

# Travellers struggle to cope with family dementia

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Gypsies and Travellers struggle to cope with dementia in family members, and are often in denial about a loved-one's condition or try to hide it, a new research report has found.

The report, "[Saying it as it is: Experiences of Gypsies and Travellers caring for family members with dementia](#)," features in-depth interviews with Gypsy and Traveller families in Derbyshire and the East of England about their experiences of caring for [family members](#) with dementia. It was compiled by researchers from Anglia Ruskin University (ARU), One Voice 4 Travellers, and the Derbyshire Gypsy Liaison Group.

The report found that while many of the carers interviewed had noticed that a [family](#) member was having problems with their memory, in some cases it took a dramatic incident, such as a fire in the home, for them to realise there was a serious issue.

Many carers indicated there was a reluctance by the person living with dementia to seek a diagnosis, due to the stigma related to dementia and a fear they might be removed from their family. None of the carers reported that the person they were caring for had been formally assessed.

Carers also mentioned the cultural importance in their communities of traditional gender roles, and being responsible for older members of the family, which was difficult when those carers also other duties, for example young children to look after.

Most people interviewed for the report were living in a trailer, and it was noted that those on the road sometimes lacked basic facilities or a suitable stopping place. Some had given up their nomadic traditions to move into housing to look after a relative with dementia.

For the carers interviewed in the report, moving their relative into a nursing home was only considered as a very last resort, when their behaviour had become so challenging that family care was no longer possible.

One carer, Sally, said: "My husband got very violent and I am not getting

any younger myself, I just couldn't look after him any longer. So we all, my daughter and my family, decided that we were going to put him in a care home. We didn't like to because, we people, we don't do that sort of thing, but it was getting more and more, he'd wander off, then the police used to fetch him back it was just terrible. It broke my heart to do it."

The 2011 census suggested there were around 58,000 Gypsy and Traveller people living in the UK, although this is believed to be an undercount as many people hide their identities due to discrimination.

Dr. Pauline Lane, Reader in Mental Health at ARU, said:

"It was clear from our interviews that dementia in the family presents significant challenges for Gypsy and Traveller people, where family is absolutely central to their traditional way of life. It is vital that these challenges are understood so suitable care can be made available and barriers can be broken down."

Dr. Siobhan Spencer MBE, Co-ordinator for the Derbyshire Gypsy Liaison Group and Visiting Research Fellow at ARU, said:

"Very little is known about Gypsy and Traveller people as carers, and even less about their experiences of caring for family with [dementia](#). Health and social care provision is often based on research evidence and, consequently, the needs of ethnic minorities are often neglected in service design and delivery.

"Therefore, this report is timely, as it helps to 'give a voice' to the experiences of Gypsy and Traveller carers, and we hope that this study will help service providers and commissioners to develop more culturally sensitive services that are responsive to their needs."

Provided by Anglia Ruskin University

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