



SAYING it as it is

Experiences of Gypsies and
Travellers caring for family
members living with dementia

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*'It would be a good thing
for them to know, it's not
only the people in houses
that gets this kind of
disease'*

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Executive Summary

Background to the study

Dementia is an issue of global concern with an estimated 50 million people living with dementia worldwide, and an estimated 920,000 people living with the condition in the UK (World Health Organisation, 2020, Wittenberg et. al. 2019). It has also been estimated that there are over 25,000 people from ethnic minority communities living with dementia in England and Wales (Parliamentary Offices of Science and Technology 2018). Research also indicates that the number of people from ethnic minority communities living with dementia will increase in the future (Koffman, 2018) and therefore 'taking action now to get appropriate services and support in place will help to ensure people can access the support they need' (All Party Parliamentary Groups on Dementia, 2013, p. 11). As ethnic minorities, Gypsies (and Travellers) have been recognised as one of the most marginalised ethnic groups in the United Kingdom (Women and Equalities Committee, 2019) and data on their health and social care needs is sparse. Currently there is no national data on the numbers of Gypsies and Travellers living with dementia (Tilki, 2016) and very little known about the experiences of Gypsy and Traveller carers. Therefore this report is timely, as it helps to 'give a voice' to the experiences of Gypsies and Travellers who are caring for family members living with dementia. We hope that this study will help service providers and commissioners to develop more culturally sensitive and inclusive dementia services.

Research methods

We conducted eleven in-depth, semi-structured interviews with carers in the East of England and Derbyshire living in their trailers (caravans) and houses. The study was developed in partnership with researchers from the

Derbyshire Gypsy Liaison Group, One Voice 4 Travellers (in East Anglia) and researchers from Anglia Ruskin University. We are indebted to the eleven carers who kindly shared their experiences of supporting family members who were living with dementia, and we are grateful to Anglia Ruskin University for funding the study.

Key findings

Recognising dementia:

The early symptoms of dementia can be difficult to recognise and our research found that while many of the carers had noticed that a family member was having problems with their memory, sometimes it was a dramatic incident (such as a home fire) that signalled that there was a serious issue. Several of the carers indicated that there was reluctance by the person living with dementia to get a diagnosis and none of the carers reported that the person being cared for had been formally assessed. This was due to a number of factors, including stigma related to dementia and fear that relatives might be removed from the family.

Everyday life as a carer

Most of the carers suggested that there was a cultural expectation that the family should be responsible for older family members and they were willing to offer support although some of the carers were also looking after children and other relatives, and clearly this was challenging. It was evident that as the condition progressed, that carers needed to play an increasing role in the lives of the person with dementia and this was often stressful. Carers described situations where they were concerned for the safety of the person (due to them wandering off in the

night, forgetting to eat, starting fires etc.) as well as the risk to themselves or others, (when the person they were caring for became violent towards them.)

Changing gender roles

In traditional Gypsy and Traveller families, caring and responsibility for the home is often undertaken by women, and many of the carers in our study were women. However, our research also found that men were primary carers and even when women were the main carers, many of the younger men in the family also offered care and support to the person living with dementia.

Dementia care in a trailer

The majority of carers who took part in this study, were, or had been, living in a trailer. It was interesting to note that living in a trailer in itself did not present a barrier to offering care to someone with dementia. However, the location of trailer did present challenges, for example, not all of the carers had access to an authorised stopping place, and not all of the carers had access to basic facilities, such as hot water. Some carers also told us how they had to give up their traditional nomadic life and move into housing, in order to support a family member living with dementia. However, the carers who were living on permanent trailer sites (with access to facilities), stated that they found that trailer life continued to offer good accommodation, as the family worked together to offer care and support for the person with dementia.

External/professional support and inappropriate care by external agencies

There seemed to be a cultural expectation that the families should manage without support from outsiders although the carers who were looking after someone with advanced

dementia, often recognised that they did need additional, external support. However, one of the significant findings from our research was that often the external support offered to Gypsy and Traveller families by health and social care services, was frequently culturally inappropriate- especially in relation to personal care needs (i.e. washing, toileting etc.). This often resulted in the family rejecting any further external care, even though they needed additional support.

Carers coping with challenging behaviour

Unfortunately, dementia inevitably results in behavioural changes and this can be a major source of distress for carers. Our research found that in the advanced stages of dementia, some of the carers were experiencing violence from the person they were caring for, these experiences ranged from them damaging objects, to more extreme physical violence. In some instances, the aggression and violence towards the family carers had escalated to the point where the family were no longer able to manage, and they were forced to look for nursing care.

Making the decision to move a loved one into a care home

Clearly the decision to move a loved one into a care home is a difficult decision for anyone. Our findings indicated that families supporting people in the early stage of dementia did not seem to envisage that they would move their loved ones into care. Our research suggests that families only took this decision when as the illness had progressed into the advantaged stages of dementia, and they were no longer able to cope. For some Gypsy and Traveller families, this was a collective decision, although one carer described how this decision had to be made without the agreement of the wider family, and clearly this was painful.

Part One: Background to the study

1.1 Rationale and aims of the study

There are an estimated 885,000 people living with dementia in the UK (Wittenburgh et al. 2019). Of these, 25,000 come from ethnic minority communities and with the ageing population, this number is increasing (All Party Parliamentary Group, 2013). However, despite the numbers of people from ethnic minority communities living with dementia, their needs are often not recognised in service development and they are often “invisible” within dementia research (Jeraj and Butt, 2018, Whitman, 2019). The absence of ethnic minorities from research is important, because 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 (Alzheimer Europe, 2018). However, while Gypsies and Travellers have been recognised as one of the most marginalised ethnic minorities in the United Kingdom (Women and Equalities Committee, 2019), there is a distinct lack of primary research on dementia and the needs of Gypsy and Traveller carers. 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 the needs of Gypsies and Travellers living with dementia and their carers.

Aim of the study

One of the most important aims of this study is to increase the understanding of some of the challenges that Gypsy and Traveller carers experience when caring for loved ones who are living with dementia. However, we also wanted to

- Identify some of the cultural barriers that

Gypsy and Traveller carers experience in accessing dementia support services.

- To highlight some of the family strategies used to offer support to loved ones living with dementia.
- To identify some of the pressures and concerns that carers face when trying to offer care and support to loved ones living with dementia.
- To make recommendations to health care professionals, commissioners, service providers and policy makers on how to make dementia services more accessible and culturally appropriate to carers and their families

1.2. What do we know about Gypsies in the UK?

Romany Gypsies were first recorded in Scotland in the 15th century (Dawson, 2005) and linguistic and genetic evidence has confirmed that they originated from India and migrated across Europe (Mendizabal, et al. 2012). Historically, the word ‘Gypsy’ originated from the mistaken belief that they originated from Egypt, or the Middle East and therefore families were often referred to as ‘Egyptians’ – later to become known as Gypsies. Today the word Gypsy is used to describe Romany Gypsies (spelt with a capital ‘G’). In England, Romany Gypsies have been legally recognised as a distinct ethnic group since the 1989 and Irish Travellers were accorded this status in 2000. Consequently, Gypsies and Travellers hold protected characteristics under the UK Equality Act (2010) meaning they are legally protected against racial discrimination. However, despite equality legislation, they have



been identified as being amongst the most disadvantaged ethnic minority groups in British society (the Equality and Human Rights Commission, 2018) and many Gypsies and Travellers will have faced a lifetime of poverty, social exclusion and discrimination (Cabinet Office Race Disparity Audit, 2018, United Nations Special Rapporteur, 2018).

Demographics

It is difficult to know exactly how many Gypsies and Travellers live in the UK, as many people hide their identity due to discrimination (Equality and Human Rights Commission, 2016). The last national census suggested that there were 58,000 Gypsies and Travellers living in England and Wales (ONS, 2011), however, this is believed to be a significant undercount, and other reports have estimated that there are over 300,000 Gypsies and Travellers living in the UK (Friends Families and Travellers, 2020). Gypsies and Travellers are usually considered to be 'young communities,' with only 6% of the community living beyond 65 years (ONS, 2011), which may in part, explain why there has been such limited research on the needs of older Gypsies and Travellers and more specifically, on the needs of carers supporting family members who are living with dementia.

Discrimination

Several governmental reports have highlighted that Gypsies and Travellers are often subjected to extreme prejudice, and often experience assault and hate crime (Cabinet Office Race Disparity Audit, 2018, United Nations Special Rapporteur, 2018). Indeed, a number of authors have stated that discrimination against Gypsy Traveller and Roma communities remains the last bastion of 'acceptable' racism in Britain (The Traveller Movement, 2017, Hutchinson and Chihade et al. 2018).

Accommodation

Although the majority of the community live in housing (Smith and Greenfields, 2013, Office for National Statistics, 2011) many Gypsies and Travellers continue to follow a traditional nomadic life. For centuries nomadic Gypsies have been permitted to use 'common land' as lawful stopping places to rest their horses, find local employment, and meet up with family and friends. However, successive governments have removed their access to these spaces and today they face a serious lack of authorised stopping places and permanent sites (Cottle et al, 2019, Richardson, 2020). Consequently, many Gypsies and Travellers are forced into stopping on unsafe and unsuitable land and face constant evictions. This often places families under considerable mental and physical stress (Lau and Ridge, 2011, Lane and Spencer, 2019) and clearly this has important implications for carers of people living with dementia. Interestingly, research suggest that the likelihood of living in a trailer generally increases with age (Centre for Policy on Ageing, 2016) which may indicate that many carers who are looking after family who are living with dementia, are potentially living on the road. However the age structure of Gypsy and Traveller residents living on permanent Local Authority trailer sites tends to be older too, so this also could be part of the explanation for the number of the ageing population living in trailers.

Authorised trailer sites

However, although many nomadic Gypsies and Travellers live on authorised trailer sites, often these are not fit for purpose and research indicates that they are frequently built on contaminated land, or are close to motorways or other land that is unsuitable and often unfit for human habitation (Equalities and Human Rights Commission, 2013; Richardson, 2007, Scottish Parliament, 2013). Indeed, community members often report that they are frequently forced to live in conditions that would not be tolerated for any other sections of society (Lane, Spencer and Jones 2014).

Changes to the planning definition of being a Gypsy

In response to poor quality sites and a lack of places to stop, some families choose to buy land and apply for planning permission to station their trailers /caravans. However, planning permission is frequently denied to Gypsies and Travellers and statistics cited by the European Court found that 90% of planning applications made by Gypsies had been refused, whereas 80% of all other (non-Gypsy) planning applications had been granted¹ (Willers, Johnson 2020). In recent years, changes to the planning laws (Planning Policy for Traveller Sites, 2015) has also meant that the definition of who might be considered as Gypsies or Travellers for planning purposes has changed² as families must now 'prove' that they are nomadic by searching for work. As Richardson (2020) suggests, these changes to the planning laws have created an impossible conundrum for Gypsies and Travellers, who are required to travel in order to prove their 'Gypsy status', but they are prevented from travelling because there is nowhere to stop. Significantly, these planning laws are having a very damaging effect upon the most vulnerable members of these communities because Gypsies and Travellers who can no longer travel (due to situations such as ill-health, old age, or because they are caring for people who can no longer travel) are

struggling with the bias in the planning application processes.

Gypsy cultural and social practices

Similar to other ethnic groups, Gypsy families often share many cultural practices and beliefs and although many Gypsies and Travellers are not literate (though less so among younger generations), they have their own languages Romany (Gypsy) and Shelta (Irish Traveller) and both have a strong oral tradition to share their culture and values. Nomadism has traditionally been a defining feature of Gypsy and Traveller life, not only as a way to find employment but also as a process involving the creation of memories through the landscape and times shared with family and friends, and a cultural way of life (Shubin and Swanson, 2010). Moreover, in many families, nomadic values often continue to inform Gypsy and Traveller people's beliefs and practices even when living in housing (Lane and Spencer, 2019). For many Gypsies and Travellers, the family is a source of pride and support and older family members are usually respected and supported by the extended family (Lane, Spencer and McCready 2012). Gypsies, and especially older people, often hold strong cultural beliefs about modesty and hygiene and this influences many of their daily activities and practices (Spencer, 2009). These cultural practices are important when thinking about providing health and social care and as this research report illustrates, many care providers seem to be insensitive to Gypsy and Traveller cultural needs when delivering dementia support services.



Health

Research suggests that Gypsies and Irish Travellers are more likely to suffer poorer health than the general population this includes lower life expectancy, high infant mortality rates, high maternal mortality rates, higher prevalence of anxiety and depression, chronic coughs, asthma, chest pain and diabetes (Equality and Human Rights Commission, 2016, Women's Equality Commission, 2019). Analysis of data from the 2011 census also highlighted that Gypsies and Travellers were more likely to report a long-term health problem or disability, despite their younger age profile, than the general population (28% compared to 20%). Similarly, they were also reported to be more likely to be limited by a long-term health problem or disability, than the general population (Office for National Statistics, 2011). Yet despite these challenges, research suggests that many nomadic Gypsies and Travellers find they are often prevented from registering with a GP surgery (Traveller Movement, 2017). Clearly, this is significant not only for routine health care and screening, but also when families need to access support for loved ones who are living with dementia.

1.3. Thinking about dementia

What is dementia?

The word dementia is often used as a generalised term to describe a range of symptoms that can be caused by a number of different brain diseases, with Alzheimer disease being recognised as the most common form of dementia, contributing to 60–70% of cases world-wide (World Health Organization 2020). Although there is a strong link between ageing and dementia, it is not an inevitable consequence of ageing and it does not exclusively affect older people. An individual's risk of developing dementia is made up of different factors such as age, genetics and lifestyle, although current research indicates that heart disease, diabetes, high blood pressure, obesity, a lack of physical activity and



smoking may put people at more risk of developing dementia (Livingstone et al. 2017). Unfortunately, dementia is a degenerative illness, and as the condition progresses people become increasingly frail, experiencing a decline in memory, thinking, language and judgement and this interferes with their ability to conduct normal daily activities (World Health Organisation, 2017). In the advanced stages of dementia, it is common for people to exhibit significant changes in behaviour and often this is challenging, especially when aggression or physical violence is inflicted upon caregivers (Wharton and Ford, 2014, Alzheimer Research UK, 2018).

Person-centred care

Although the medical model has defined much of the debate concerning dementia, Tom Kitwood (1997) has been a pioneer in the field of dementia care as he promoted the idea of 'person-centred care' that focused on the needs of the individual and their relationships with others, as well as the environment that they are living in. Significantly, Kitwood (1998) also highlighted the significant role of carers, not only in responding to the person's physical care needs but also in their role in helping to maintain the story of the person's life and identity, as their cognition declines. Importantly, his work recognised the significance of the relationship between the

person doing the caring, and the person being cared for, and his work laid the foundations for later discussions on how to live well with dementia (Small, 2007); the role of memory in identity (Sabat, and Collins, 1999); the significance of person-centred care (Brooker, 2004, 2006) and the value of relationship-focussed care (Kontos, 2005). Moreover, in the last few years there has been a growing movement to recognise the human rights of people living with dementia (Butchard and Kinderman, 2019, Cahill, 2018).

Dementia in Gypsy and Traveller Families

Very little is known as dementia in Gypsies and Travellers, although one study by Rattigan and Sweeney (2018), sought to understand community awareness of the symptoms, as well as the ways to reduce the risk of dementia. This study found that although the participants had a good understanding of the signs of dementia, they showed less awareness of steps they might take in order to reduce the risk of dementia. This study also found that health campaign messages about reducing the risk of dementia were not reaching Gypsy and Traveller communities, mainly because most of the information about dementia depended on the written word and many community members are not literate. Many participants also stated that they would not approach dementia services due to their concerns about a lack of cultural appropriateness.

UK Policy Context

With increased concern about the rising number of people living with dementia, successive governments have developed a

number of strategies including *The Prime Minister's Challenge on Dementia 2020* (Department of Health, 2015) the *Dementia 2020 Challenge: 2018 Review Phase 1* (Department of Health, 2018) and the *NHS Long Term Plan* (Department of Health and Social Care, 2019). However, it has only been in recent years that there has been a recognition that mainstream services for people with dementia are not meeting the needs of people from ethnic minority communities (Powell and Baker, 2019).

Significantly, the government review of the *Dementia 2020 Challenge* (published by the Department of Health in 2019), was the first government document to acknowledge that the national dementia strategy needed to improve Gypsy and Traveller awareness of dementia risk factors in order 'to achieve parity in risk reduction across the population' (Department of Health, 2019, 22). However, at the time of writing (2021) little progress appears to have been made to improve Gypsy and Traveller awareness of the risk factors for dementia.

1.4. Carers supporting people living with dementia

It is thought that there are around 700,000 families who are providing care for people with dementia in the UK (Dementia Carers Count, 2020) and one in three people will care for someone with dementia in their lifetime (Powell and Baker, 2019). Research suggests that family and friends (i.e. unpaid carers), are providing dementia care to a value of £13.9billion a year and this is predicted to increase to £35.7billion by 2040 (Alzheimer's Society, 2019). Moreover, it appears that women predominantly carry out most of the caring responsibilities in the UK (Glasby and Thomas, 2018).

Clearly, a diagnosis of dementia can often have a profound impact on the individual, as well as their families and friends and learning to care for someone with dementia poses many



challenges because of the complex, unpredictable and progressive nature of the illness. Consequently, carers find that they have to adapt their own lives to the needs of the person living with the condition, which can often have an adverse effect on the carers physical and emotional health (Newbronner et al., 2013, Millenaar et al., 2016).

Learning to become 'a carer'

Although much of the literature talks about 'family carers' or 'informal carers', people do not always define themselves as 'a carer', because caring is often considered as an extension of an existing relationship (i.e. being a spouse, partner, daughter, son, friend etc.). Consequently, many carers do not access support services or information that they need (Carers UK 2016, Parliamentary Offices of Science and Technology, 2018) although a lack of service provision in some areas also makes it difficult for carers to access support (Innes et al., 2020). Moreover, there is only very limited research on the needs and experiences of carers for people with dementia from minority

ethnic communities (Race Equality Foundation 2018, Jeraj and Butt, 2018), so little is known about their needs.

What is known about Gypsies as carers?

The last national census found that 11% of the Gypsy and Traveller respondents were carers, and they were amongst the highest ethnic category of those providing in excess of 50 hours a week of unpaid care (ONS, 2014). However, very little is known about the experiences and lives of Gypsies as carers, and even less about Gypsy and Traveller people caring for family with dementia.

¹ (see Chapman v UK (2001) 33 EHRR 399 page 420, para 66).

² removing two words from the planning definition, Gypsies cannot be recognised as "Gypsies for the purposes of planning law", if they have to stop travelling permanently through illness.



Part Two: Research Methods

This study aimed to understand the lived experiences of Gypsy and Traveller families caring for people with dementia. We conducted eleven in-depth, semi-structured interviews with Gypsy and Traveller carers in the East of England and Derbyshire living in their trailers and houses. Anglia Ruskin University (ARU) funded the study and the research was developed in partnership with researchers from the Derbyshire Gypsy Liaison Group, One Voice 4 Travellers (in East Anglia) and researchers from ARU.³

Recruiting participants

Prior to starting the research, the team applied for ethical approval to conduct the study from ARU and this was granted in 2019. The research team developed the interview guide, but the researchers (from the Derbyshire Gypsy Liaison Group and One Voice 4 Travellers) recruited the participants and conducted the face-to-face interviews.

Informed consent

Informed consent is an ethical requirement for all research, and this is usually obtained in writing. However, as many of the carers are not literate, the University ethics committee agreed that we could ask for verbal consent to take part in the study. However, this is not unusual, as it is well recognised that oral consent can be substitutes for written consent where people are unable to sign a document (World Health Organization, 2002) and the oral consent to participate in the study was recorded.

The interviews

These were conducted at a time that was convenient for carers. The researchers made it clear that the interview could be stopped at any time and that the carers also had the right

to withdraw from the study. On meeting the carers, the researchers told them about the study again, and they were assured that their real names would not be used in any publications. The carers were asked if they would give their informed consent (verbally). All of the carers kindly gave their permission to a) participate in the study, b) to allow the researcher to record the interview and use the data.

Data coding and analysis

All the recorded interviews were transcribed verbatim and during the transcription process, all the participants' names and location details were removed, in order to protect the identity of the carers and the person they were caring for. All the data was stored in accordance with the UK Data Protection Act (2018) and ARU regulations. In common with other studies (e.g. Porter et al, 2006), two members of the research team coded the data separately and then discussed the findings (i.e. Siobhan from the DGLG and Pauline from ARU). The data was analysed using thematic analysis and the findings were generated by the data (Braun & Clarke, 2006). Firstly, we identified the emerging codes within each interview and then we looked across the codes and analysed the data for emerging themes. All the researchers reviewed the full draft report prior to publication.

Limitations of the study

We recognise that this study has some limitations due to the fact that we only interviewed a small number of Gypsy and Traveller carers (11n), within the defined geographical areas of the East Midlands and the East of England. We are also very aware everyone is unique and other Gypsy and Traveller carers may have different experiences from the carers represented in this report.



About the carers we interviewed

We interviewed eleven carers. Eight of whom were living (or had been living) in a trailer, of these, four were living on the road with no access to authorised stopping places, and four were living on permanent trailer sites. The other three carers were living in housing. Five of the carers were located in the East Midlands and six in East Anglia. Five of the carers were looking after their immediate family (i.e. mother, grandmother, husband), while six were looking after people in their extended family (i.e. Aunts, Uncles, Brother, brother-in-law). All of the carer's names have been changed in order to protect their identity and older members of the community (aged over 45), have been addressed as Aunt or Uncle in this report, as a sign of respect.

Vera is aged 40 is also the mother of three children and is also the main carer for her Aunt aged 78 – who is now living with fairly advanced dementia. The family are nomadic and are currently living in the East Midlands in a disused factory yard, this is a 'tolerated site' where the council have established a water connection, portable toilets and collect refuse from the site.

Eunice is aged 38 and is also caring for her Aunt who is living with dementia. However, they also have some support from the extended family. The Aunt is living in housing in the East Midlands, while Eunice is living in a trailer on the road.

Aunt Grace is aged 59 and is also living in a trailer on the side of the road and is caring for her brother-in-law (aged 70) who has dementia and is deaf. Aunt Grace and her brother-in-law, are both living in trailers on the side of the road in the East Midlands. On the day that the interview was recorded, Aunt Grace and her relatives were in the process of having a section 61 served by the police.⁴ This was served on her and her family then had to move their caravans in the early hours of the morning and she had to try and find to a safe stopping place.

Aunt Charity is aged 66 and she is caring for her husband who is aged 81 years old who is living with dementia. The couple are living in housing in the East Midlands.

Aunt Sally is aged 80 and had been caring for her husband aged 84 years old. She looked after him for four years before needing to place him in a care home (due to his aggression). Aunt Sally and her husband live were living on a council run trailer site but recently Aunt Sally has moved into sheltered accommodation in the East Midlands.

Tillie is aged 39 and is the carers for her Uncle Mattie who is aged 76. Tillie and her family have been looking after their Uncle for seven and a half years. But over the past few years his behaviour has become more challenging, and the family are struggling to manage, especially as he has dementia and muscular dystrophy. The family are living in a house in a town in East Anglia.

Mahala is aged 42 and is living on a trailer site close to her mum and stepdad, who are living on a private trailer site in East Anglia. Mahala's mother is aged 67 years old and has Alzheimer's disease and arthritis. Mahala has been trying to help her stepdad who retired in order to look after his wife as her health has deteriorated.

Margaret is aged 32 and is married with her own children. Sadly, over her lifetime, Margaret has had to care for her grandmother and mother, both of whom have had dementia. The grandmother lived in a flat and her Mother lives on an authorised site with Margaret in East Anglia.

Kezia is aged 27 and supports her grandmother aged 79 who has dementia and cancer. Kezia has two children and her son has attention deficit hyperactivity disorder and needs constant support- so she is helping to care for family with quite different care needs (although for the purposes of this study, we asked her to focus on her role as a carer for her

grandmother). At the time of the interview, Kezia was living on roadside, while her grandma was on a trailer site in East Anglia.

Uncle John is aged 73 and he is living on a trailer site and supports his brother aged 82, who is in the early stages of dementia and he is also diabetic and has serious bowel problems. The brother was living roadside in a trailer but he moved into housing in East Anglia to be closer to his family.

Uncle Henry is aged 57 and was caring for his Aunt aged 72 who had dementia. Uncle Henry lives in a house in East Anglia and his Aunt used to live in a bungalow. When the Aunt could not care for herself she moved in with Uncle Henry, but finally she ended up living in a care home.

³ The Derbyshire Gypsy Liaison Group (DGLG) has been running projects for the elder and disabled community members and their carers for the past five years. This has involved working with adult care social services departments and negotiating the difficulties and dilemma of continuing health care and or social care funding. It is DGLG experience that most people in the Gypsy and Traveller community have little, or no knowledge of what is available to them for assistance in paying for care.

⁴ The police have a power to remove 'trespassers' under section 61 of the Criminal Justice and Public Order Act. However, it is important to note that successive governments have prevented Gypsies and Travellers for stopping at traditional halting places. Consequently, with few authorised stopping places, nomadic Gypsies have little option but to stop on unauthorised land.

Part Three: What did we learn from the carers?

In order to seek help for dementia, the person needs to recognise that they have a problem, but this is not always easy and it may take some time for family and friends to notice that their loved ones are struggling with their memory. Also, it can often be difficult to recognise the early stages of dementia, especially as many of the symptoms (such as depression and confusion), can be due to other factors such as other clinical conditions, the side effects of medication and/ or emotional distress (such as bereavement).

The recognition of dementia

All of the carers that we interviewed, described how they had started to recognise small changes over time in their family member, and this alerted them to the fact that there might be a more serious problem. However, most of the carers also reported that their loved ones had tried to hide, cover up, or denied that there was a problem with their memory. For example, **Mahala**, who is helping to care for her Mum, explained how she first recognised that something was wrong:

"She kept forgetting things and repeating things over, like excessive. Over and over and over. I don't think she really realised herself. Then one day she had a bit of a do, and she started realising she was forgetting things and I told her she was forgetting things. We made an appointment with the doctor and she went, but then after she went, she just, sort of, put it to one side again and just said it was lack of sleep".

Aunt Sally who had been looking after her 84-year-old husband also recalled some of the early days:

"The ol' boy was bad for a few years before me daughter said to take him to the doctor. He kept repeating hiself, kept asking me for the same thing even after I'd give it him, or told

him whatever it was he'd asked for... Once one day we was down the town shopping and we was in this shop, he was asking the woman behind the counter for things you could only buy in the war! God love him (laughs) the poor woman's face was a picture! (laughs again) But he kept insisting that he needed them (laughs). He'd sit on the bunk talking about the old days for hours."

Uncle John who is supporting his 82-year-old brother had also started to notice small changes in his brother's behaviour and he recalled:

"I'm noticing that now with this dementia he knows he forgets things and instead of coming to meet me yesterday, he went off somewhere else and saw his daughter. So to get out of it, he made up an excuse to say that he spent the night with his daughter, that's why he couldn't meet me, which to me, I think he's trying to cover up that he'd forgotten what he was supposed to be doing... He hasn't had a diagnosis, but I think he does realise at this stage that he forgets things and that is why he tries to cover it up and make an excuse."

A significant event

While most of the carers had noticed a gradual deterioration in the memory of behaviour of their loved ones, sometimes there was a dramatic incident, or a series of incidents, that signalled to the family that there was a serious issue. This often resulted in the family needing to step in and make a decision about their future care. For example, **Eunice** talked about her early concerns with her Aunt and how things became more serious, she recalled:

"About 7 months ago we finally got told off the doctor that she had dementia. We really didn't know what was happening at first, it was just little things, like not packing her shopping away, or forgetting the children's

names. Then she started with more serious things, like leaving the taps running or the front door wide open all one night. We thought it was her tablets she was on for her chest and that [was] making her dopey maybe, but she kept getting worse and if we mentioned it to her she'd start shouting, but we had to take her to tell the doctor in the end"

Uncle Henry, also described his experiences of his Aunt who was living in a bungalow and how he had to increase surveillance of his Aunt in order to protect her, he recalled:

"She was in a bungalow, but she kept wandering off in the night... Yeah, she'd wander off in the night, then I'd go looking for her. Then I arranged for her to have meals on wheels and she kept phoning them up so much, in the middle of the night... Anyway, and then before that, she used to drive, but she had an accident, so she couldn't drive no more, and I used to drive her about, but she got so, she couldn't live in the bungalow no more, because she put something in the microwave and set the bungalow alight."

Kezia who had cared for her mother and her grandmother, also recalled how the family became more concerned:

"Like with my Gran and that, she turned the cooker on one day and near enough set herself alight. Come down home, and realised, well she never realised until she went back home and it was... clouds of smoke, kettle burnt, so we used to have to keep a very close eye..."

Listening to carers it seemed that it was difficult for them to share their concerns with their family and it sometimes it was hard for family to accept that someone in the family had dementia. For example, Mahala talked about her stepdad saying:

"I think her husband didn't want to accept it and he kept saying 'it's just a lack of sleep' and they just wanted to deny it, I think. I still think other members of my family like sisters and brothers still want to deny it."

Mahala also expressed concern that her stepfather did not always allow the wider family to help. She thought this was because the travelling community like to keep personal things very private as she explained:

"He goes to all the hospital appointments, which I think makes it hard for me and my sisters, as they're not allowed to go and he keeps a lot of it private. It's guesswork of what stage she's at and where she's at because he's not sharing, which I think is not really fair to children..."

Uncle John who is caring for his 82-year-old brother, also suggested that dementia might be stigmatised in the Gypsy and Traveller community, he explained:

"With the Travellers they think this is a shameful thing and they would be embarrassed, what we would say ladged [i.e. embarrassed/ ashamed] but they would be embarrassed to tell someone that somebody had got dementia or Alzheimer's, so they would try to keep it to themselves as long as possible".

Seeking a diagnosis

Our research suggests that there was often a reluctance to go to the doctor to get a diagnosis for memory problems. Early diagnosis can be helpful as it can improve the management of dementia and support advanced-care planning. As suggested above, while many of the family recognised that there was a problem, it was often difficult to persuade the person living with dementia to go to the doctor for an assessment. For example, **Aunt Grace** who is supporting her brother-in-law, explained that she was concerned about him, she reflected:

"He hasn't had a diagnosis as yet – it is very hard to get him to go to a doctor. I have made appointments loads of times and he won't go. I don't know what to do about him. I can't trust him in his place. He'd set his self a fire if I didn't watch him. He eye sight isn't all that good as well, so you've got to keep an eye to him all the time. He don't know where he is half the time..."

Mahala explained that her mother was only 63 when she was given a diagnosis:

"I found out she had Alzheimer's about four years ago. I took her to the doctors, but she never followed it through. Her and her husband never followed it through... Didn't want to accept it, I think. Probably didn't want to accept that she had Alzheimer's, even though when she took the test it looked like she did, but the doctor said that he couldn't diagnose until she went and saw the specialist. She never carried on with it until perhaps last year where she got fully diagnosed that she had got Alzheimer's..."

Listening to the carers, it was clear that it often took a long period of time to recognise that their loved ones were facing problems with their memory. Other research suggests that delays in recognising dementia and seeking a diagnosis is common (Perry-Young and Owen et al, 2016).

3.1. Everyday life as a carer

Our research has found that as the condition progressed, family carers necessarily played an increasing role in the lives of the person with dementia. This also meant that family roles needed to change as the condition progressed and sometimes this was difficult for the carers to negotiate. For example, cleanliness is very important in Gypsy culture and **Mahala** talked about the fact that it would be normal for an older Gypsy woman to ask her daughter for help as she aged. However, as her mother had Alzheimer's disease, it had become more difficult for **Mahala** to offer support to her Mum, she told us:

"I think it's hard in helping the person cleaning wise. They don't seem to be cleaning how they were, but then this person had asked me for help before, like, "Would you help me do?" The things she couldn't do, like in the caravan wash the roof, lift the bed up. It has to be cleaned."

Mahala also suggested that accepting help was also a problem for her stepdad, who was the main carer, she explained:

"He cooks the food and does help her a bit, but I think if you insist that she needs help it's like, "Oh, there's nothing wrong with me, I can do it." It's like I think she feels like you're getting at her and saying she isn't capable. She doesn't want to accept that she's not."

Maintaining normal activities

A number of the carers described how they tried to include the person living with dementia into daily activities as much as possible, while maintain their own lives. For example, **Aunt Charity** described how she tried to include her husband when shopping and that it was important to take his needs into account:

"I try to reassure him everyday, take him out in the day for his bird seed, he often tries to buy dog food, but we don't have a dog, he believes he has, he hasn't, 'cos it died five years ago- but we still have to buy dog food for it" (Laughs).



Eunice explained how she and her family juggled the demands of everyday life:

"Yeah, the girls come in and see me and we take Aunt out some days to have a look round the town or for dinner and my cousin sits with her on a Friday night while I go to the bingo (laughs)... Well I have to give her, her medicine and make sure she has had a wash or a shower, also make sure she has had a bit of food. Somebody has to stay with her nearly all the time now. She can be on her own for a short while but someone on the street keeps an eye out if I go down the shops or anything. We definitely don't leave her at night in case she gets up and we don't know where she is".

Supporting multiple health needs

A number of reports have suggested that the majority of people living with dementia also live with one or more health conditions (All Party Parliamentary group, 2016, Public Health England, 2019). Similarly, many of the carers in this study also described how their loved ones were often facing other health challenges. For some of the carers this meant that they had more demand on their time. For example, **Uncle John** who is supporting his 82-year-old brother with dementia, talked about some of the challenges of supporting his brother's other health needs:

"He had a problem with his bowel and had to go in and have an operation, but I noticed that with this he had to keep ordering the stoma bags and he's also diabetic so he has to order his tablets. I'm finding that instead of telling you two weeks beforehand that he needs a prescription, he'll leave it until he's completely run out and then he'll tell you he needs a prescription, which causes a problem because then you've got to hurry the people up and say, "I need it as an emergency," and that kind of thing."

Tillie, also talked about the fact that her Uncle had muscular dystrophy disease, and this had caused additional problems for him and the family, for example she explained what happened when he fell over:

"His right leg has started to give way with him a lot now... and when he goes down, he's no small man to try and lift, he's heavy. Yeah, I bet he's about 14–15 stone and when he's going down, he's heavy".

Kezia also described that how her grandmother had been diagnosed with cancer and later was diagnosed with dementia, she reflected on her experiences:

"With cancer, that's a bad thing anyway, which nobody ever likes, but with dementia you can see them slipping away and not remembering and recognising anything. And when you go there, and they don't recognise you, and there's a close relationship, that is hard. But with cancer you know what's more or less coming with that".

Encouraging loved ones to eat

Because eating well is vital for both physical and mental health, how older people eat at home represents an important part of their physical and mental health management (Berman, et al. 1994). Yet many of the carers mentioned that eating had often become an issue for the person living with dementia. Sometimes they had forgotten to eat and sometimes they refused to eat but many of the carers had developed strategies to encourage the family member with dementia to eat. For example, **Margaret** explained how she and her family used to encourage her mother to have food:

"Well, the only thing we could get down her, we did try. "I'll have a boiled egg", she used to say. I used to buy her an egg, and when I give it to her, "No, I don't want it". So, I'd say, "Right, what do you want Mum?" "I'll have some grapefruit, but I want plenty of juice". Now, she'd eat that at times. Then another day you'd say to her, "Mum, nice bit of fish I've got you". "No, I'll have some of that other stuff you give me yesterday". I'll say, "What grapefruit Mum?" "Yeah". She just used to leave it... Not food, don't want food. So, I used to say, "Nice cup of tea". "Oh, I don't want the tea". I'd say, "You'd like this one". So anyway, she used to taste it,

she went, "Mm, that's nice". Now she'd drink that. But the last three or four mornings I couldn't even get a sip of water down her. She just didn't want to know".

Tillie also explained how eating had also become an issue in caring for her Uncle. She told us that the family would take him food shopping then he would often come home and throw all of the food in the bin while still in the packet. He would also eat three or four cream cakes at a time and sometimes he would not eat at all. However, the family worked out a strategy to help him to eat healthier food, she explained:

"he'll say he don't want nothing. But you cook, he'll smell it frying and say, or you know 'what are you cooking? And then change his mind, and then he'll eat. Once he can smell it cooking... and if he don't like the smell of it, even when it's cooking, then he won't have it. He just won't have it."

Aunt Charity also described some of the challenges that she faced and some of the strategies she used to help her husband to eat:

"He can't remember what's on his plate. When he's having his food sometimes and I have to describe what he's eating 'afore he'll eat it... I have to cut up his food sake of him choking, and he has to have porridge every morning for his breakfast, if he doesn't he gets in a mood, he can get very persistent until he does get food, he is very particular only has a routine he still thinks he's a young man..."

Vera, who is living in a trailer, also faced frustrations in trying to get her Aunt to eat, she explained:

"Well, its hard it is it is really hard, she won't eat what you give her, she puts it through the back window to the floor"

Uncle John also had to keep an eye on his brother, he reported:

"I take him the odd meal in and check his cupboard to see if he's been and got groceries

because I feel sometimes that if he's already eaten he forgets that he will need groceries in for the evening, etc. So he needs a bit of prompting."

Caring roles and family relationships

Caring for someone with dementia can be demanding and there was a strong message from the carers, that there was a cultural expectation that the family should be responsible for caring. For some carers this was difficult as they were also juggling caring for children, or other family members. However, many of the carers highlighted how the family worked together to support the person living with dementia. For example, **Aunt Charity** told us:

"I have a very large family and they always help me out if I need to talk, any help, or anything like that".

Aunt Sally also found support from the family:

"Yes, my children, they would come for a visit and watch him for me while me and me gal had a little time for ourselves. Sometimes they took him off for the day, to the park or somewhere, it was nice to spend some time on yourself, when they took him off for a few hours... Other family members do help me, they take him out visiting his family even though he doesn't remember any of them."

Kezia, who is a young carer with a family of her own, similarly talked about how her family pulled together to look after the grandma, she reflected:

"Well, where we was at the time, there was only like me and my mum, my Auntie, two cousins, and a sister-in-law. Like my sister-in-law, we never used to put so much on her, because she was only an in-law, but she did help when we wanted her to. So, we used to take it, not take it in turns each day to look after her, we all had our own set, little jobs. Mum and that used to wash her, we'd go in and clean her trailer up and do her shed. One would do the cooking, so we all had a certain little bit, we used to keep up"

But **Kezia** also talked about how hard it was to maintain her caring role as she also had young children, including a son with special needs, she recalled:

"Sometimes it was very hard, especially when you had your own things to do. Then you got like young children, what always wanted this, that and the other, and then you was trying to make space and time to help out down there, so it did used to get quite difficult... somebody always had to be there, and if mum was gone out, one of us had to be there for her, so she always had to have somebody, and we had to make plans around each other".

Margaret (who had looked after her mother and grandmother with dementia) also talked about the challenge of juggling the needs of her own family with the needs of her Mum. She recalled:

"yeah, it did make it awkward because you had to do the washing for her, you had to do the cooking for her... she wouldn't eat it half of the time, food do you know what I mean? Then I had my own children to look after, my sister helped me, but she was away half of the time, so therefore it left me. And it isn't right, for my husband to go in and do things for her. He couldn't change her, he couldn't do things like that, and half the time, if he come in, she'd chuck him out anyway..."

Margaret also told us how role as a carer had an impact on her marriage, and that it often caused tension between her and her husband, she recalled:

"I used to sleep up there, if she got really bad, and then if I walked off, to say, "Right, I'm just going to mum's, see if she's alright?" He'd say, "You've only just come back" and he used to get bored and miserable because he never had nobody there to talk to, and Bob [name changed], he could get stroppy at times, and some nights I used to say, "Right, I'm sleeping with mum tonight" and then when my sister was free, she used to sleep with her. We like used to take it in turns, but yeah, he could get very stroppy".

Changing gender roles

In traditional Gypsy and Traveller families, caring and responsibility for the home (including cooking, cleaning and childcare) is usually seen as work undertaken by women (Casey, 2014), although more recent studies have shown that gender roles are changing and an increasing number of Gypsy and Traveller men are now carrying out caring roles including housework and personal care when needed (see for example, Lane and Spencer, 2019, Spencer 2018, unpublished PhD thesis)

Our research with the carers found that some of the men (such as Mahala's stepdad, Uncle John and Uncle Henry) were the main care providers. However, it was also clear that many of the young men also offered care in quiet ways, for example **Tillie** commented that, 'one of the boys' would get the Uncle into the shower each day, and Aunt Eunice commented that the younger men in the family would keep the trailer clean for her Aunt living with dementia (cleanliness an important part of Gypsy and Traveller culture).

Mahala talked about some of the challenges for the men in the Gypsy and Traveller community, she explained:

"I think it's worse. I think it's harder for a male in the travelling community because... well, I suppose men in all communities- they haven't got the patience that a woman has got. They haven't got the patience. I suppose travelling men, some are domesticated and a lot aren't, so I think that makes a big difference too. Whereas if it's the other way around and it's the woman, I think a woman copes better than a male, in my opinion".

Uncle John who is caring for his 82 year old brother stated that:

"I think it's very hard for a travelling man to be a carer, especially if it was for a woman because they've got to sort their clothes out and see to their personal washing and dressing".

Uncle Henry also acknowledged that in many Gypsy and Traveller families there are traditional gender roles. He suggested that while the women might know about caring for someone with dementia, that men often did not know this. He appeared to be suggesting that Gypsy and Traveller men might need more information about caring and dementia, he stated:

"You see some, travelling communities, the men go out to work and they leave it to the women to sort out the home. Well, all the problems, what comes into that home, the women has to have more responsibility with that person. I think it's because the men don't understand more about it. If it was told to the men more, like to the women or young girls, about different things, well then..."

Listening to the carers, it was clear that although they freely offered physical and emotional care to their loved ones (and implied that they often found the relationship emotionally enriching), that the caring role often placed the carers under significant strain. **Uncle John** reflected on some of the daily pressures:

"If you're looking after somebody 24/7 it can get very stressful, and especially if they don't sleep a lot so you're getting woken up in the night, so you haven't had a full night sleep. I think that you do need to have the regular respite if you're looking after somebody 24/7 to make it easier to look after somebody".

Mahala has witnessed some of the pressures on her stepdad, who had undertaken most of the care for her mother:

"I think it's physically draining, in like they're not getting a rest. They're not getting a rest because, I suppose with anybody with dementia, they won't let that other person go on their own, so that person is not getting a rest. They're not getting a rest away from the person with dementia or Alzheimer's because they're clingy to them, like I suppose somebody with a baby that won't let its mother out of its sight. So, I suppose it can be

quite draining which makes them snappy because they're not getting a break."

Tillie reflected poignantly on the impact of caring for her Uncle, when she described how she felt:

"It's not an easy thing to try and care for somebody what's got that. It leaves it mark on you. Forever how long you've got to live, it leaves a mark on you. And, hope and pray that nobody else in your family gets it, and that's what you think every day, I hope and pray to God, nobody else gets it, nobody else in the family."

3.2. Dementia care in a trailer

Research suggests that the social location of a family can make a difference not only to how the family view dementia, but also how they are able to manage the challenges resulting from the condition (Hulko, 2002). Gypsies and Travellers have traditionally been nomadic, and they have a right to live in accordance with their traditional, nomadic way of life⁵ Our research found that for the nomadic families caring for someone with dementia, trailer life itself was not usually a problem but the wider environmental issues, such as a lack of access to running water, made caring difficult. At the time we interviewed Aunt Grace she was caring for her brother-in-law with dementia, the family were living roadside (i.e. was nomadic) and were about to be evicted by the police. Although Aunt Grace did not want to comment on this during the interview, other studies have highlighted that constant evictions create stress and fear (Lane, Spencer, McCready and Roddam, 2019).

However, Vera did highlight some of the challenges she faced because of the location of her trailer. Vera is looking after her Aunt who is now in the advanced stages of dementia and at the time of the interview, they were parked

on a disused factory yard. Vera described this as a 'tolerated site', where the council had provided a water tap and a portable toilet and they also collected the refuse from the site. However, caring for her Aunt's needs had become increasingly difficult, and Vera described what she really needed:

"We need a legal place you know what I mean, so we can get the things you know, it would be a lot easier to shower her in the mornings, you know she's clean and all that, its hard to keep her clean. They [social workers and health workers] think everyone has a shower and running water! I think they [are] shocked when they see what they have to work in and I think that's why they don't want to come and cos it's the Gypsies. They are used to hot water being on the tap and all that you know. We have to boil the kettle!"

It also became apparent that some of the nomadic families needed to change their living arrangements when the health of the person that they were caring for deteriorated. For example, **Uncle John** explained that his brother had been living in a trailer but he was forced to move when he had bowel surgery and that now that he had dementia, the family were glad that he was nearer to them and living in accommodation that suited his needs. **Uncle John** reflected:



"Yeah, familiar surroundings where he'd been when he was young. So that was one of his decisions, to move back closer. Then when he had the operation [bowel surgery] and he was living in a trailer it wasn't really convenient for him. He had a small trailer. It didn't have an inside toilet and bathroom, so he had to go out to the toilet and bathroom. He thought that he'd go into an old people's housing, which is housing controlled, so people can watch him. He's found that since he's been in the bungalow, he's got the shower and toilet that he needs and he's managing to look after himself."

Caring on a permanent trailer site

However, for other families living on a permanent site, trailer life continued to offer good accommodation, even when a family member had dementia. For example, **Mahala** explained:

"I don't think being in a caravan really presents any problems. One of the reasons that's easier for her is she's not really mobile. I think if she was mobile you'd be more worried of her walking off, but because she's not too mobile that doesn't seem an issue... Yeah, I think that's helped because with Alzheimer's I don't think you could be on a set up where you were with all other people, like a site, because it would be too open. On a private site away from others .. your own place with gates you can close the gates and you can watch. But if you were on a site, I think it would be harder because there's more people up and down."

Aunt Sally and her family were also living on a trailer site and she described how the family had worked together as a team to support her husband:

"On the site where we was there was a utility shed with running water and a bath. Every morning me and my daughter would get him out of bed then take him

into the shed for a wash, my daughter would give him a shave and then I would give him his breakfast”.



3.3. Seeking external support

Listening to the carers, it was clear that there was a cultural expectation that families should manage without the support of outsiders (i.e. people outside of the family or community). Certainly, some of the carers who were looking after loved ones in the early stages of dementia seemed adamant that they would not seek external support and many of them felt that dementia was a private issue. For example, **Aunt Sally** also emphasised her self-reliance and dependence on her family: she stated:

“No, I never needed anybody else’s help, I got my family.”

Aunt Eunice who was caring for her 71-year-old Aunt, was also adamant that she didn’t want external agencies involved in their lives and she explained her fears:

“No, I don’t want the social services coming round, they might want to put her in a home.”

Aunt Grace also reflected:

“I think Travellers hide things, in, they’re private people, they don’t want people

knowing things. I think Travellers are silly sometimes there should be a special number that they could use if they needed it.”

Other families were also reluctant to ask for help. **Mahala**, who was supporting her mother in the early stages for Alzheimer’s disease with her stepdad, was asked if the family would accept outside help, she stated:

“No, because I think it’s something that you couldn’t even bring up or discuss. I don’t think he’d discuss it. It’s just going on every day. She’s just getting worse every day, and I don’t even know if he’s even accepting it and they’re just going about every day and I don’t think they’re even thinking about it...”

However, it was notable that many of the carers who were supporting those with advanced dementia, seemed to be more open to external support. Although a few family carers did put in place some low levels of support in the early stages of dementia for example, **Uncle Henry** initially put ‘meals on wheels’ in place for his Aunt, but as her condition deteriorated, he was no longer able to manage to support her and she was finally placed in a care home.

Other carers also sought more formal support, for example **Aunt Charity** told us that she was offered a care needs assessment⁶ for her 81-year-old husband and told us:

“Yes, I have been offered but I declined, because we people don’t like to be a burden to others when we can care for him ourselves... the Christian church has asked us if we need anything, they have been very generous and supportive... I don’t think the health or social worker people need to know anything else about my life because we are a very private people, but that’s not saying that if I really needed them, I wouldn’t call them.”

A local Gypsy support group helped Vera with some of the practical issues (such as buying and storing incontinence pads for her Aunt)

and they also acted as an advocate for the family and managed to gain access to formal support. **Vera** told us how much she appreciated the help, she stated:

"The office [The support group] told me about carers support and they got a social worker down here she's a nice lady and they have done a lot to help, we could not have coped at all... one or two different people come, its nice to chat you know, and they will help- like they sort the tablets out and collect them and bring them, they have helped with sorting out the care and helped sort out the benefits and all that..."

However, she also talked about the discrimination they experienced:

"They got someone to help me keep her clean in the mornings. The woman is lovely, but she brought another woman with her to do the morning a week [when] she can't come. But

the woman's husband wouldn't let her come to the Gypsies – so we have to struggle on a bit..."

Culturally inappropriate care offered by paid care professionals

While some of the carers who took part in this study did benefit from external support, others found that the support that was offered was culturally inappropriate. This was especially true in relation to personal care (i.e. washing, toileting etc.). This was mainly because the paid care professionals seemed to show little or no cultural sensitivity to the families' needs. For example, it is not considered 'proper' to discuss personal health issues with mixed genders, and most families have very strict gender roles (and this is particularly true for older people who may prefer more traditional ways). For example, it is traditional for women not to undress in front of strangers. Indeed, there is a general shyness about bodily





functions as a whole for Gypsy people (Lane and Spencer, 2019). For example, **Margaret** explained how she needed support with care for her mother near the end of her life, but found that the health workers were not sensitive to her mother's cultural needs, she reflected:

"Well, like my mum, when it come to her end, she was in like nappies, and mum... when the nurses used to come out to her, and they sent these male nurses out, I said to him, "What you coming in here for?" He said, "To see to mum". I said, "No, you're not". I said, "No". Well, anyway, this other nurse done it, but I just watched her, and I said, "No, I can do this", and I said to her when she come the next day, "I don't want you; I've done it, I've finished". So, she said, "Well, I've still got to come in". So I said, "You can, but he can't". Because it's not our way – it's not our culture is it? To let men mess about with your mum, I wouldn't have that. And, if it was my dad, I wouldn't have let the nurse in, it'll only be a male nurse"

Kezia, who had been looking after her grandmother who had cancer and dementia, was offered some support from paid care professionals but she also suggested that the

care offered was culturally inappropriate, she explained:

"When the male nurse come in, he thought he was going in, washing her whilst she was laying in her bed, and he couldn't understand why we wouldn't let him in... He went to go in the door to wash her, and my mum stopped him, she said, "Where do you think you're going?"

He said, "Into her".

She said, "Ah, but you don't".

He said, "Why?"

She said, "Because we don't believe a man should

be in the same room as where a woman is being washed".

He said, "But why?" and like my mum said, that is our beliefs.

He said, "But I've got to go in there to check her over".

Mum said, "You can go in there when that nurse has finished doing what she's got to do, then you can go in"

And, after that we told the nurses not to bother to come. We'll do it all ourselves, and right up until she went, we done it...Then my mum told the other nurse not to bother coming out anymore, and she wanted to know why, and they told her that we was going to wash and do her, that was our way of life, so we didn't need them to come in anymore."

It was clear listening to the carers that they needed support, however, when the support that was offered broke cultural taboos about modesty and gender roles, the carers predominantly decided to struggle on without external support. However, not all of the carers were aware that they could access some support and it was notable that both of the male carers we interviewed for this study (**Uncle John** and **Uncle Henry**) stated that they did not know what help was available to them or how to access support outside of the family.

3.4. Carers coping with challenging behaviour

Dementia inevitably results in behaviour changes and this can be a major source of distress for the carers. Behavioural challenges can vary with different people but they include behaviour that is a risk to themselves (such as running off in the night) and/or risk to others (such as smacking, pinching, grabbing, verbal abuse) and more extreme forms of physical violence. Although there is limited research on abuse towards carers, it has been suggested that violence towards caregivers is the strongest predictor of nursing home placement and the risk to safety and well-being of caregivers can be high in these situations (Wharton and Ford 2014, Cahill & Shapiro, 2008). Yet caregivers often receive little information about dealing with challenging behaviours (Cooper et al., 2010).

Our research seems to indicate that in the early stages of dementia many of the Gypsy and Traveller families developed strategies to protect the person they were caring for, however in the later stages of dementia, families were often unable to continue to offer care due to risks to the person with dementia, or the risk of violence to themselves. For example, **Mahala** explained that she was worried about her mother being exposed to external risks, as her mother's behaviour started changing due to the dementia:

"She couldn't be left on her own. She's not left on her own. There's always somebody there in case she came out. She's got worse just lately. I've noticed that now I think she could go on a wander. When I first realised she had Alzheimer's she wasn't coming out as much as she was. She wasn't coming out, but now this is getting into the second stages she's coming out more. So she's coming out more and you think she could get into, like a child, perhaps get into more mischief. She's coming visiting more and sometimes seems a bit lost outside so you think she could get into more danger now so you couldn't really leave her on her own."

Uncle Henry described how his Aunt had increasingly become a risk to herself and how this impacted on his family life, he explained:

"You know, and so you couldn't take her out to communicate with anybody else, and it made it very awkward because I'd, at the time I had two grandchildren, and even to the grandchildren, if they were playing that got on her nerves. She didn't like it, so it came to a point where the grandchildren couldn't come over much... I tried to support her all I could, and at the end it got too much for us, because her wandering off, we had to lock the doors, make sure the windows were shut... Even a nice day, you had to have the doors locked, because she'd wander off. One morning she wandered off to do some voting, 3 o'clock in the morning... I searched the village for her, found her, brought her back, but it was getting too much".

Margaret, told us about her grandmother and how the family coped with her challenging behaviour:

"My gran, she had dementia and she didn't know what she was doing... [she would] just like reach out and smack you, or she'd pick something and hit you with it, but she didn't know that she'd done it. Do you know what I mean? And, till afterwards and you explained it to her, then she'd say, "I'm sorry, but I didn't do that". She would get nasty about it. So, we used to say, "You did Gran, you did hit me". She'd say, "No, I bloody never" and mum used to say, "Just leave her alone, she'll remember it". But she never did, remember what she'd done..."

Vera also described how her Aunt had presented the family with a range of challenging behaviour, she reflected:

"She don't know what she doing half the time, she has thrown money in the rubbish... she goes over and over what she already said, it drives yer mad sometimes it really do... She cuts up her bedding up and says she wants something to eat and then [she] won't eat... She makes water [urinates] where she sit you

know...? And the other [defecates], God forgive me for talking about such things. She won't let you take her for shower, she ain't good on her legs and I think she frightened of falling. She has to have everything done for her from getting up to going to bed."

Coping with violence against carers

In the more advanced stages of dementia, some carers were faced with managing violence from the person they were caring for, these experiences ranged from damaging objects, to more extreme forms of physical violence. For example, **Tillie** who has been helping to look after her Uncle talked about some of the challenges that the family faced, she stated:

"He's very difficult, a very difficult man to look after, because he gets so upset so quick over anything, even something what didn't happen, but he thinks he has. He gets so, he smashes everything up and he's got over it, and there's something when it happened, or he thinks has, and nothing has happened, until he calms

down. Or if he has an accident, he'll wet himself and then he... ah... God... It's... and he tries to hide it..."

Tillie went on to describe some of the issues that she was managing when caring for her Uncle, she stated 'sometimes he falls over and because he is a big man, he is difficult to get up off of the floor'. Equally worrying, **Tillie** also told us that sometimes her Uncle could be violent, she described her experiences saying:

"You've just got to let him calm down. You can't do anything else. You try and take anything away from him, makes it worse. It makes it 50 times worse, so leave him".

Aunt Sally, who had struggled to look after her husband found that in the end, his violent behaviour made it impossible for her to continue to look after him. She recalled:

"I'd put him in bed at night and put the tele [television] on for him, and then two minutes later, he'd be out the bed again, then I



couldn't get him back in, so I would let him lie on the bunk and sit with him. I had to lock the door at night when we went to bed 'cos he would try the door all the time. He was a very strong old man and used to push me about he also hit me sometimes.

...I didn't know about any support available or anything like that then, but I did in the end because as I said, my husband got very violent and 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 was 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 my children they told me it was too hard to look after him, it was getting more and more, he'd wander off, then the police used to fetch him back it was just terrible. It broke me heart to do it but that's what we did. I had to [take him to a] care home because of violent behaviour"

Listening to the carers it was clear that the person living with dementia remained as someone who was loved and 'known' by the family, not only in their family role (as grandparent, parent, Aunt or Uncle) but also as a person who continues to exist in both the past while also accepting that they are in the process of becoming someone different. While in some instances the family were able to accept that their family member had different needs and different ways of behaving, in some instances, where there was aggression and violence, this new behaviour was not reconcilable with what the family could offer and they were forced to look for nursing care.

3.5. Making the decision to move a loved one into a care home

As suggested above, families are important in Gypsy and Traveller culture and there is a cultural assumption that families will look after older family members (Lane and Spencer, 2019). However, in the advanced stages of dementia, some of the carers found that they

could not manage any longer and had to make the difficult decision to move their loved one into a care home. But even in the early stages of dementia, some of the carers recognised the decisions that would have to be made in the future. For example, **Mahala** had already started thinking about the future for her mother, she reflected:

"Yeah, I think it could get to a stage where probably you wouldn't be able to cope, but the trouble is with the travelling community they don't believe in putting people in [care] homes and that's when it becomes a big problem. The thing with Alzheimer's is it would be a 24-hour job and it depends if the family pull together or they don't... [I've] always been brought up that you shouldn't put your elderly people in a home, but as I'm getting older I realise that there comes a time when it's not possible. There's times when it's not possible to be able to look after somebody and that's what worries me because I can't see how, when she gets to the last stages, how she could be looked after at home..."

Margaret talked about looking after her grandmother with dementia. She reflected on how difficult it was for the family when her grandmother talked about her own future, she recalled:

"She lived on her own, and she used to say to my mum, "Please don't put me in any homes, I don't want to go in a care home or anything", so mum said, "No, alright".

As suggested above, **Vera** and her family faced a number of problems in caring for their Aunt who was living with advanced dementia, not only because of the practical issues relating to care (i.e. only cold running water and a portable toilet) but also because of the Aunt's behaviour. She described how a local Gypsy support group had help to find winter respite care for the Aunt:

"Yes she went into that respite wintertime because we couldn't do the washing you know with her problems, she was ill then as well, so over the winter she was there. We haven't got

any showers or anything, no place to wash and all that at the side of the road, you know what I mean. I think we have to stop this, this its like what you call it a stigma about sometimes they going into care, they feeled shamed to say they have had to put someone in care but I think it's the kinder thing. They [are] clean, tidy and well fed that place she was in was lovely. A lot of our people won't say they have someone in care but they have, it's the truth. I think they needs to be learning on both sides I do".

However, some of the carers found themselves in a difficult position, for example, **Aunt Sally** had struggled to look after her husband but in the end, his violent behaviour made it impossible for her to continue to look after him and the family made the decision to move him to a care home. **Aunt Sally** reflected:

"The people in the care home was lovely, nothing wasn't too much for them. They let us visit him whenever we wanted. The first place we put him in was horrible they did things that we don't agree with..."

Uncle Henry also described how he and his wife had to manage alone when caring for his elderly Aunt but finally they reached a point where they could not cope any longer with her behaviour and she was placed in a care home. However, the family made it know that they didn't agree with that decision. Consequently, **Uncle Henry** found himself in a difficult position, as he explained:

"Because it was us that put her in there [the care home], though they didn't want to help look after her, but beings it was us two what put her in there, they've pushed us out of the community really".

Clearly the decision to move a loved one into a care home is a difficult decision for anyone. Our findings indicated that families supporting people in the early stage of dementia did not seem to envisage that they would move their family members living with dementia into care and this decision was only taken when as the illness had progressed into the advantaged stages and the carers found that they were no longer able to offer support. For many Gypsy and Traveller families, this was a collective decision, however as **Uncle Henry** suggested (above), sometimes a decision that had to be made without the agreement of the wider family and clearly this was painful.

⁵ *The Mayor and Burgesses of the London Borough of Bromley v Persons Unknown* [2020] EWCA Civ 12, <https://www.bailii.org/ew/cases/EWCA/Civ/2020/12.html>

⁶ The local authority has a duty to assess the care needs of a person with dementia. The assessment will determine what care needs they have, and whether the local authority will contribute towards meeting them.

Part Four: Summary of the findings and recommendations

This final section offers a short discussion on the findings, and makes recommendations for health and social care practitioners and providers, as well as commissioners.

Summary of the findings

Reflecting on the experiences of the carers from different families, it is clear that we cannot talk of a single carer experience' and our research suggests that although many carers were facing similar experiences, this varied according to the levels of family support, the context of care and most significantly, the stage of dementia of the person that they were caring for.

Recognising dementia can be difficult and our research found that while many of the carers acknowledged that a family member was facing difficulties with their memory, it was often difficult to persuade them to get a diagnosis. Some of the carers described how health issues were often stigmatised in the Gypsy and Traveller community, and this might help to explain why families often tried to hide the condition for as long as possible, or deny that there was a concern.

Our research found that the families often worked together to support the person with dementia. However, although many women were the primary carers, our research also demonstrated that Gypsy men were also primary carers, and some of the younger men also had hidden caring roles, (such as helping out with activities, such as cleaning the trailer). Many of the carers emphasised how much they valued family support, especially in the later stages of dementia, when the person needed care and supervision during the day and the night. However, this was not true for everyone, and one carer explained how he and his wife had received little support from their family. The carers described how they adapted their own lives to the needs of the person with dementia. Because all of the carers were in an established relationship, they clearly played an important role in the life of the person living with dementia. Their pre-existing relationship with the person living with dementia, was important in helping to meet their needs (such as knowing what foods they liked), as well as helping them to retain their sense of personhood, through discussing past events and



relationships. However at times, some of the carers were juggling different caring roles, for example, Kezia was supporting her grandmother who has dementia and cancer, and she was also caring for her own children, including a son with special needs. Therefore, our research highlighted how important it is, not only to recognise the expert knowledge of carers, but also to understand that they may have multiple caring responsibilities and needs. Although none of the carers overly highlighted their own needs, listening to their narratives, it was clear that caring for someone with dementia was demanding in terms of the meeting the physical care needs of the person with dementia, as well as keeping them safe, and coping with the emotional impact of caring. Many of the carers described the disruptions and on-going adjustments that they had to make to their own lives, as they responded to the needs of others. Many of the carers seemed to be resilient (and often stoic) and some of them used humour as an important 'coping' technique, however, it was also clear that the burden of care was considerable.

Yet most of the carers seemed hesitant to seek support outside of the family in part, this may have been because health issues are seen as private concerns. However, our research found that when the families did seek external support, it was often culturally insensitive, and we heard of several reports where male carers were sent to carry out personal care for an older Gypsy woman. This was not culturally acceptable, nor patient-centred, and consequently many of the carers were reluctant to use dementia services that did not meet their cultural needs. This issue of 'culturally appropriate care' is important, not only because of the service providers need to make reasonable adjustments for people with protected characteristics under equality legislation (Equality Act, 2010) but also because culturally sensitive services have the potential for better outcomes for both the carer and the person with dementia.

Another dynamic of caring was the location of the family. Listening to the carers it was

interesting to note that living in a trailer, in itself, did not present a barrier to offering care to someone with dementia. However a lack of authorised stopping places, (see the accommodation section of this report) and the associated environmental issues, such as a lack of access to hot running water, often made caring difficult. However, for other families living on a permanent trailer site with access to facilities, trailer life continued to offer good accommodation, even when a family member had dementia.

Our research found that caring for people in the later stages of dementia was the most demanding with many carers finding that they could not manage any longer and needed to make the difficult decision to move their loved one into a care home. However, this process was different for individual families, for example, Aunt Sally had struggled to look after her husband but his violent behaviour made it impossible for her to continue to look after him. However, the move into care was discussed with the wider family who had also been involved in his care, and so the decision-making was shared with the wider family. In contrast, Uncle Henry and his wife had to manage alone when caring for his elderly Aunt, and finally they reached a point where they could not cope with her behaviour and she was placed in a care home. However, their decision was not supported by the wider family, even though Uncle Henry and his wife had been left to care for the Aunt alone.

Recommendations

Our recommendations are structured in two parts. The first part is based on recommendations made by the carers and this is followed by recommendations based on the wider findings of the study.

Recommendations made by the Gypsy carers

We asked the carers if they would like to offer any advice to others. Although a number of the carers did not want to offer any advice, those who did, had some interesting insights. For example, **Eunice** reiterated the issue outlined

above, that external agencies were often not sensitive to cultural needs in relation to personal care needs, she stated:

"I think they need to know we can look after our own ok. We don't want them sending no mashes (men) round to wash women or nothing, my poor Aunt would die of fright, but I do think they need to give people more help sorting papers and doctors' appointments and things 'cos sometimes it's hard to understand everything that you're being told".

Aunt Sally reflected:

"it would be a good thing for them to know, it's not only the people in houses that gets this kind of disease".

Tillie, who had been caring for her Uncle with her family for over seven years, thought that other Gypsies did not really understand enough about the condition and reflected that:
Nobody really wants to talk about dementia. Nobody don't want to know about it.

Uncle John who is caring for his 82-year-old brother also highlighted the need to talk about dementia more in the Gypsy and Traveller communities, he stated:

"I think talking about it and having conversations that people understand that dementia and Alzheimer's is an illness and it shouldn't be something that should be embarrassing and be swept under the carpet. So you can't speak out about it. I think it would be better to have conversations with people one to one, to let people express and know and so they get aware of there's other people out there going through the same position... And learn about what's available for them, yes, because I think people can be isolated in this position and they don't know where to look for help so they just carry on with it.

Uncle Henry also suggested that there was a need for greater information:

"I think, personally myself, if people, the travelling community was more of aware of help

they could get, they would want it more. At the moment, they don't know enough about it and they haven't been told anything about it."

Mahala, who was helping to support her Mum, also highlighted the need for more information, she reflected:

"Well I think not just amongst the travelling community, but I've watched different things on telly, I don't think there's enough put in place for people with Alzheimer's and dementia. There's not enough help for anybody out there because in a lot of cases it's one person looking after their husband or their wife on their own with no help at all. I don't think there's enough put in place myself for anybody with Alzheimer's or dementia. Not enough help."

She also had some recommendations on how to support people in the community to learn more about dementia, she stated:

"We don't get a lot of literature on things. I wonder if perhaps people give people discs [DVDs]. I don't think a lot of people actually think about it until it comes upon them... Another thing, like I said, it's hard because you're not the sole carer. If you were the sole carer, I think it would be good to learn about things like meals, healthy meals, or if it can help the person. Especially perhaps, not so much Alzheimer's, but [the] first signs of dementia [also], if people know about healthy food. I know they say also walking and exercise can help with dementia. I think a lot of people don't realise that."

Recommendations based on the findings from this study.

1. Our research found that there is a need to raise awareness in the Gypsy and Traveller community not only about dementia but also on offering information on health promotion. These resources should be developed in partnership with Gypsy and Traveller community members, ensuring these are accessible for anyone with low literacy. It would be useful to produce a

series of short films to be distributed on social media, so that families can access them on their telephone and wider support groups can share them on their websites for health practitioners. In addition, GPs should ensure that questions used in memory clinics are relevant to Gypsy and Travellers communities (for example supporting assessments that do not depend on literacy⁷).

2. Our research suggests that many Gypsy and Traveller families are able to offer care as an extended family, however, is important to avoid the assumption that all the carers will have family support and adult social services should endeavour to reach out to families who may be struggling.
3. Our research found that maintaining and supporting a family member with dementia in a trailer is not generally an issue. However, it is the location of the trailer, and the facilities that are available to the carer (such as access to hot water), that influences the quality of care that they are able to offer. Moreover, the Equalities and Human rights Commission (2019) have also identified that Gypsies and Travellers who have stopped travelling due to old age, ill-health, educational needs or being disabled are being forgotten in planning authorities' site allocation processes (following changes to policy definitions). It is particularly important therefore, that the needs Gypsies and Travellers are considered by Local Plan Authorities in their general assessment of housing needs and special consideration should be made for vulnerable community members such as people living with dementia and their carers. Moreover, Adult Social Services should ensure that wherever possible, that those living with dementia should be supported to stay in the accommodation of their choice, if that is within a trailer site setting, then resources to support care should be available for the family.
4. Our research indicated that there is a need for dementia services to recognise the cultural needs of Gypsies and offer support that responds to their cultural needs for modesty and gender appropriate services. Indeed, culturally tailored professional may be able to help to support carers before institutionalisation appears to be the only feasible option. Clinical commissioning groups should develop a protocol in partnership with Gypsy and Traveller communities, to avoid any misunderstandings in relation to culturally appropriate care and training pack should be available for health and social care staff about cultural needs, in order to improve the quality and cultural appropriateness of care.
5. Nomadic Gypsy and Traveller families should also be able to apply for Direct Payments, so that they are in control of the care for their relatives. Clinical commissioning groups should also consider funding peripatetic outreach for Gypsies, who are often not linked into support services.
6. Our research suggests while many families did not wish to move their loved ones into a care home, in the advanced stages of dementia, many families were unable to cope with the significant challenges they faced. Therefore access to appropriate information, support and advice on respite care, as well as information on care homes may be helpful to families.

⁷ For example, many people in the Gypsy community may fail an assessment on the question about their own birth date, due to birthdays not being considered important to be celebrated or remembered, in many of the elder generation. Many Irish Travellers may consider their baptism date more important and therefore will give that date. Literacy is a problem so some questions may be problematic.

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Front cover in memory of:
Ryalla Duffy

‘It would be a good
thing for them to know,
it’s not only the people
in houses that gets this
kind of disease’

June 2021

