Leeds Black and Minority Ethnic Communities Awareness Conference Report 2015

In Partnership with
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National Perspective

In the UK, between 670,000 - 800,000 people are living with dementia. The Alzheimer’s Society estimate that by 2021 it will be more than a million. Dementia is one of the biggest health and social care challenges facing our society.

More people than ever are now getting access to a diagnosis, are being given the right information to help live with the condition, and are receiving real person-centred care. But there are thousands of people living with dementia every day are not getting the services they are entitled to, or services are not properly coordinated. The All-Party Parliamentary Group on Dementia reported on the BME experience in 2014, and gathered evidence that disproportionately it is people from Black, Asian and minority ethnic (BME) communities who are being failed by the system.

The largest ethnic minority communities in the UK are the White Irish, Indian, Pakistani and Black Caribbean communities. The area of the UK with the highest Black, Asian and minority ethnic population is Greater London, with significant Asian communities in the West Midlands, and the North West, extending into West Yorkshire. The number of people with dementia from BME groups in the UK is increasing as people who moved here during the period from the 1950’s to the 1970’s are reaching their seventies and eighties.

Impact of Dementia on BME Communities

- Increasing indications that prevalence of dementia in Black African, African / Caribbean and South Asian communities is higher than average. This may also apply to some White UK communities where there is higher incidence of long-term health conditions.

- This may be linked to higher incidence of diabetes, high blood pressure and heart disease, contributing to vascular dementia.
Local Perspective

Information and local statistics provided by Leeds City Council has estimated that:

- 8,500 people living with dementia in Leeds (2015); this is approximately 8% of people aged 65 and over in Leeds are currently diagnosed with dementia.
- Estimated to become over 12,000 people with dementia by 2030 (40% increase in 15 years).
- At March 2015, over 5,700 people registered with Leeds GPs had a diagnosis of dementia; a “diagnosis rate” of 67%.

In the coming years, services will need to respond to:
- The increasing diversity in the local population
- An ageing population.
- Raised awareness and expectations
- Better diagnosis

Number of BME older people with dementia will increase

- "Black and Minority Ethnic"
- "white UK"

The number of people with dementia in the BME populations of Leeds is expected to double in the next ten years.
**Event Aim**

The launch of the National Dementia Awareness Campaign initiated the local focus to reach the increasing BME aging population, the communities in which they reside, their carers and family members.

**Event Rationale**

To BME communities a greater voice within the health care system

To encourage BME Communities to make their health a priority and take simple steps towards a healthier life

The day will bring together minority communities, health agencies, charity organisations, community groups and NHS to initiate discussion towards discussing solutions to known barriers

**Aim of the Day**

- By raising awareness of dementia among BME communities.
- Raising awareness amongst Service providers of sensitive cultural stereotypes that mean some communities are assumed to 'look after their own',
- Encouraging services to reach out
- Empowering communities to access services that do not reach out

The focal point of event was the round table discussions which on the exploring solutions to the known barriers.

The conference also developed the following themes through the key speakers.

- Breaking myths and taboos
- Sharing experiences
- Being heard
- Understanding the signs
**Keynote Speakers**

Nigel Gray  
Chief Executive  
NHS Leeds North Clinical Commissioning Group

**Key Message**

- More people will have a timely diagnosis  
- Diagnosis will always lead to information and opportunities for support  
- People with dementia alongside other health needs will experience joined-up care  
- We understand that equality does not mean treating everybody the same  
- Meeting peoples diverse needs and overcoming barriers

![Nigel Gray Presentation Feedback](chart.png)

Useful 90%  
Not Useful 5%  
Don’t know 5%
Key Message

“We must ensure that everybody person gets the treatment and support which meets their needs and their life “

The Key Objectives

- Improved rate of diagnosis (67%)
- Better support for carers
- Dementia friendly communities
- Improved research

Prime Minister’s Challenge
(Department of Health 2012)

Dr Oliver J Corrado Presentation Feedback

- Useful 92%
- Not useful 8%
- Don’t know 0%
Key Message

‘What is good for the heart is good for the head’

- Keeping vascular risk factors under control; high blood pressure (hypertension); effective management of diabetes, and lowering cholesterol;
- Stopping smoking and reducing alcohol intake
- Keeping weight down (but caution regarding being underweight)
- Keeping active- regular physical activity is key
Key Presentations

The conference ensured the inclusion of community organisations, who gave a brief outline of their history and their activities and how it has influenced their surrounding community to become dementia friendly.

The conference acknowledged the work within communities, which is laying the foundation within communities to achieve the goal of the City of Leeds becoming a Dementia Friendly City.

Therefore, alongside the key speakers opportunity was given to community organisations to present their work, challenge more communities to become involved and share solutions to barriers they faced within their communities and share stories of how support has been given to those living with dementia.

Community Friendly Communities Presentations

- **Peter Ruickbie** - Manager, Leeds Alzheimer's Society
  Shared the principles of the organisation and the aim to create dementia friends and dementia champions throughout Leeds
  Encouraged communities to become involved by creating safe places, supporting existing Dementia Cafes and where appropriate establishing a community led Dementia Café

- **Maggie Graham** - Dementia-friendly Leeds Campaign Manager, Leeds Older People’s Forum.
  Spoke for the importance of community organisations and local business’ becoming involved in the campaign to bring greater awareness but also to support those within the community who are living with dementia to live well.
  Organisations are encouraged to join the Leeds dementia Alliance and ‘Work to become Dementia Friendly’

- **Peter Smith** - Dementia-friendly Rothwell / Tea Cosy Memory Café
  Shared their journey and the impact of how the community and front line workers have become involved to create a Dementia Friendly Community.
  Within Rothwell community Police officers have taken up the challenge and are now Dementia aware supporting local residents and local shops owners to walk alongside those living with dementia to now live well with dementia.
Sharing Experiences

An integral feature of the conference was the inclusion of BME community members affected by dementia, sharing their personal journeys as carers and also persons living with dementia (PWD).

Identifying carers and those living with dementia supported the theme of breaking barriers and taboos. Dr Khalsi attends South Asian Dementia Café but spoke for the first time publically about his diagnosis and its impact on his life, the life of his wife who is his main carer, his family and his community.

Mrs Khan became the main carer for her mother-in-law over 8 years ago, she spoke with support of the having to give up work, curtail her social life, and how it has made her feel isolated as a carer with no identified services for those who are in her circumstances.

Through both speakers, the following impacts were identified:

- Isolation – for carers and person living with dementia
- Misunderstanding
- Viewed with suspicion
- Creates barriers in the cultural community
- Limited support for carers
- Lack of frequent community provision

Mrs Sajida Khan (Carer)  Dr Sewa Singh Khalsi PLWD and Mrs Khalsi (carer)
Solution Focused Round Table Discussion

The focal point of the conference was to begin the process of developing solutions to the current existing barriers surrounding Dementia within BME communities in access to services, awareness, barriers and cultural interruption of what dementia is.

This process was facilitated by three round table discussions themed by the following statements, which developed the core issues of sustainability and solutions.

- Creating Dementia Friendly Communities
  - Raising Awareness through targeted work
    - Schools
    - Communities
    - Cultural specific groups
    - Places of Worship
    - GP Practices
  - Solutions
    - Programme to educate Dementia Friends / Dementia Champions
    - Cultural Awareness Training
    - Front line service trainers
    - Creating Dementia Friendly Community Corridors with local business’s
  - Impact
    - Reduce Isolation
    - Create open discussions / understanding
    - Confidence to ask for help and discuss issues
• Overcoming Barriers

- Dispelling myths and taboos – awareness raising
  - Continuous Education and Training

- Working holistically with and for the person living with dementia and their families

- Up skilling established community groups such as Places of worship

- More media discussions utilising radio, social media, co-production within 3rd sector, improved websites in community languages

- Joint up 3rd sector and statutory partnership work / projects
  - Partnership working developing working effectively together

- GP surgeries initiating appointment system for annual dementia health checks
  - Referral pathway becoming much clearer

- Structured recruitment of BME volunteers / paid support workers

- Solutions
  - Befriending / friendship groups
  - Effective partnership working with 3rd sector and across statutory services
  - Open transport referral
  - Access to information without formal diagnosis
  - Weekly dementia café rather monthly
- **Reducing Risk**
  - Health Education Programme
    - Access to social activities / groups
    - Community based Physical exercise programmes
    - Awareness of Healthy Lifestyle Choices
  - Using known media programmes “Soaps” to get the message across
  - Supported community specific groups
  - Religious establishment taking lead on discussing dementia
  - Tackling frontline GP surgery staff attitude
  - Solutions
    - Reminiscing activities
    - Health and Education
**Emerging Needs**

- Negative perceptions of dementia needs to be addressed across BME communities
- Better promotion and signposting of services that already exist
- Clear diagnosis referral pathway for health professional and carers / those living with dementia
- Campaign to increase Dementia Friends / Champions across BME communities
- Effective Community Engagement training for Health Professionals
- Safe spaces for both people with dementia and carers to share and be supported

**Needs Based Recommendations**

- Schools and the community can play an important role in reaching youth and determining their understanding of Dementia.
- Effective Dementia Awareness promotion in educational and community settings in turn strengthens the core objectives of Leeds as Dementia Friendly City
- Sign posting needs to be appropriate to needs of the individuals in all aspects of social, practical and cultural
- Awareness campaigns and earlier education awareness raising for young adults, young people and children
- Integration of to Dementia awareness within Adult Social Care / Age UK/ Care Support assessment of needs for individuals inclusive of aids and adaptations
Recommendations on priorities for commissioning / service improvement

Dementia Awareness, NHS Priorities & Plans

- Continue to monitor and address diagnosis data for BME communities, and the quality of this data.

How can we overcome the barriers that people experience?

- Consider dementia training for interpreters, so Leeds can draw on a skilled resource for people for whom English is a second language, which might be "lost" as dementia progresses.

Dementia Friendly Communities

How can we make our communities more dementia-friendly, and support people to live well with dementia?

- Local BME organisations, supported by commissioners, to work to develop dementia-friendly communities in neighbourhoods of Leeds with high BME populations

Reducing the risk of dementia and assessing memory problems.

- Public Health and community groups to include the risk of dementia as a message in health campaigns linked to eg. blood pressure, diabetes and heart disease; and to do this in a way that does not further stigmatise people with dementia.
- To explore the experience of clinicians and BME people in using standard memory tests, and identify alternative approaches.

Accessing current services / identifying ‘gaps’ / solutions to current problems

- Improve access to memory cafes and other service models for BME people with dementia.
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