



# Caring for dementia in BAME communities



Dementia  
Dekh  
Bhaal

**tide**<sup>TM</sup>  
together in dementia everyday

# What are the concerns?

Black Asian Minority Ethnic (BAME) communities are several different communities with their own identities and characteristics. Therefore, they are not the same, and there is no one set approach to supporting their needs.

There is no generally accepted word for 'dementia' in the various BAME communities in the UK. Therefore, not recognising dementia, they tend to be less aware of the symptoms and behaviours associated with it. This results in late access to support, a delay in acquiring information, general crisis by the time carers seek health or social care intervention.

The stigma amongst BAME communities further impacts carers in getting care in how they can cope with dementia care.



## 1. Impact on person living with dementia

- Confusion and upset not knowing why they are finding difficulties with everyday tasks or remembering well-known names and words
- Delay in getting professional support in understanding dementia and its effects
- Further isolation due to feeling isolated, especially where dementia is seen to be a mental illness, black magic or jinn possession.



## 2. Impact on family carers

- Misunderstanding and frustration not knowing why the family member is behaving difficult or 'different'
- Confusion regarding changes in behaviour or attitude of the person with dementia
- Delay in getting support with any assessments or medical intervention
- Delay in getting support with support for carers or a carer assessment to help them understand and cope with the progression of dementia
- Face stigma and challenges from relatives and the wider community.

# Dementia in BAME communities

Currently, there are approximately 20-25,000 BAME people living with dementia in the UK. This number is projected to increase by seven to eightfold in the next few decades. This will also mean that the number of BAME dementia carers will also increase.

The combined impact of not having a word for dementia, not recognising symptoms and behaviours will mean cares may already be managing complex health issues without being aware of the added complexities of dementia.

Community and faith-based interventions may be favoured, but the stigma will mean that they are not able to seek support from known agencies.



## 3. Impact on communities

- Lack of awareness of dementia will mean less likely to offer peer-led or community-based support for individuals living with or caring for dementia
- Stigma will further isolate and alienate knowledge and awareness of dementia
- Lack of awareness will restrict the development of culturally competent, community-based services.



## 4. Impact on services

- BAME people with dementia or their carers not asking for help will reinforce staff unconscious bias - especially that they look after their own
- Carers struggling to cope will have an impact on employment - more absence days
- Costly crisis care
- Lack of development of culturally competent/appropriate care

Dementia Dekh Bhaal, meaning 'caring for dementia', has been a Tide project (Together in dementia everyday) by Shahid Mohammed. Shahid's experience as a former carer and his expertise in community engagement has meant that Tide has championed the work of BAME care needs. Supporting carers with awareness, learning, and advocacy, Dementia Dekh Bhaal has brought together dementia carers from across the UK to strengthen BAME dementia carers' voices.

For further information on how we can support BAME people living with dementia, BAME carers of a relative living with dementia or organisations wanting to help dementia care in the BAME communities, please contact Shahid Mohammed on:

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<https://www.tide.uk.net/dementia-dekh-baal-evaluation-report/>