



Executive summary

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## Art and dementia in the UK South Asian Diaspora

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*Elizabeth Lynch with Spare Tyre*

## **Executive summary: Art and dementia in the UK South Asian Diaspora**

*By Elizabeth Lynch with Spare Tyre*

### **About Spare Tyre**

Spare Tyre is a leading participatory theatre company producing multisensory, accessible and inclusive work. For 25 years they have created theatre for, with and by older people aged 60 plus and for eight years they have focused projects on people living with dementias. Their interactive and non-verbal flagship show *The Garden* targets audiences at the later stages of dementia and has been highly acclaimed across the UK.

### **About the Baring Foundation**

The Baring Foundation is an independent foundation which protects and advances human rights and promotes inclusion. Since 2010, the Foundation's arts programme has focused on supporting participatory arts with people over the age of 60, particularly those facing disadvantage or discrimination.

**Cover image: Women's group at the Highfields Centre in Leicester.**

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# Art and dementia in the UK South Asian Diaspora

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## EXECUTIVE SUMMARY

There is growing awareness of the intrinsic and therapeutic value of artistic work for people living with dementia and provision for them by arts organisations has expanded. However, this has not reached the South Asian communities spoken to in this research in any significant way.

Performances of Spare Tyre's dementia-inclusive show, *The Garden*, in selected South Asian care homes were successful as managers saw the show's positive impact on residents and relatives.

The number of older BAME people living with dementia is growing. There are important roles for funders, arts organisations and artists to engage with South Asian communities to ensure the benefits of the arts are more widely shared.

## BACKGROUND AND CONTEXT FOR THIS RESEARCH

Spare Tyre's interactive and non-verbal flagship show *The Garden* targets audiences at the later stages of dementia and has been highly acclaimed across the UK. However, despite the inclusive nature of *The Garden*, the company have been acutely aware that the UK South Asian diaspora community has not significantly engaged with theatre, arts and dementia.

Spare Tyre are now asking why not?

They are aware of some dedicated residential South Asian care homes that offer dementia care that is culturally specific in terms of faith – Hindu, Muslim and Sikh. They also know that most South Asians living with dementias are living at home, with some accessing South Asian day care services or within a culturally diverse service that often does not meet cultural or religious needs.

South Asian is a broad term for many different communities and Spare Tyre are aware of and sensitive to language, cultural attitudes, behaviours and faith. This report

specifically talks about engaging communities from the Indian, Pakistani, Bangladeshi and Sri Lankan diaspora.

This research was supported by Baring Foundation and is limited to the UK South Asian Diaspora as a first step to researching with care the 25,000 BAME people living with dementias in the UK.

*The Garden*'s Director, Arti Prashar, wanted to know about the reasons for the lack of engagement with artistic work when the wider society has opened up to creative interventions.

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### This research asks:

- Is stigma attached to dementia within the South Asian communities?
- Can Spare Tyre use their multi-art form artistic practice to dismantle this stigma by offering creative workshops and engaging artistic experiences for people living with dementias, their families and carers?
- How culturally specific does an arts project need to be for an ageing South Asian population to take part?

During March – June 2019 we interviewed 123 people in eight South Asian community groups and eight individuals working professionally in the dementia field. For context and specific data and commentary on dementias in UK South Asian communities, reading included online material and a range of reports, written between 2009-2018, and literature on artistic work with people living with dementias, e.g. funded by Baring Foundation, Arts Council England, Wellcome Trust and others. In addition, the researchers attended several conferences, symposia and seminars on dementias, health and wellbeing, and spoke to arts and community colleagues working with older people. Spare Tyre performed *The Garden* in five specialist South Asian Care Homes for residents and families.

Whilst material was found on stigma, ethnicity and culture in government, academic and other literature, there was no mention of artistic work with South Asian communities. In contrast, artistic work for people living with dementias has been well documented and is advocated as beneficial for both therapeutic and intrinsically valuable reasons, notably in the All Party Parliamentary Group Inquiry on Arts, Health and Wellbeing, 2017. However, this artistic practice, as Spare Tyre had observed, has not reached the communities we spoke to in any significant way.

*“Artistic practice with people living with dementias has not reached the communities we spoke to in any significant way.”*

## FINDINGS

### Dementia, stigma and culture

The findings from our conversations with the groups and dementia professionals supported our literature review. BAME people living with dementia and their carers face difficulty in accessing services and often access services later. Choice in care and support services is limited due to lower levels of awareness about dementia and higher levels of stigma. The communities have different expectations about care and services.

Service providers have often stereotyped BAME communities in terms of ‘they look after their own’. Services are generally not culturally appropriate. In South Asian languages there is no word for dementia, which makes framing and describing the disease difficult. Not planning for the specific needs of BAME communities with dementia can lead to their marginalisation but narrowly focusing on the distinctiveness of their needs can also create exclusion.

In addition to these findings we observed that the knowledge gained from the lived experiences of South Asian families, especially women who take the main responsibility for caring in the home, is a valuable resource for their peers and for professional and volunteer dementia services. Their voices are underrepresented and greater efforts should be made to reach out and engage with them by dementia service providers and artists/arts organisations working in this field.

*“The women really wanted to add their voices to those that are normally heard and seen... Once you are able to access those communities we shouldn't be surprised that they have a lot to say.”*

Dementia care professional

Stigma around dementias continues to be prevalent although there are indications that this is starting to shift, especially where targeted health outreach is being undertaken and where GPs are providing good information and signposting support.

Grassroots cultural and community organisations can play a vital role for under-served groups by facilitating access to services and raising awareness of dementia care and support. These groups are often operating with slender resources and have part-time and/or voluntary staff.

The main barriers to taking the initiative to engage with mainstream services or being aware of what is on offer are social isolation, language/communication and trust. These factors are also cited across the specialist literature and the cultural reasons are covered in some detail.



Faith institutions can play a significant role in addressing issues around stigma and dementia and in promoting access to services and support for dementias. They are often important social hubs. Silence by faith leaders on mental health and dementias can contribute to the maintenance of stigma.

### The role of the arts

Spare Tyre's offer to discuss stigma, dementias, arts and culture was swiftly accepted by the eight groups we contacted. Three of these groups booked follow up workshops to co-create content for Spare Tyre's new show *Love Unspoken*, which will tour to theatres from Autumn 2019. This new interactive, multi-sensory performance will respond to the research findings and reflect the cultural specificity required to engage an ageing South Asian population in a meaningful way.

*“Maybe when people know that music is like medicine then their perception of it will change. Music is medicine, we know this. Even if it is religious music, it is still there.”*

**Broadcaster working with dementia**

All the groups described arts and creative activity as part of their cultural landscape. This varied depending on the faith, social and regional backgrounds of the individuals. Examples given included music – both religious and secular, film and photography, dance, folk arts, food and celebrations to mark festivals and weddings. Content created for artistic activity will need to take into account this cultural diversity in terms of art forms and genres. However there are many artistic and cultural references that are shared between the older generations across the diaspora communities.

*“The perceived risk of booking *The Garden* transformed to revelation as care home managers saw the show's positive impact on residents and relatives.”*

Spare Tyre's persistence in reaching out to South Asian care homes was ultimately fruitful. The perceived risk of booking *The Garden* was transformed to revelation as the care home managers saw the show's positive impact on residents and relatives and the opportunity for follow-up professional development for their care staff. Being able to talk about specific cultural content, as is planned for *Love Unspoken*, will make a difference for future approaches to these care homes and encourage other artists to consider a similar approach to making inclusive work.

*“I thought to myself, why not try something new just once in our lives.”*

**Staff member, Bhakti Shyama Care Home, Balham**

None of the literature on dementias and the BAME communities mentioned the role arts could play as part of a cultural offer either to engage South Asian communities with information about dementia or to bring enjoyable, inspiring and uplifting experiences to people living with dementias, families and carers. It is hoped that this research and the inspiring model of practice that *Love Unspoken* can shift thinking within South Asian diaspora communities, the services they encounter and the professionals and agencies who work with them.

The qualities, knowledge and insights of Spare Tyre enable their understanding of the creative tension between linking the essential, culturally specific elements to fresh innovative approaches that are respectful of cultural etiquettes. The performers are skilled at understanding the smallest, slightest responses from people living with dementias, often with other complex physical conditions. Through non-verbal communication they can respond in the moment. For carers, family members and loved ones with a dementia, taking part together is something that makes their lives more enjoyable.

## RECOMMENDATIONS

The value and role of arts and creativity in health and wellbeing is now widely recognised. National and local arts organisations and individual artists offer a wide range of artistic experiences for people living with dementias,

some of which includes activity that specifically supports physical and mental health and wellbeing. The benefits of artistic activity have been recognised at government level.

### 01

**Strategic private funders, Arts Council England and Care Commissioning Groups** need to work better with the Alzheimer's Society, Age UK and similar organisations to connect with BAME communities in order to

consult, engage and share the opportunities and the benefits the arts can bring to the dementia care landscape. Social Prescribing<sup>1</sup> is one avenue to pursue but can only be part of the wider approach.

### 02

**Arts, culture and heritage organisations** could direct critical attention and resources to ensure that their programme strategies reach out to, invite and welcome BAME people living with dementias. If South Asian communities are not

engaging with your offer for elders, consult with grass roots community groups to find out what could make a difference. How could the cross-sector system come up with the best ideas?

### 03

The researchers urge **all artists interested in arts, community, justice and inclusion:**

– to engage with South Asian communities at a local level

– to encourage South Asian artists from the UK diaspora to bring their artistic and cultural sensibilities and language skills to the table for this generation of elders and the next

– to change the stories we tell about dementias involving the people who are living them.

**The full report is available at [www.baringfoundation.org.uk/resource/art-and-dementia-in-the-uk-south-asian-diaspora](http://www.baringfoundation.org.uk/resource/art-and-dementia-in-the-uk-south-asian-diaspora)**

<sup>1</sup> Health Secretary Matt Hancock pushed the arts up the health policy agenda in 2018 by announcing £4.5m investment in GP Social Prescribing. Social prescribing is a non-clinical intervention in someone's life that should enable improved health and wellbeing. It's not like medical or surgical treatment. It can be any activity that a person enjoys that supports their ability to manage their health – from sport and walking to painting and dance to volunteering.



**Rehearsal for Love Unspoken.**

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