

# Race Against Dementia - A Call to Action

## Good practice guidance

### Introduction

This document lists activities, actions and examples of good practice for working with Black, Asian and minority ethnic (BAME) people, families, communities and organisations affected by dementia. They were compiled at a workshop with a number of BAME organisations represented held in September 2015 as well as information sent by email. They are listed as bullet points under headings describing key areas of dementia policy and practice.

Contributing organisations included:

- Asian People's Disability Alliance
- Alzheimer's Society Waltham Forest & Connecting Communities Project
- Chinese National Health Living Centre – Dementia Project
- Community Action on Dementia – Brent
- Culture Dementia UK
- Mental Health Foundation
- Nubian Life
- Irish in Britain

#### **1. Accessible information about dementia being generally available e.g. in GP waiting rooms, including information about reducing the risk of developing dementia**

- Community radio talks + short inserts about dementia in health programmes – also 2 below
- Alzheimer's Society information translated on YouTube
- Importance of producing/providing information about dementia that is translated in audio/video/visual formats
- Irish in Britain has a whole community approach to addressing the dementia need within the Irish community. Our Cuimhne strategy and campaign (pronounced qu'eevna and is the Irish word for memory) is raising awareness, delivering training and supporting our Irish services to be inclusive of person living with memory loss. We use the word memory loss to include age related forgetfulness, dementia and Alzheimer's. However like all BAME communities we do not receive funding or support to deliver this strategy and we are concerned for the lack of cultural awareness by mainstream provision of the needs of Irish who are not accessing mainstream services.

#### **2. The person or their family identifying something is wrong e.g. memory problems**

- Community events that have a dementia focus but are also community social events with food, personal stories, music, and a range of ages in the audience e.g. young children – also 1 above
- More needs to be done to raise awareness to help Chinese elders with memory problems to access services/screenings

**3. Seeking and being given a dementia diagnosis (in a timely, sensitive and helpful way).**

**Usually via a GP and a specialist assessment but sometimes as a result of a hospital admission**

- Bringing the memory clinic on site (i.e. to a community organisation) where the client feels safe and less fearful of meeting a healthcare professional – also 3 below
- Having a Chinese (and other culture/language specific) version of the mini mental state examination (MMSE)
- Services need to fulfil their duty of care, with appropriate risk and safety assessments

**4. Being given good quality information about a dementia diagnosis – the effects, prognosis, care, support and treatment available for the person and their family**

- Person-centred care where the next of kin (NOK) are able to speak to qualified staff openly. Developing relationships that encourage robust conversations in order to explore best activities/pathways for the client and enable the NOK to step back / have respite –also 4 below
- Lasting Power of Attorney (LPA) information sessions encourage people to have plans
- Partnership work among community groups, statutory and voluntary, and conversations to support the person and their carers

**5. Being put in touch with a dementia “advisor”, “Navigator”, Admiral nurse, etc.**

- BAME specific dementia support worker in Tower Hamlets for Bangladeshi community with Alzheimer’s Society
- Meri Yaadain team (<http://meriyaadain.co.uk/>) is a social services led initiative in partnership with Bradford and Airedale Teaching Primary Care Trust, Age Concern Bradford and Alzheimer’s Society Bradford. The team consists of a manager and two part-time staff who undertake a wide range of activities to reach out to and engage with older people who have dementia and their carer’s and families who need educating about the condition as well as the services available to help them.

**6. Having peer support available e.g. peer support groups, memory cafes, Alzheimer cafes, drop-ins, etc.**

- Circles of Support approach – informal, unstructured approach within a wider structure of support. Circles of Support give space and allow the group to work as they wish within the moment – not having any other agenda apart from asking the person what they want to, what they like, etc. right now. The Circle collects as much info as possible about the person and NOK to get a picture of the individual in order to design activities they enjoy
- Essential to have bilingual advocacy services and service navigators to help BAME people access services
- Café facilitated on Sylheti for Bangladeshi community in Tower Hamlets
- Information Programme for South Asian families project led by Alzheimer’s Society in partnership with local South Asian organisations - nationwide

**7. Other forms of support being made available (and 'dementia friendly') e.g. community groups, faith organisations, local Age UKs, etc.**

- Circles of Support (see above), portfolios of pictures to enable people with dementia and their families to reflect, writing poetry, music, dancing, etc.
- Finding out from the person how they want to be cared for – choice and control
- Information about diet – link between diabetes and dementia – provided by Seventh Day Adventists
- Dementia Friendly Gurudwara: <http://dementiafriendlygurudwaras.com/>
- Being aware of people with learning disabilities + dementia
- Life story work
- Methodist church, Roman Catholic Church and Church of England developing dementia friendly church work including “dementia Sunday” (see websites)
- Carers Information and Support Programme (CrISP) – Alzheimer’s Society programme provides carers with excellent insight into dementia, coping strategies, support and support services
- Embedding clients with dementia into the general activity schedule of the service e.g. generic day centre, so they feel part of a great group, “normal” and included, rather than being treated differently e.g. one lady with dementia who had often wandered from home and got lost, scared and angry when she first came to the day centre for older Asian people, as a result of this approach the day centre had enhanced her wellbeing and engagement, and got her involved in helping out at the centre
- Difficulty of generic BAME day services having to provide specialist support to people with dementia but without sufficient resources, training etc.
- Many statutory, advocacy and national voluntary organisations not understanding the role of local BAME organisations
- Some faith organisations may have barriers to people with dementia accessing faith support
- Irish in Britain under, our Cuimhne campaign, approached Brent which has the highest population of Irish in England to become a dementia friendly Borough. We were confident that the Cuimhne model was broadly transferrable to all people with memory loss but especially those from various BAME groups. This has led to Community Action on Dementia – Brent a new Charity which aims to address the needs of BAME communities and working with an ambition to make the Borough dementia friendly. We are about to launch the findings of an ethnographic research study and are using a system leadership approach to address needs identified from the research. The research findings highlight the need for peer support and one person living with dementia is being supported to fundraise to set up peer support in Brent.

**8. Availability of social care – personal budgets, domiciliary care, personal assistants, etc.**

- Telephone assessments by social services often not appropriate for BAME people with dementia
- Cuimhne and CAD – Brent are working with faith and community groups who are keen to have a role in raising awareness and addressing the needs of people with dementia and their carers. Again the progress is slow as we do not have funding to deliver the training required.

**9. Ongoing support for family carers, including information about the respite breaks, the right to a carers assessment, etc.**

- Chinese Carers Support is useful + support from Alzheimer's Society, Age UK, etc.
- Consultations that include NOK – developing a relationship with NOK and being able to signpost clients to relevant bodies for assessments, respite, housing, benefits, etc.
- Importance of translating information + interpretation/advocacy when in contact with health and social care, housing etc.
- An organisational strategy that is inclusive of families caring for a person with memory loss and works with member services to ensure they understand the specific needs of families caring for a person with memory loss.

**10. Appropriate hospital care if the person needs to be admitted because of their dementia, or for other reasons**

- Need to ensure awareness in mainstream health services of barriers faced by BAME people and how to work with BAME communities

**11. Appropriate intermediate care and reablement for people with dementia coming out of hospital**

- Advice for Alzheimer's Society, Dementia UK, Admiral nurses, carers organisations, regarding help available + raising awareness of dementia, BAME groups in intermediate/reablement services

**12. Appropriate housing with care, telecare, assistive technology**

- More bilingual staff
- More befriending and volunteers recruited by mainstream statutory and voluntary sector services
- Cuimhne are working with an Irish housing association who have undertaken memory loss awareness training and aims to develop more activities and support for their elders living with dementia.

**13. Availability of good quality care homes and nursing homes**

- Example of facilitating conversations involving a person with dementia having falls and not being able to cope with living in their own home any more. Negotiations involving social services, Alzheimer's Society and a care home for her to move into – now the person is very happy in the care home and has a new social life

**14. Good quality end of life care**

- No examples

**15. Swift, appropriate responses to emergencies, crises, or safeguarding issues**

- Example of services responding well to a fracture that a person with dementia incurred following a fall
- Importance of identifying delirium among people with dementia

**16. Information for the person and carers about rights, entitlements, welfare benefits e.g. Care Act, Mental Capacity Act, Mental Health Act, Equality Act, etc.**

- Example given of using an LPA as a way of making important and appropriate decisions about a person's jewellery
- Example of person with dementia getting the Blue Badge disable parking scheme
- But staff themselves sometimes don't understand legislation etc.
- This will be included in the website that is being designed for Community Action on dementia – Brent. Under the Cuimhne strategy we send out information and articles to our members and are working on a series of Policy Advisory Group meetings to promote this further.

**17. Communities becoming more 'dementia friendly' aware, supportive, inclusive**

- EKTA organisation in Newham (charity working with South Asian families) just received international award for its drama "Dementia's Journey" to raise awareness of dementia
- Dementia Friends materials have been adapted to be better suited for people who do not read and write English.
- Training for BAME community centres to become more dementia friendly.

**18. Opportunities for people and carers to participate in research**

- There are a number of research project underway regarding specific BAME issues by UCL partners and others. These should be ready to be reported on during 2016/17.
- Community Action on Dementia - Brent has carried out ethnographic research where we hear the voices of BAME communities and their needs. We have 4 videos as well as a full report.

**19. Opportunities for people with dementia and carers to use their experiences to influence services, policies**

- All Party Parliamentary Group report on "Dementia Does not discriminate"
- Dementia Engagement & Empowerment Project (DEEP)
- Supporting person(s) within the BAME communities to have a voice at a strategic level but also to utilise their skills and knowledge to help make the changes in the Borough.

**20. Anything else?**

- Training for BAME community organisation staff, volunteers and NOK

- Importance of the advocacy role BAME organisations play – both representing communities and individuals.
- Example of an organisation (Culture Dementia UK) building links with local housing service so tenants can be referred to the organisation for social support
- Importance of community groups co-ordinating the support they give to people
- Example of the Chinese Healthy Living Centre (CHLC) acting as a “navigator” for 90 year old widow cared for by her granddaughters, reverted to speaking Chinese, unwell with an infection and not coping at home – referred to Chinese Community Centre, Alzheimer’s Society + statutory services involved – multi-disciplinary and multi-agency involvement provided information to granddaughters and negotiated with the lady that she was not coping – she happily agreed to go into a care home
- Dementia Friends programme has now amended materials to include BAME specific ones and piloting materials with Chinese community.
- The Gypsy and Traveller communities have a high risk of dementia despite very poor longevity. They are largely forgotten and considering their limiting long term physical and psychological morbidity, social marginalisation and low access to services need to be considered as a distinct group with a high risk of dementia.

For more information on Race Against Dementia contact David Truswell at: [david.truswell@nhs.net](mailto:david.truswell@nhs.net)

December 2015