

In this blog, Commission Member Jabeer Butt, considers the experience of dementia for Black, Asian and minority ethnic communities.

In a conversation that followed the birth of her latest grandchild, my mother said she did not really like babies. We responded: “but Mum you’ve had six babies!” My mother replied that she loved children once they were walking and talking, it was just babies. As more grandchildren arrived we saw the pleasure she got from spending endless hours with them; whether on a walk, helping them to ride a new bike, playing football in the playground behind her house, or demanding her immediate attention while she was trying to cook a meal for 20. But first, after a stroke, and then the onset of vascular dementia, the joy of the everyday became more infrequent and was replaced by the gradual loss of control. It was also replaced with ever more challenging care needs, soon beyond the ability of the family and requiring regular professional carers.

Unfortunately, these carers changed regularly. Sometimes they moved on because we were unhappy. But often it was because the carers had moved to a new agency or had secured a new job and were leaving caring. The best of them seemed to understand what was important to my mother, even though she had long lost her speech. If tasked with getting her ready, they would ensure her salwar kameez was immaculately ironed and carefully put on, making sure that this woman, who was always elegantly dressed, would once again be able to share celebrations, such as Eid, in the manner that she did in the past.

The experience of dementia and of caring for someone with dementia, whilst a comparatively new experience for Black, Asian and minority ethnic communities, is becoming a more common one. There has been a significant rise in numbers of Black, Asian and minority ethnic older people, from less than 40,000 in the 1990s to a projected 140,000+ by 2020, reaching the age range where the risk of developing dementia rises significantly. Furthermore, there is some evidence that in the case of vascular dementia, some minority communities may be at risk at earlier ages. How well individuals, families and communities respond to these new challenges will inevitably be impacted by how well care services respond too. The increasing evidence of tighter eligibility criteria, poor terms and conditions for staff and the financial crisis faced by adult social care, does not bode well. But my hope is that we are able to improve current care provision, so that all can still experience the joy of the everyday.

Jabeer Butt OBE, is a Member of the Archbishops’ Commission on Reimagining Care and is Chief Executive of the Race Equality Foundation. He is writing in his personal capacity and his views do not necessarily represent the views of the Archbishops' or the Church of England.

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