Dementia among Gypsies and Travellers

In the first of two articles looking at the impact of dementia on Gypsies and Travellers, **Mary Tilki** and colleagues explore the challenge for services

Although Gypsies and Travellers have a very low life expectancy, there is growing evidence of dementia in these communities. They experience extremely poor health, and much of this has the potential to increase the risk of dementia. Factors related to the lifestyle and experience of travelling people increase the risk and make it more difficult for people with memory loss and their families to cope with the condition.

There is a growing body of research around the health of Traveller communities (for brevity we'll use this term to include Gypsies), but very little relating to dementia despite increases in prevalence reported by community organisations (LeedsGATE 2015, MECOPP 2012). Here, we will explore some of the challenges for services and a few of the beliefs and experiences to be taken into account when reaching out to travelling communities.

There are three main ethnically defined groups which come under the term 'Gypsies and Travellers': Romany Gypsies, Irish Travellers and Scottish Gypsy Travellers. Romany Gypsies are a related group whose ancestors are believed to have left India in a gradual diaspora across the world from 1000 AD and are first recorded in the UK in the 1500s. Irish Travellers are distinct from other Irish populations and it is argued that they have been a specific group for about 3000 years (Gmelch & Gmelch 2014). Scottish Gypsy Travellers may have ethnic links to both Irish Travellers and Romany Gypsies, but have recently been recognised as distinct from both groups.

The inclusion of a Gypsy or Irish Traveller category in the 2011 census generated a self-defined population of 58,000 people in the UK (ONS 2014). However civil society groups argue this is a significant undercount, reflecting authorities' inertia in obtaining the data (LeedsGATE 2015, Prior 2013). There are clear difficulties getting information about Travellers, but at the same time little effort has been made to obtain the data needed to plan services (Prior 2013, Inclusion Health 2013, KMPHO 2014). Aggregating several groups into a single category masks differences in culture and ignores socio-economic, health and illness profiles which differentiate them.

Poor health status

Research over the last decade demonstrates that the health of Travellers is worse than that of the general population in socially deprived areas (Parry *et al* 2007, Ryan *et al* 2014). Travellers have high levels of cardiovascular disease and an increased risk of diabetes (European Union 2014, Greenfields 2009). Chronic physical and mental illness exacerbates social isolation in an already excluded society and all increase the risk of dementia in a community with low life expectancy.

Despite this health profile, Travellers find access to health services difficult (van Cleemput 2012). The travelling lifestyle or being unable to register with a GP leads many Travellers to go straight to A&E (KMPHO 2014). Literacy is a barrier, precluding those who can't read information or use online resources. Discrimination breeds mistrust of officialdom and previous insensitive encounters with health professionals make people reluctant to seek help. However when a GP, health visitor or community nurse is trusted, Travellers will return from travelling to consult them (Cemlyn *et al* 2009, KMPHO 2014). These barriers are exacerbated for people who develop dementia and impact disproportionately on those who care for them.

While there is a growing body of research on the health of Travellers in the UK and more widely (Greenfields 2009, Goward *et al* 2006, Dion 2008, KMPHO 2014,RCGP 2013), there is as yet limited consideration of dementia (Truswell 2013). It is unclear whether the low levels of recorded dementia relate to short life expectancy, lack of access to GPs or low diagnostic rates in general. Community organisations suggest that lack of awareness of dementia and perceptions of memory loss as a normal part of ageing are factors, but worryingly they are seeing people with dementia at an earlier age than would be expected (LeedsGATE 2015).

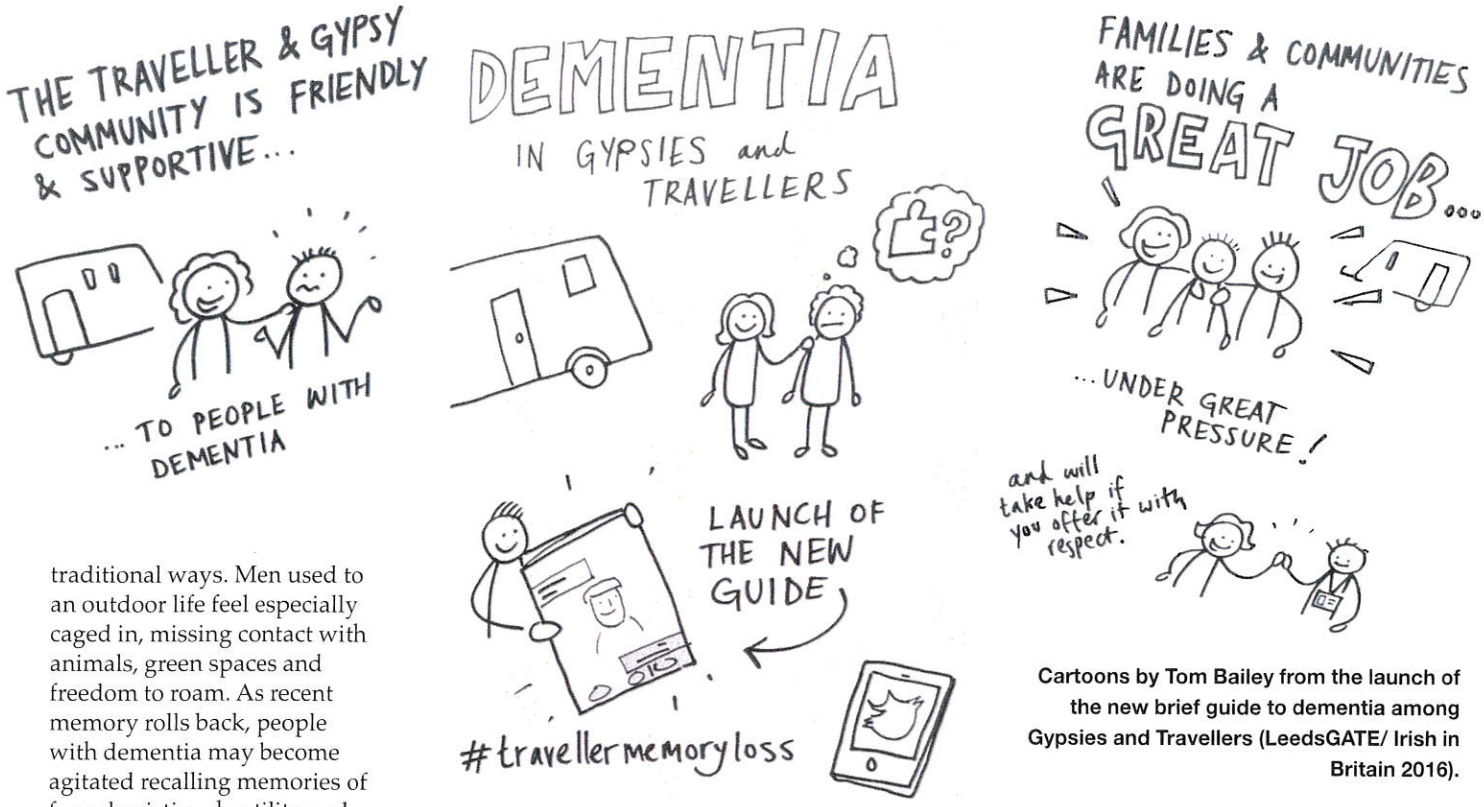
Coping and caring

The difficulties of caring for a relative with dementia are magnified for Travellers for practical, psychological and cultural reasons. Nonetheless, Traveller families expect to care and do so willingly, not seeing themselves as carers (APPG 2013, MECOPP 2012) but as families doing what families do. Invariably the bulk of caring relies on women, but even when relatives rally round, one person often undertakes most of the caring. Carers often misunderstand dementia, assume forgetfulness or confusion are features of ageing but are embarrassed to talk about this outside the family (APPG 2013, Truswell 2013). Norms of respect additionally generate reluctance to talk about this to an (older) person or to take action which they think their loved one might dislike.

The shortage of sufficient, decent Traveller sites (KMPHO 2014) adds to the stress of people living with or caring for somebody with dementia. Inadequate facilities make helping with hygiene, toilet use or additional laundry more difficult. Travellers with dementia used to being on the move risk wandering off the site and getting lost. Keeping a confused person safe on a site where cars are broken or metal recycled poses an added difficulty.

Travellers with increasing disability can feel forced to move into housing and those obliged to support a relative with dementia on a site or in housing experience isolation from family, community and

Mary Tilki is former chair and Charlotte Curran is health coordinator of Irish in Britain while Kim Moloney is chair and Helen Jones is CEO of LeedsGATE. This article is based on a brief guide for commissioners and providers of dementia services developed in consultation with travelling families and a third sector organisation established and run by Travellers (LeedsGATE/Irish in Britain 2016).



Cartoons by Tom Bailey from the launch of the new brief guide to dementia among Gypsies and Travellers (LeedsGATE/ Irish in Britain 2016).

traditional ways. Men used to an outdoor life feel especially caged in, missing contact with animals, green spaces and freedom to roam. As recent memory rolls back, people with dementia may become agitated recalling memories of forced eviction, hostility and even imprisonment.

Health beliefs

There is a culture of self-reliance among Travellers, coping with problems within the family or community. Being in control is important and Travellers are reluctant to be a burden. They are more likely to provide 50-plus hours of informal care to family members each week than the general population (ONS 2014). They are clear about their duty to sick or elderly relatives and the idea of a care home is deplorable to them (van Cleemput *et al* 2007a).

Reluctance to seek external help can arise out of respect for the person with dementia or the inappropriateness or cultural insensitivity of services. It can also be due to pressure from the family or community and women often feel unable to express distress or burnout because of cultural norms and respect for the person they are caring for. They may see this as 'giving in' or being weak (MECOPP 2012) or they may fear reproach from the community if external services are sought. However, this does not mean that families will not accept help if it is negotiated by a trusted professional and allows them to care in a manner meaningful for them and which respects Traveller ways (MECOPP 2012).

Travellers widely believe that illness in general is caused by stress, environment, accommodation and any threat to the travelling lifestyle (Cemlyn *et al* 2009.) They often show fatalism about illness and little confidence in doctors' ability to treat it, coupled with low expectations of their health and a tolerance of chronic conditions (RCGP 2013, KMPHO 2014). Dementia itself is often seen as an inevitable feature of ageing about which nothing can be done (KMPHO 2014). Travellers may seek help only in a crisis because of their beliefs, fears and mistrust of health professionals.

Addressing barriers

The greatest barrier to timely access to diagnostic or support services is Travellers' past experiences of trying to obtain social care. MECOPP (2012) highlighted how approaches to social services often resulted in inappropriate or unhelpful responses, cases closed or left without a care package in place. Being listened to can be a rare experience for Travellers and somebody who is struggling may not have the physical or emotional energy to battle with services who at best don't understand or at worst don't care. Muddling through alone or with the help of family may be more dignified and expedient.

What is clear is that further research is necessary, especially for data to challenge assumptions that lower lifespan means lower levels of dementia. Commissioning bodies should reach out to Travellers, through respected professionals or community groups, to identify what is needed and what culturally appropriate services mean to them. They should offer help proactively rather than assume it will be rejected, and there is potential to train Travellers as lay trainers and advocates in relation to dementia and healthy lifestyles, which might ultimately reduce the risk. After all there is a legal obligation to address health inequalities faced by people with dementia and Gypsy Travellers. In our next article we will look in more detail at what commissioners can do. ■

References

APPG on Dementia (2013) *Dementia does not discriminate: the experiences of Black, Asian and Minority Ethnic communities*. House of Commons All Party Parliamentary Group on Dementia.

Cemlyn S, Greenfields M, Burnett S, Whitwell C, Matthews Z (2009) *Inequalities experienced by Gypsy and Traveller Communities: A Review*. London: Equality and Human Rights Commission.

Dion X (2008) Gypsies and Travellers: cultural influences on health. *Community Practitioner* 81(6) 31-4.

European Union (2014) *Report on the health status of the Roma population in the EU and the monitoring of data collection in the area of Roma health in the Member States*. Brussels: European Commission.

Gmelch S, Gmelch G (2014) *Irish Travellers : The unsettled life.* Bloomington: Indiana University Press.

Goward P, Repper J, Appleton L, Hagan T. Crossing Boundaries. Identifying and meeting the mental health needs of Gypsies and Travellers. *Journal of Mental Health* 2006 15(3) 315-317.

Greenfields M (2009) Falling by the wayside. *Diabetes Update*, Winter 2009 24-29 .

Inclusion Health (2013) *Standards for Commissioners and Service Providers : The Faculty for homeless and service providers*. London: Inclusion Health/Faculty for Homeless and Inclusion Health/College of Medicine/Pathway.

KMPHO (2014) *Kent Gypsy, Roma* ➤