

# Who is Touchstone?



- UK based Mental Health Charity organisation
- provides range of innovative services that improve health and wellbeing.
- strongly committed to equality, independence and choice.
- services shaped by the needs of and by service users.
- staff are diverse, committed, resourceful and knowledgeable. They reflect the multi-cultural community in which Touchstone operates.

# About Me



- Bme (Black & Minority Ethnic) Dementia Worker
- Started in July 2012
- Speak Punjabi, Hindi and Urdu
- In partnership with Alzheimer's Society
- Raise dementia awareness within Bme communities by attending local community groups and day centres
- Formed and runs Bme Dementia Workers Forum
- Involved in various local dementia projects, e.g Dementia Pathway project, National Dementia Awareness project.

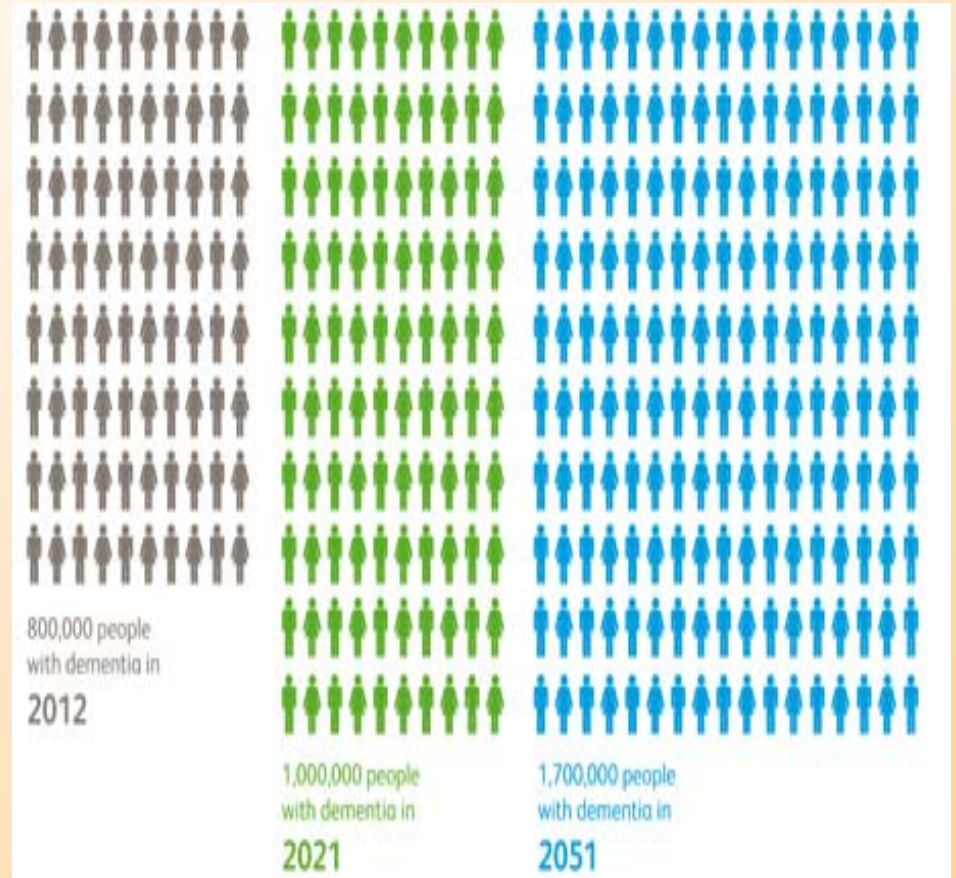
# What this presentation covers

- Dementia and its types
- Dementia Stats
- Associated Risks and Managing those risks
- Barriers for people with dementia from BME communities
- How to overcome these barriers
- Leeds Dementia Café
- Hamari Yaadain Café in Leeds



# Dementia Stats

- There are currently 8,00,000 people with Dementia in UK
- There are over 25,000 people with dementia from black & minority groups in UK
- There will be over a million people with dementia by 2021 in UK





# Associated risks



- Poor mobility- leading to increase in falls.
- Poor judgement- this can lead to items being dropped, poor eye sight, not knowing what objects.
- Wandering out of one's home.
- The person becoming aggressive physically.

# How can we manage the risks?



- Planning ahead
  - Raising Awareness and educating people about difference between memory loss with ageing and developing dementia
  - Targeting the people in the local communities
  - Making city dementia friendly
  
- Identifying risks and how to avoid or minimise them
  - Support Planning
  - Services by people and for people
  
- Getting support
  - Culturally and Religiously appropriate services
  - Services to be inclusive for all communities

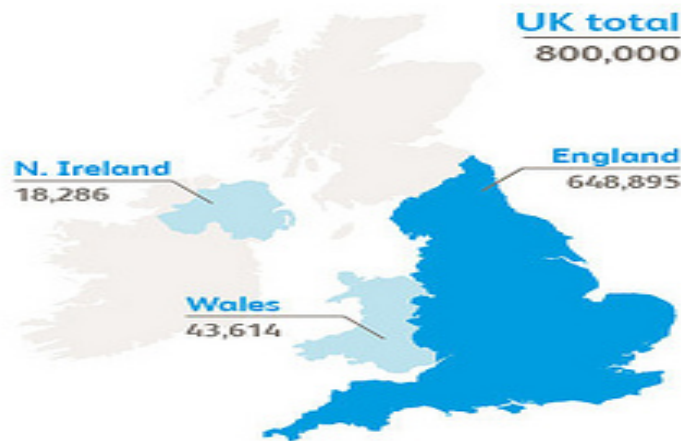




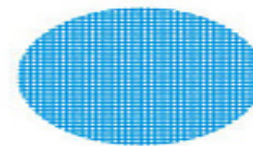
- Throughout the day you have been talking to various people, making eye contact with fellow attendees.
- How many will suffer from Dementia?

### The size of the challenge

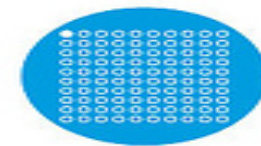
The breakdown of the population with dementia across the UK.



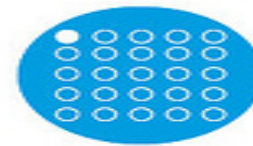
Dementia is most common in older people but younger people (under 65) can get it too.



40-64 years  
1 in 1,400



65-69 years  
1 in 100



70-79 years  
1 in 25



80+ years  
1 in 6



Two thirds of people with dementia are women



One in three people over 65 will develop dementia

# Barriers

- No word for dementia
- Lower levels of awareness about dementia
- Language
- The ability to speak English may be lost if it is a second or additional language as some people may revert back to their first language
- The use of family interpreter may breach confidentiality and cause conflict of interest issues
- Existence of stigma within BME communities



# Continued...



- Some assessment tools might not be suitable
- Carers of Bme people with dementia may feel reluctant to ask for help
- Life history of someone from Bme background – earlier life in a different country and culture
- Staff working in dementia services not trained to give culturally acceptable care and support to Bme people

This disease actually never existed in our community. Nobody would think that this is a health problem. People in my community would say that the person has gone mad or lost his mind.

(Pakistani carer, Ethnos research )

My son lives in Buckinghamshire. He has his own family and can't live with us. He is very nice and caring and comes with us to all hospital appointments.

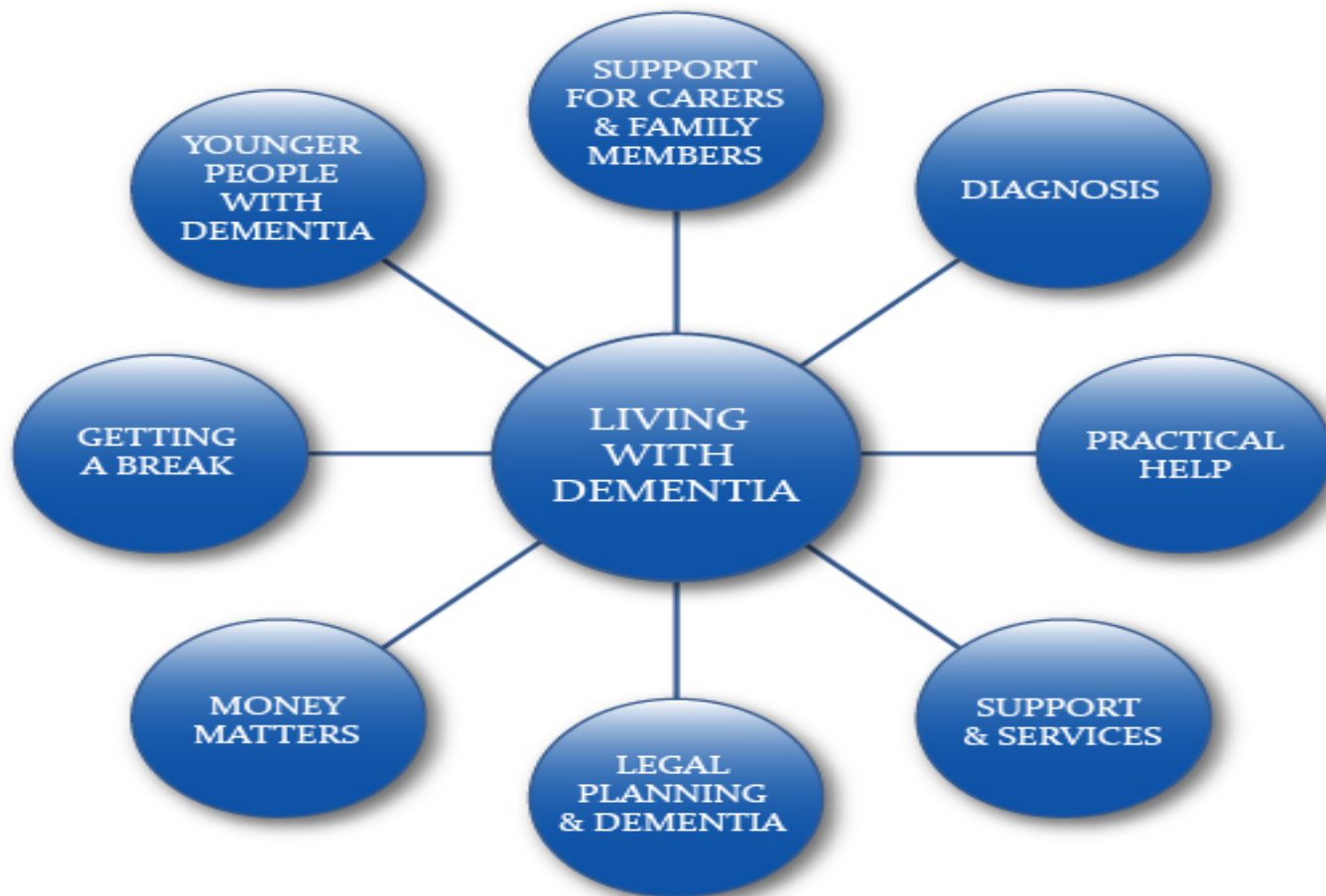
(Indian carer)

People come from villages outside Hong Kong, Taiwan or Malaysia. Back home everyone lived in one big house. But here that is not possible. If you have started your own family then it's hard to support older people.

(Chinese service provider)

I finally decided to call the social worker for help. She asked me why I didn't have family to help because Indian people always have relatives. She asked me so many questions that I felt guilty and put the phone down.

(Indian carer, Ethnos research)



# What is a dementia café?



- A memory café is an 'open' event that is free to attend and is designed for carers and the person with dementia to meet others in the same situation.
- It is a relaxed and fun place to talk and share memories.
- It promotes empowerment and unlocks potential.
- Provides a safe environment to ask questions, gather information and express thoughts and feelings.
- Helps to support transition.
- It is a community lead initiative which promotes social interaction and combats isolation.

# Dementia Cafes in Leeds



- Around 17 Dementia cafes in Leeds
- Share fears and concerns about dementia
- Providing help and support
- Information on local services available for people with dementia and their families
- Help tackle the loneliness that often comes with the illness

# Our Story – Hamari Yaadain



- Started about 3 years ago after consultation with Bme communities
- Need for a café for South Asian people
- Meets cultural and religious needs of attendees
- Limited funding from Peer Support, Adult Social Care
- Venue- Touchstone premises (free)
- Referrals – self-referrals, communities, awareness talks, memory services, General Practitioners, Social/support Workers.





# Criteria



- Free admission
- £1 contribution from attendees towards drinks and cakes
- Monthly/ at least 10 times a year
- Avoid cancelling two meetings in a row
- Emphasis on emotional and psychosocial aspects
- A variety of professional visits, e.g Telecare
- Involvement of local Alzheimer's society branch involvement
- If there are no people with dementia, it is not 'real' dementia cafe

# What are we trying to do



- Develop support circle for members
- Provide language support in Hindi, Punjabi and Urdu
- Share experiences, knowledge and information
- Carers get advice, support and breaks
- Encourage/help people with dementia to live independently with any support needed.

# How we do it?

- Members meet up first Thursday of every month over cup of tea and nice cakes
- Dietary needs due to health or religion are kept in mind while ordering cakes or any food for the members. e.g both eggless cakes and cakes with eggs are ordered
- Two workers runs the café in mother tongue of Hindi, Punjabi and Urdu
- Simple, non-judgemental and empathetic approach
- Members share same interests as they come from same cultural background
- Carers attends the café too unlike other Day centres and activities
- Important to build up trust within minority communities and push them little bit to attend services.
- Cultural and religious understanding of people.
- Reminiscing activities/discussions proves helpful

# Case Studies

- Mr S was diagnosed with Alzheimer's disease seven years ago. His wife, Mrs S, didn't want to leave him alone for long, but she really needed a break from caring. They were both in their late-seventies.
- Mr K was offered a place at the local day centre, but he didn't want to go and Mrs S was worried about getting him there and back. Mrs S enjoys socialising and had enjoyed going to a local women group and meeting with her friends, but hadn't been able to go for months because of caring for her husband.
- When Mrs S called us, I did their assessment and arranged for a sitter to come to the house to be with Mr S in the afternoons, so Mrs S could go to her group. The sitter also supported Mr S to do things he liked to do – take the dog for a walk, or work in the garden.

It proves that people can

**Live Well With Dementia**



# Continued..

- **Key messages for practice**
- Encouraging and facilitating the involvement of people with dementia in planning services is an important aspect.
- Participation in service development may help the person with dementia to feel that they have something worthwhile to contribute and a useful role to play following diagnosis.
- If commissioners hear and respond to the views of people with dementia they may develop services that make a difference and offer value for money.
- Commissioners, support organisations and carers all have a role to play in facilitating and enabling the participation of people with dementia.
- Practical tools, individual support and reminders and reassurance are all essential if people with dementia are to participate effectively and benefit personally.

## The Challenge:

- M is a 84 years old widow with dementia who has lived in Leeds since she got married and moved from India.
- Lives alone and has two sons who are settled with their own families.
- She regularly becomes disoriented, not knowing what time it is or where she is.
- M leaves her house in the early hours of the morning to go to the shops despite the fact that they are not open.
- M attends day centre 4 times a week and has two visits per week for bathing.
- She receives meals on wheels but often tries to cook food in her microwave without assistance which concerns her family.
- M told her sons that she would like to remain living in her own home for as long as possible.

## ■ The solution:

The telecare package installed included:

- Lifeline 400
- Personal pendant
- Property exit sensor
- Smoke detector
- Extreme temperature detector



## ■ The Outcome :

- Son's are assured knowing that they will be alerted
- can continue living independently at home
- improved quality of life

# Dementia Does Not Discriminate



**Thank you  
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