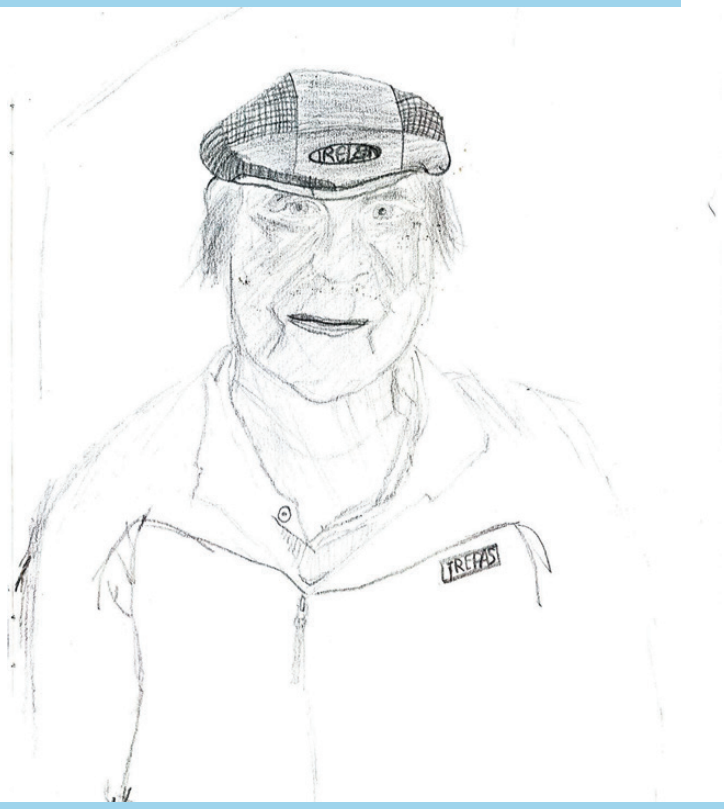
Dementia in Gypsies and Travellers



a brief guide for commissioners and providers

LEEDS GATE
Gypsy and Traveller Exchange

Irish in Britain

Cuimhne
Irish Memory Loss Alliance

Report author: Dr Mary Tilki, *Irish In Britain*

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Cover illustration by Paddy Hanrahan: drawing of his Old Daddy

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Foreword

As someone who is totally committed to helping society tackle the many challenges that people with dementia and their carers face daily, I am really delighted to write a foreword for this guide for commissioners and providers of services for Gypsies and Travellers with dementia. There is widespread recognition at the highest level of government about the present and potential future impacts of dementia. The search for ways to enhance the quality of life for those affected is a constant and complex one. This guide will provide a body of knowledge and recommendations that have the potential to open up new ways that commissioners, providers and the community understand and support the needs of Travellers and Gypsies. It also provides examples of good practice and guidance of how this can be achieved.

There is an increasing recognition that some highly vulnerable groups such as Gypsies and Travellers remain hidden. Gypsies and Travellers have some of the poorest health in Europe and although their life expectancy is short, there is growing evidence that they experience dementia at an earlier age. The discrimination they experience, inadequate living conditions, the Travelling lifestyle, inability to access healthcare and the lack of culturally appropriate services make life more difficult for people with dementia and those who care for them. I welcome and fully support this guide which raises the awareness of the issues of dementia faced daily in Gypsy and Traveller communities.

Ian Kenneth Grant Sherriff

Academic Partnership Lead for Dementia Peninsula School of Medicine and Dentistry.

Chair of the Prime Minister's *Rural Dementia Task and Finish Group*, and a member of the Prime Minister's *Dementia Friendly Challenge* group.

Introduction

Although Gypsies and Travellers generally have a low life expectancy (CLG 2012), there is growing evidence of dementia in these communities.

Gypsies and Travellers (herein, for brevity, referred to as Travellers) experience extremely poor health. This ill-health, much of which is caused by cardio-vascular disease and depression, potentially increases the risk of dementia. Social factors related to the lifestyle and experience of Travelling people also increase the risk and make it difficult for people with memory loss to cope with the condition. These matters also impact on the ability of family and community to cope, although their willingness and skill to do so is strong.

The aim of this guide is to raise awareness of the increasing evidence and risk of dementia in Traveller communities, to highlight the factors which predispose to this and to examine the additional difficulties experienced by Travellers with memory problems and the people that care for them. The intention is to draw the attention of policy makers and commissioners to this multiply disadvantaged group, and to make recommendations about how their needs should and could be met.

The inclusion of a Gypsy/ Traveller category in the 2011 national census generated a self -defined population of 58,000 people in the UK (ONS 2014) although civil society groups argue that this is a significant undercount (LeedsGATE 2014, Prior 2013). The census category "Gypsies and Travellers" fails to distinguish between the three main ethnically defined groups, Romany Gypsies, Irish Travellers and Scottish Gypsy Travellers and others often included in this catch –all term (Appendix A). Aggregating several groups into a single category masks differences in culture and ignores socio-economic, health and illness profiles which may differentiate ethnic groups. In addition, there is a distinct lack of effort by Joint Strategic Needs Assessment (JSNA) bodies to obtain the information needed to plan services for Travelling people, leaving scant information about Traveller sites or knowledge about local communities. The lack of data allows commissioners

and providers to assume that Travellers choose not to access services. Delayed or limited access to services is seen as self-segregation, but few attempts are made to understand why Travellers avoid using mainstream services, or to reach out to them.

The health of Travellers is poorer than that of the general population, or of non-Travellers in socially deprived areas.

Literacy, travelling and suspicion among Travellers can make data collection difficult, but there are examples of good practice (Appendix B).

It has been shown for some time that the health of Travellers is poorer than that of the general population, or of non-Travellers in socially deprived areas (Parry et al 2004, 2007; Ryan et al 2014). Much of this ill-health is of a chronic nature and many suffer from multiple health problems, exacerbated by their social conditions and ever-present racial abuse and discrimination. There are high levels of psychological illness in Gypsy/Traveller communities (Van Cleemput et al 2007) related to the fear or experience of eviction or the separation of people forced to live in settled housing far from family, friends and their Travelling lifestyle. The premature death of family members, and the high level of suicide evident in Traveller communities, also contribute to poor psychological status (Van Cleemput 2012) and increase the risk of dementia (Appendix C).

Despite their poor health profile, Travellers find it difficult to access health services (Traveller Movement 2016). This is only partly related to their Travelling lifestyle, because settled Travellers also have difficulty registering with GPs or having their problems taken seriously.

Experiences of racism, discrimination and insensitivity during previous encounters with health professionals play a bigger role in generating...reluctance to seek help.

While some beliefs delay Travellers accessing services, their experiences of racism, discrimination and insensitivity during previous encounters

with health professionals play a bigger role in generating mistrust and reluctance to seek help. However, this does not mean that families will not accept help if it is negotiated by a trusted professional and if it allows them to care in ways which respect Traveller ways. Research shows that when a GP, health visitor or community nurse is trusted, Travellers will return from long distances to consult that professional.

Dementia in Gypsy and Traveller communities

Although dementia is widely discussed in the UK, there is limited attention to its incidence in minority groups and even less in relation to Travellers.

Community groups highlight growing numbers of families caring for older relatives with dementia.

It is unclear whether the lack of evidence of dementia among Travellers is a true reflection of prevalence, or is due to lower life expectancy, lack of engagement with GPs, or under-diagnosis. Community organisations suggest it reflects a lack of awareness of dementia in Traveller communities, combined with an acceptance that memory loss is a normal part of ageing.

Despite the lack of evidence, community groups highlight growing numbers of families caring for older relatives with dementia, and increasingly, supporting people with young-age dementia.

Coping with dementia in a Travelling community

Learning to cope is a struggle for everybody with memory loss and their families, but the problems for Travellers and their carers are magnified.

Traveller families expect to care, and do so willingly, without seeing themselves as "carers".

Traveller families expect to care, and do so willingly, without seeing themselves as "carers" but as family doing what they are supposed to do. Invariably the bulk of caring relies on women and often on one main carer.

There is a culture of self-reliance in Traveller communities and they tend to cope with problems within the family or community. Being in control is an important aspect of how Travellers see their health and they are reluctant to be a burden to anybody. Many feel clear about their duty to care for ageing or ailing relatives, and the idea of a care home is particularly unacceptable. However, past experiences of trying to access social care, unhelpful or insensitive responses or inappropriate services are a greater barrier than self-reliance (MEECOPP 2012). Muddling through alone, or with the help of family, is often more dignified and expedient than battling with services.

The shortage of sufficient, decent Traveller sites adds to the stress of people caring for somebody with dementia. Travellers caring for older relatives on camps and sites are faced with the inadequacy of water, electricity or waste disposal, which make everyday living frustrating.

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Inadequate services make it harder to help the person with dementia with hygiene, toilet use or additional laundry. Travellers with dementia may be at risk of wandering off the site or getting lost. The response of police towards a confused Traveller may be insensitive, and past experiences of police services may be particularly frightening for a Traveller who is

lost. Men used to an outdoor life feel caged in, missing contact with animals, green spaces and freedom to roam. Travellers who find it difficult to cope with increasing disability may feel forced to move into housing; but the health of housed Travellers is worse than those who are mobile. Equally, family members obliged to give up their Travelling lifestyle to support a relative with dementia feel isolated from extended family, community and their traditional way of life, and risk worsening health.

Travellers hold health beliefs which need to be understood. Lay beliefs and the inherent mistrust of health professionals delay access to services, often seeking help only in a crisis situation. Travellers have low expectations of health, and tolerate chronic conditions so long as they can carry out their daily activities. There is fatalism about health problems and little confidence in doctors' ability to treat illness. Many Travellers lack knowledge about symptoms of dementia, and see it as a normal part of ageing. The fear of a relative being taken into a care home prevents them talking about memory loss or altered behaviour outside the family. Initiatives such as the National Dementia Strategy, Prime Minister's Dementia Challenge or Alzheimer's Society Dementia Friends fail to target messages at Traveller groups and therefore they have less access to information.

Supporting Travellers with dementia

There are issues for commissioners, providers and professionals which are general to all areas of health, such as remembering that Gypsies and Travellers have rights under Race Relations and Equality legislation.

Clearly the social determinants of health must be addressed, such as poor trailer sites with inadequate services, but Travellers who are housed are also likely to have significant ill-health (Traveller Movement 2016).

It is important not to assume that Travellers will reject support, if time is taken to build trust, identify what they feel they need, and provide ways of working which they find acceptable. See Appendix D.

• Don't assume the younger age profile of Travellers precludes dementia. There is a high probability of young-age dementia associated with a wide range of risk factors.

• Recognise the high incidence of long-term physical and psychological ill-health which increase social isolation and so exacerbate dementia risk.

• Consult with Travellers about barriers at professional and provision level. Work with Traveller groups to facilitate access to sites where professionals may be fearful, and consult them about the needs and wishes of people with dementia and their carers.

• Reach out to Traveller communities via recognised Traveller groups or trusted professionals, because open-door policies don't work. (Appendix E).

• Use the term "memory loss" rather than "dementia" or "Alzheimer's", as they are less frightening and stigmatising for Travellers.

• Provide information which does not rely on literacy, such as DVDs, videos, drama. Use Gypsy and Traveller events to access the community, offering funding as necessary to achieve this.

•Provide training for Travellers to become lay trainers and advocates, and empower them to raise awareness of dementia in their own communities, and offer information and support to family carers.

• Encourage early diagnosis so that Travellers with dementia and their families have time to prepare for later stages of life. This may allow those who are suitable to be prescribed drugs which can delay progress. Early recognition may also allow the family and community to learn ways of adjusting to enable the person with memory loss to maintain independence as long as possible.

• Recognise that family carers do not see themselves as 'carers' but as family doing their duty. They feel obliged to care and are willing to do so, but have added difficulties whether the person with dementia lives in a trailer or in a house.

• Offer help proactively, liaising as appropriate through trusted professionals. Don't assume external help will be rejected – many will accept help if it is sensitive and culturally appropriate. Be sensitive to and work with the social, cultural and economic factors impacting on the ability of the family to care.

• Provide specialist support and funding for lay trainers/ advocates, to enable them to develop appropriate skills and resources to empower people with dementia, family carers and the wider community.

• Work in partnership with statutory bodies, Traveller groups, third sector organisations and volunteers to make sites dementia friendly and expand culturally appropriate facilities for Traveller with dementia, recognising the mobility of the community.

• With a view to preventing dementia, encourage and fund Travellers to become lay trainers/advocates in cardiovascular disease, smoking cessation, weight management, healthy living.

• Consult with Travellers, especially those with dementia and their carers, to identify what culturally sensitive care might mean on a Traveller site, in settled housing, or in residential care homes.

• Although Travellers are reluctant users of residential or nursing homes, when they do need respite or long term care, their beliefs and traditions are generally misunderstood. Staff need training to understand the barriers faced by Travellers and to learn how to care for them in ways which respect their culture and way of life.

Conclusion

This guide is based on the limited evidence which is available. A fuller review of relevant research evidence is available in the more detailed report on LeedsGATE's website, **www.leedsgate.co.uk.**

Although there are challenges to be overcome in reaching out to Gypsies and Travellers living with dementia and providing services which are sensitive to the culture and lifestyle of Travelling people, there is some evidence of what works best and also some examples of good practice (Appendix F).

References

CLG (2012) Progress report by the ministerial working group on tackling inequalities experienced by Gypsies and Travellers. London. Department for Communities and Local Government. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/6287/2124046.pdf

LeedsGATE (2015) Dementia in Gypsy and Traveller communities. Leeds Gypsy and Traveller Exchange. http://www.LeedsGATE.co.uk/2015/09/07/dementia-in-gypsy-and-traveller-communities/

MECOPP (2012) Hidden carers, Unheard voices: informal caring within the Gypsy/ Traveller community in Scotland. MECOPP.

ONS (2014) Gypsy or Irish Travellers smallest ethnic minority at 58,000 http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/what-does-the-2011-census-tell-us-about-the-characteristics-of-gypsy-or-irish-travellers-in-england-and-wales-/sty-gypsy-or-irish-travellers.html

Parry, G., Van Cleemput, P., Peters, J., Walters, S., Thomas, K., Copper, C (2007) Health status of Gypsies and Travellers in England. Journal of Epidemiology and Community Health 61, pp 198–204.

Prior, P .(2013) Support and care for people living with dementia from minority communities. Produced for North East Dementia Alliance .

Ryan, L., D'Angelo, A., Puniskis, M., and Kaye, N. (2014) Analysis of 2011 Census data. Irish community statistics, England and selected urban areas: Report of England, Irish in Britain/ Middlesex University

Traveller Movement (2016) Impact of insecure accommodation and the living environment on Gypsies' and Travellers' health. London Traveller Movement/ Inclusion Health. http://travellermovement.org.uk/wp-content/uploads/NIHB_-_Gypsy_and_Traveller_health_accs.pdf

Van Cleemput, P. (2012) Providing healthcare to Gypsy and Traveller communities. Nursing in Practice May/June 2012) ;26-28

Van Cleemput, P., Parry, G., Thomas, K., Peters, J. (2007) Health-related beliefs and experiences of Gypsies and Travellers: A qualitative study. Journal of Epidemiology and Community Health 61: 205-210

Appendices

Appendix A: Definitions

• Using the catch-all term "Gypsies and Travellers" requires some explanation. There are three main ethnically defined groups within this term - Romany Gypsies, Irish Travellers and Scottish Gypsy Travellers.

•Romany Gypsies (Gypsies, Romanies) are a related group of people whose ancestors are believed to have left India in a gradual diaspora across the world from 1000 AD. Romany Gypsies are first recorded in the UK in the 1500s.

•Irish Travellers are a related group of people, distinct from other Irish populations. The distant history of Irish Traveller people is less well understood but it may be that they have been a distinct group for at least 3000 years (Gmelch and Gmelch 2014).

•Scottish Gypsy Travellers may have ethnic links to both Irish Travellers and Romany Gypsies but they are identified as distinct from both groups and have recently been recognised as such in case law.

•There are other groups, not considered in this work, who are sometimes included in this catch-all category. This includes European Roma people who are related to UK Romany Gypsies but have distinct culture, traditions and European experience. Showmen and Circus People are not ethnically defined in UK law but also have distinct cultures and experiences. There are also sub-groups of the mainstream UK population who have adopted a 'travelling' or alternative lifestyle, sometimes over several generations.

Appendix B: Data deficits

There are clear difficulties getting information about nomadic groups and this can be exacerbated by literacy problems and suspicion within these communities. However, with commitment and creativity more accurate information can be obtained.

For example, in the total absence of data at the time, Leeds Baseline Census of Gypsies and Travellers 2005 (Leeds REC 2005) captured baseline information about Gypsy and Traveller communities in Leeds. The researchers used a chain referral or Andalusian snowball sampling method to identify fellow community members. It was innovative in that it was undertaken by community

researchers using a very simple form, which required little literacy to complete or to understand.

This approach elicited a count of around 3000 individuals in the Leeds Metropolitan area in comparison with 687 from the national census. While this research is a decade old, there is still evidence that very little effort is made to obtain Gypsy and Traveller data (Prior 2013, Inclusion Health 2013, KMPHO 2014).

Appendix C: Health profile

It has been shown for some time that the health of Gypsies and Travellers is poorer than that of the general population or of non-Travellers in socially deprived areas (Parry et al 2004, 2007, Ryan et al 2014). Much of this ill-health is of a chronic nature and many suffer from multiple health problems, exacerbated by their social conditions and ever present racial abuse and discrimination. Various studies in Europe, including Ireland and the UK, suggest Gypsies and Travellers have high levels of cardiovascular disease as well as some increased risk of diabetes (European Union 2014, Greenfields 2009).

Gypsies and Travellers experience high levels of chronic illness which limits their daily activities and predisposes them to social isolation in an already excluded society. High levels of smoking persist in Gypsy and Traveller communities, often related to the various stresses they are exposed to.

There are also high levels of psychological illness in Gypsy Traveller communities (Van Cleemput et al 2007). The inadequacy of authorised sites and the fear or experience of eviction from unofficial sites creates great stress, particularly as families are separated and displaced. Travellers who have settled in housing equally experience distress, having lost their traditional lifestyle and generally exposed to racism in new and hostile environments. There is a reluctance to talk about mental health in Traveller communities and there is evidence of a tendency to resort to alcohol, prescription drugs or drugs prescribed for somebody else as coping strategies (Fountain 2006).

Because of the very extended notion of the family, bereavement is a major cause of depression which lasts for prolonged periods among Travellers. The premature death of family members and the high level of suicide evident in Gypsy/Traveller communities contribute to poor psychological status (Van Cleemput 2012). All these physical and psychological factors potentially increase the likelihood of dementia.

Appendix D: Generic issues to be considered in planning and providing for Gypsies and Travellers with dementia

• There are issues for commissioners, providers and professionals which are general to all areas of health, such as reminding them that Gypsies and Travellers have rights under Race Relations and Equality legislation.

• Authorities have a duty to obtain evidence about Gypsy and Traveller communities and incorporate this data into Joint Strategic Need Assessments, Health and Wellbeing Strategies. This is patchy to date.

• There is widespread evidence of a need for data on Gypsies and Travellers, with sound mechanisms for data collection and monitoring.

• There is a need to ensure that Gypsies and Travellers understand that ethnicity data gathering is for the purpose of monitoring the effectiveness of services and not for surveillance.

• Gypsies and Travellers should not be defined by their Travelling status and the diversity within this broad category must be recognised.

• As a minimum, HWB/CCGs bodies should have an "inclusion" Champion with knowledge and understanding of the circumstances of Gypsy/Traveller community members.

• There is a need to outreach to Gypsy and Traveller communities, accessing them as necessary through existing groups and/or trusted professionals

• Established groups such as LeedsGATE, FFT, Traveller Movement or local Travelling community organisations should be collaborated with and funded to connect with and identify the needs and wishes of Gypsies and Travellers

• Cultural awareness training for professionals can be delivered very effectively by Gypsies and Travellers (Carr et al 2013)

• Do not assume Gypsies and Travellers will reject help and support, but be prepared to take time to build trust, identify their needs and not your own agenda (Leeds GATE 2013).

• Recognise and address the social determinants of health i.e. poor trailer sites, near motorways, sewage works, municipal dumps which impact on the health of Gypsies and Travellers.

• Recognise that there may be even worse health and exposure to discrimination among Travellers living in houses.

Appendix E: Outreach to Gypsy and Traveller communities

• Outreach works when (potential) users are involved in planning and decision making. Engaging from within a community allows trust to be established, reduces suspicion and makes for services which are acceptable to marginalised people.

• Outreach is more than a one-off event. It is a longer term activity, associated with establishing links, building trust in order to develop the capacity of Traveller communities to improve their own health.

• Mobile services might be needed initially to establish trust before mainstreaming a service, so long as provision is culturally sensitive. They are not a long-term solution.

• Outreach is not uni-directional. It is about engaging with disengaged communities and working with them to change systems and processes which currently exclude them

• Outreach is about recognising the strengths and resilience in Travelling communities and working with them, consulting, listening and building on existing support systems and networks.

• Outreach is not about imposing a particular viewpoint, but about working with people who understand the community and learning what would work and how.

• Cultural awareness training delivered by Travellers can be effective in improving knowledge and understanding among professionals, but must be paid for.

• One size does not fit all. While lay trainers may be acceptable with some groups or to address some health matters, trusted professionals may be more acceptable and credible for other groups or issues.

• Lay trainers or Traveller groups have a significant role to play in consulting with Travelling communities, raising awareness of dementia or providing culturally sensitive support to people with memory loss and their carers.

• The involvement of lay trainers or Traveller groups in consultation or health promotion is not cost free, but a modest investment in their services has the potential to be cost saving and effective in the long term.

Appendix F: Examples of guidance/good practice which could translate into dementia services

Carr S et al (2014) Outreach programmes for health improvement of Traveller Communities: A synthesis of the evidence. Public Health Research 2, (3). NHS/NIHR

Inclusion Health (2013) Standards for commissioners and service providers: The Faculty for Homeless and Inclusion Health/ College of Medicine/Pathway

KMPHO (2014) Kent Gypsy, Roma and Traveller Populations JSNA Chapter Update 2014. Kent and Medway Public Health Observatory

LeedsGATE/ FFT (2015) The National Gypsy and Traveller Health Inclusion project 2012- 2015 LeedsGATE Gypsy and Traveller Exchange /Friends Family and Travellers

LeedsGATE (2013) Gypsy and Traveller health: who pays? Health pathways: cost benefit analysis report. LeedsGATE Gypsy and Traveller Exchange /Real-Improvement

LeedsGATE (2011) How to engage with Gypsies and Travellers as part of your work. LeedsGATE Gypsy and Traveller Exchange / Inclusion Health

MEECOPP Carers Centre: Gypsy Traveller Carers Project http://www.mecopp.org.uk/services-gypsy_traveller_carers_project.php?section_id=231

MEECOPP Carers Centre: Gypsy Traveller Seminars http://www.mecopp.org.uk/services-gypsy_traveller_seminars.php?section_id=264

RCGP (2013) Improving access to health care for Gypsies and Travellers, homeless people and sex workers: An evidence-based commissioning guide for Clinical Commissioning Groups and Health and Wellbeing Boards. Royal College of General Practitioner/ Inclusion Health

Roma Support Group: Empowering the Roma Community since 1998. http://romasupportgroup.org.uk/

Traveller Movement Health and Wellbeing projects http://www.travellermovement.org.uk/what-we-do/projects/health-wellbeing/

Irish in Britain, through the ***Cuimhne*** *Irish Memory Loss Alliance*, aims to empower services to be knowledgeable and inclusive so that all Irish people living with memory loss and their family carers are supported within their own communities.

We recognise that the Irish Travelling community have very distinct unmet health needs, and therefore we are working in partnership with LeedsGATE to develop strategies that are inclusive of the cultural needs of those living with memory loss.

Produced by

Leeds GATE
169 Cross Green Lane, Leeds LS9 0BD
0113 240 2444
www.leedsgate.co.uk
facebook.com/LeedsGATE
twitter.com/LeedsGATE

Irish in Britain
356 Holloway Road, London, N7 6PA
0207 697 4081
www.irishinbritain.org
facebook.com/irishinbritain
twitter.com/irishinbritain

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