families. One of the films showed how a local South Asian family supported their loved one through the stages of dementia – and highlighted the negative impact of the stigma and discrimination that can surround the subject. These really helped to bring home the importance of understanding this condition, and how it can affect anyone.



5. Feedback from Participants

It was agreed with all participants that no individual, community or group would be named in this feedback.

Due to time constraints at each session, the large numbers involved and the multiplicity of written languages favoured, all feedback was collected verbally.

95% of participants said they found the programme informative and significant numbers reported that they now felt empowered to support families and individuals in their communities if they were affected by the condition.

2% of participants shared that they had concerns around memory for themselves or a family member

1% said they had already approached their GP but had not been referred for further investigation. (They were advised to go back to their GP and/or contact the Living Well Resource Centre for further support.)

At almost every meeting, participants discussed issues of memory loss that were currently affecting themselves.

Significant numbers of participants said that they found written information in their own first language helpful. However, a number of participants reported back that the Gujarati version was in a very old dialect and difficult to understand.

The audio and visual imagery was welcomed by all groups and those that preferred it to be played in their mother tongue said this was very helpful

Many participants wanted to embed exercise and healthier diets in their life. (They were all referred to RedbridgeCVS's Fit for Fun exercise programme.)

Almost all groups asked for future workshops on anxiety and depression.



6. Future Priorities

A significant number of participants called for similar information programmes focusing on anxiety and depression, which were discussed at these sessions only in terms of their relationships to dementia. Many groups felt that these were very important areas that they would like to learn more about in order to help them and their communities maintain psychological wellbeing.

Acknowledgements

RedbridgeCVS would like to thank NHS North East London and the City for funding this important work, the Redbridge Living Well Resource Centre, the hosts of all the community meetings, and all the participants for their enthusiasm and willingness.

Appendix

The workshops were delivered to the following groups:

-  Redbridge BAME Psychological Health Network
-  Apana Elderly Men's group
-  Awaaz
-  New Commonwealth Mental Health project
-  Redbridge Disabled Women's Welfare Association (group 1)
-  Aanchal
-  Disabled Asian Women's Network (group 1)
-  Hindu Temple (A Hindu place of worship)
-  Disabled Asian Women's Network (group 2)
-  Redbridge Indian Welfare Association
-  South Asian elderly gathering (Green Lane)
-  Redbridge Gujarati Welfare Association
-  Melting Pot (session 1)
-  Redbridge Disabled Women's Welfare Association (group 2)
-  Gurudwara (A Sikh place of worship)
-  Redbridge Asian Mandal
-  Redbridge Asian Social Klub
-  Satkar
-  Melting Pot (session 2)
-  Mosque (A Muslim place of worship)