

Agenda – Health, Social Care and Sport Committee

Meeting Venue:	For further information contact:
Committee Room 3 – Senedd	Sian Thomas
Meeting date: Thursday, 23 March 2017	Committee Clerk 0300 200 6291
Members pre-meeting: 09.00 – 09.15	SeneddHealth@assembly.wales
Meeting time: 09.15	

At its meeting on 15 March, the Committee agreed a Motion under Standing Order 17.42(vi) to exclude the public from item 1 of today's meeting

Informal pre-meeting (09.00 – 09.15)

Private

1 Inquiry into loneliness and isolation – inquiry refresh

(09.15 – 09.30)

(Pages 1 – 5)

Public

2 Introductions, apologies, substitutions and declarations of interest

3 Public Health (Wales) Bill – stage 2 proceedings

(09.30 – 15.00)

Rebecca Evans AM, Minister for Social Services and Public Health

Chris Tudor-Smith, Senior Responsible Officer

Nia Roberts, Legal Services



Cynulliad
Cenedlaethol
Cymru

National
Assembly for
Wales

The [Health, Social Care and Sport Committee](#) agreed on 16 February 2017, under Standing Order 26.21, that the order of consideration for Stage 2 proceedings will be:

Sections 3 to 26, Section 2, Sections 27 to 52, Sections 54 to 91, Section 53, Sections 92 to 124, Schedules 1 to 4, Section 1, Long title

Documents relevant to Stage 2 proceedings are available on the [Bill page](#).

4 Paper(s) to note

Letter from the Chartered Society of Physiotherapy, Royal College of Speech and Language Therapists and College of Occupational Therapists regarding the Welsh Government's draft national dementia strategy

(Pages 6 – 9)

Letter from Lynne Neagle AM to the Cabinet Secretary for Health, Well-being and Sport following the Cross-Party Group on Dementia regarding the Gypsy, Traveller and Roma community

(Pages 10 – 33)

5 Motion under Standing Order 17.42 to resolve to exclude the public from the remainder of the meeting

6 Inquiry into the Welsh Government's draft national dementia strategy – consideration of draft letter

(15.00 – 15.15)

Document is Restricted

Agenda Item 4.1

Ymroddio i achysu Cofal Cymdeithasol a Chwaraeon
Health, Social Care and Sport Committee
HSCS(5)-10-17 Papur 2 / Paper 2

Dr Dai Lloyd AM
Chair, Health, Social Care and Sport Committee
National Assembly for Wales
Cardiff Bay
Cardiff,
CF99 1NA

13 March 2017

Dear Dr. Lloyd AM,

Re: Health, Social Care and Sport Committee Inquiry into Draft Dementia Strategy

The Royal College of Speech and Language Therapists (RCSLT), Chartered Society of Physiotherapy (CSP) and the College of Occupational Therapists (COT) welcome the Health, Social Care and Sport committee's decision to undertake a short inquiry into the draft Welsh Government dementia strategy. Allied Health professions (AHPs) have a key role to play in transforming dementia care and enabling people to live well with the condition. As organisations representing AHPs, we have a number of key concerns about the strategy in its current form and would be grateful if the committee could give consideration to the important issues which we raise.

COT, CSP and RCSLT welcome the Welsh Government's work to date on developing Wales' first Dementia Strategy. Our members want to ensure that the vision for dementia care for Wales is ambitious and delivers real change. We have listed below seven key improvements which we believe must be included if the strategy is to deliver on its commitment to create a dementia friendly nation.

We believe that the Dementia Strategy should:

1. **Include a separate theme on prevention and early intervention** with a focus on enabling people with dementia to maximise their own wellbeing and build resilience and skills to support them in later stages of the journey. This should include support to maintain relationships, roles, work and occupation. This would be consistent with the aims of both the Social Services and Wellbeing (Wales) Act 2014 and the Wellbeing of Future Generations (Wales) Act 2015, which are quoted within the document. Prevention also needs to be highlighted as a key theme in the section on living as well as possible with dementia.
2. **Include separate themes for palliative care and end of life as key stages within the pathway.** There should be references within these themes to the proposed Welsh Government End of life Strategy but the prognosis for the disease necessitates a greater focus on this area within the strategy, with particular reference to legal issues such as power of attorney and overcoming barriers which may prevent people with dementia being able to die in their place of choice.

3. **Recognise the key role of AHPs in supporting people living with dementia** –AHPs have a unique spectrum of professional skills which are crucial in helping people with dementia to cope better and have an improved quality of life. We believe that the document, in its current form, misses a crucial opportunity to set out a new vision for how care could be delivered differently by enhancing a multi-disciplinary approach to care at home and in care homes, following diagnosis. In our view, dementia support post diagnosis should include access to multi-disciplinary support from a range of therapists to promote independence and support people to develop the skills they will require in the later stages of dementia. There is much we can learn from the Scottish approach where AHPs are regarded as a key pillar within the post diagnostic stage and are explicitly highlighted within the 2013 strategy and proposals for the 2017 strategy. For example, the proposals for Scotland’s National Dementia Strategy has a key action of working collaboratively with the new Integrated Joint Boards to support locality planning and re-design of dementia services. This includes ‘enhancing a multi-disciplinary approach to care at home, including the promotion of therapeutic and enabling role of AHPs for people with dementia¹. A proposed key action added in **page 26** of the draft Welsh dementia strategy might be:

Health boards, local authorities, housing providers, primary care clusters and third sector providers should:

- Support people who have been diagnosed with dementia and their families to access daily activities which are enjoyable, meaningful and support feelings of self-worth.
 - Teach people who have been diagnosed with dementia strategies and techniques to maintain their independence doing the daily activities that are important to them.
 - Ensure timely access to therapy services including occupational therapy, physiotherapy and speech and language therapy as routine.
4. **Recognise the importance of rehabilitation and reablement and enablement within the strategy document and include specific actions in this regard-** the document needs to highlight that enablement and reablement are important, not just for prevention and delay of onset but in the prevention and loss of skills and abilities. An enablement approach includes identifying the strengths and abilities of people with dementia. Dementia should not be used as a screening tool for excluding people from accessing the services they need.
5. **Recognise the importance of communication support and support for swallowing, eating and drinking difficulties within the strategy document** - We are very concerned about the scant references to communication within the document. Communication problems occur in all forms of dementia and in the later stages, these problems become increasingly challenging. Communication difficulty has been described as one of the most frequent and hardest to cope with experiences for family members² (Egan et al 2010) and can be exhausting for the person with dementia and affects their identity and relationships. We strongly believe that the strategy should include greater detail on communication needs given its strong link with challenging behaviour, relationships, safeguarding issues and consent. Proposed actions should include access to communication support for people with dementia and their families. Speech and language therapists as experts in communication with the specialist knowledge and skills to directly assess and manage problems should be explicitly referenced within the document, as are other professions. In addition, it is concerning that no references to swallowing, eating and drinking difficulties and associated actions within the strategy. Dysphagia is a recognised challenge for people with dementia, particularly in the later stages of the disease. As a minimum, we would expect these needs to be highlighted within key sections of the document including – support to stay safe and secure in the home and community, safeguarding, addressing workforce training needs, care homes.
6. **Make changes to the safeguarding section of the document** to recognise the safeguarding issues for carers of people with dementia who may also be at risk.
7. **Reference the importance of AHPs with regard to ‘silent harms’** – AHPs can ensure people with dementia remain active and are not prevented from activity by a risk averse approach.

¹ Scottish Government (2016) *Proposal for Scotland’s National Dementia Strategy*.
<http://www.gov.scot/Resource/0049/00497716.pdf>

We would be very happy to discuss these points with you further if it would be helpful to do so. We also include in **Annex A** a number of references to documents which may be of interest to the committee, including three joint documents produced by Alzheimer Scotland and the Scottish Government on the contribution of AHPs to dementia care.

Yours sincerely,

Ruth Crowder, Wales Policy Officer, College of Occupational Therapists

Philippa Ford MBE MCSP, Public Affairs and Policy Manager for Wales, Chartered Society of Physiotherapy

Dr. Caroline Walters, Wales Policy Officer, Royal College of Speech and Language Therapists



College of Occupational Therapists
Coleg Therapyddion Galwedigaethol



Annex A – Links to documents of potential interest to the Health, Social Care and Sport committee

[Allied Health Professionals Dementia Champions - Agents of Change](#) features practice examples provided by some of the AHP Dementia Champions, illustrating how they are implementing new ideas and developing innovations in practice. It describes the impact that they are having as they work in partnership with healthcare support workers, paid carers in care homes, home care services, relatives, students, GPs and Alzheimer Scotland.

[Allied Health Professionals Delivering Post-Diagnostic Dementia Support](#) features the role AHPs can play, including best practice examples, in supporting people with dementia in the first year after diagnosis, based on Alzheimer Scotland's 5 Pillar model of Post-Diagnostic support and implemented by the Scottish Government through their Post-Diagnostic Support Guarantee. The work of AHPs, through early interventions and therapeutic approaches, can make a huge difference to how well someone can live with dementia.

[Allied Health Professionals Delivering Integrated Dementia Care](#) - AHPs have a vital role to play in the delivery of integrated care, support and treatment for people with dementia, and those who care for them, in Scotland's communities. In particular, AHPs have a unique spectrum of professional skills which are crucial in delivering a range of non-pharmacological therapeutic interventions which tackle the symptoms of dementia, help people cope better and improve their quality of life. This publication shows the work AHPs are already involved in at several test sites of Alzheimer Scotland's 8 Pillar Model of Community Support across Scotland. This is directly linked to Commitment 4 in [Scotland's current National Dementia Strategy](#).

Questions to Vaughan Gething, Cabinet Secretary for Health, Well-being and Sport following the Cross-Party Group on Dementia (9 March 2017)

Questions submitted by Lynne Neagle AM, Chair of the Cross Party Group on Dementia, on behalf of Alzheimer's Society Cymru and the British Association of Social Workers Cymru.

'Travelling to a Better Future' was developed because Welsh Government acknowledged that 'Gypsies and Travellers have long been one of the most disenfranchised and marginalised groups in society and that Welsh Government is committed to redressing the inequalities faced by Gypsies and Travellers by improving equality of opportunity for all'.

What is Welsh Government doing to ensure that the Gypsy, Roma and Traveller citizens of Wales:

1. Are aware of the consultation on the draft Dementia Strategy for Wales?
2. Are being supported in engaging with the consultation process?
3. Will be part of reviewing the implementation of the strategy?

As 'Travelling to a Better Future' clearly asserts 'Wales's unique position and commitment to Gypsies and Travellers and also our continued commitment to equality issues, community cohesion and human rights in Wales'.

4. How will an all Wales Dementia Strategy ensure that the equality, community cohesion and human rights of GRT citizens in Wales are guaranteed?

LYNNE NEAGLE AM

Assembly Member for Torfaen

Vaughan Gething AM
Cabinet Secretary for Health, Well-being and Sport
Welsh Government
Correspondence.vaughan.gething@gov.wales

Cynulliad
Cenedlaethol
Cymru

National
Assembly for
Wales



14 March 2017

Our ref: LN/CK
Your ref: VG/00400/17

Dear Vaughan,

Thank you for your reply (copy attached for convenience) on the impact of the Dementia Strategy on the Gypsy, Traveller and Roma community in Wales.

I remain very concerned however, based on your response, about whether there has been any real engagement with the GRT community and these are concerns that are shared by the Alzheimer's Society and the representative of the British Association of Social Workers who raised this with me following the CPG. The attached document highlights some of the particular challenges that exist in terms of supporting people in the GRT community who are living with dementia.

I very much welcome the efforts that the Welsh Government are taking to consult on the Strategy. In particular welcome the engagement that is taking place with those living with dementia and really believe that this will help to ensure that the final strategy is a plan that can really make a difference in Wales. I know that the events that the Alzheimer's Society have run with DEEP were not geared towards any specific minority communities. I therefore hope that given that these concerns about the GRT community have been brought to your attention it will be possible for you to give urgent consideration to holding further, additional dialogue with specific groups including the GRT community.

I would also be grateful if you could consider how they can play a part in reviewing the implementation of the Strategy.

Thank you for giving this matter your attention.

Yours sincerely,

LYNNE NEAGLE AM

Assembly Member for Torfaen

CC Julie Morgan AM, Chair of the Cross-Party Group on Gypsies and Travellers
BASW, British Association of Social Workers Cymru
Alzheimer's Society Cymru

Vaughan Gething AC/AM
Ysgrifennydd y Cabinet dros Iechyd, Llesiant a Chwaraeon
Cabinet Secretary for Health, Well-being and Sport



Llywodraeth Cymru
Welsh Government

Ein cyf/Our ref VG/00400/17

Lynne Neagle AM
Assembly Member for Torfaen
73 Upper Troisant Street
Pontypool
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Lynne.Neagle@assembly.wales

21 February 2017

Dear Lynne,

Thank you for your email of 9 February following the cross party group discussion on dementia.

I understand a number of questions were raised specifically around the impact of the Dementia Strategy on the Gypsy and Traveller communities in Wales.

To inform development of the Strategy, a number of engagement events were held across Wales to hear from people living with dementia, family members, carers, health professionals, voluntary organisations and other people with an interest in dementia. My officials have been working in partnership with the Alzheimer's Society and DEEP (Dementia Engagement and Empowerment Project) who have engaged with over 500 people affected by dementia.

The Alzheimer's Society has also undertaken a specific engagement event to better understand the specific needs of the BAME communities and we will ensure that the recommendations from the event are considered when developing the final draft. The feedback has told us that people want significant investment from organisations that promote dementia awareness initiatives to be more inclusive of people affected by dementia from BAME communities using media, information points and engagement events within communities. They want support and services to be delivered with 'a rights based approach' and that action considers all stages of a pathway, starting with awareness of dementia, whilst being sensitive to a person's culture and/or religious beliefs.

Drafting of the plan has been supported by a task and finish group which has included people living with dementia, carers and family members, the Alzheimer's Society and Diverse Cymru to ensure the needs of un-represented groups are fully reflected. The group will continue to meet prior to its publication. As part of the development of this plan, we

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

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We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

have also carried out an Equality Impact Assessment (EIA) which will be reviewed following the consultation period. This process should enable the final document to better reflect the needs of the people of Wales. The final EIA will also be published on the Welsh Government website.

Progress on the delivery of this plan will be overseen by a Delivery Assurance Group that reports to the National Mental Health Partnership Board. The membership of the group will consist of a wide range of stakeholders to ensure it can undertake this function effectively. People with dementia have played an important role in getting the action plan to this stage, and it is important their participation continues. The plan will also be formally reviewed and refreshed after three years, to ensure it remains relevant and appropriately targeted.

The final version of the plan will set out the actions, with performance measures, to be delivered by the Welsh Government and external partners to support people affected by dementia including reviewing any recommendations deriving from the engagement events across Wales.

In addition, the Strategy will complement and interact with other Welsh Government strategies, including a refreshed 'Travelling to a Better Future' and its supporting delivery plan 2017 -2021 due to be published this year, as well as 'Travelling to Better Health', published in 2015 which commits local health boards to achieve a number of outcome measures to improve the health and well-being of gypsy and travellers.

As you know, the strategic action plan is currently out to consultation until 3 April and I would ask you to encourage everyone to respond to the consultation. It is important that people share their experiences of dementia, including unrepresented groups that are seldom heard, so we have a final plan which reflects the needs of people living with dementia or affected by dementia, such as carers and families.

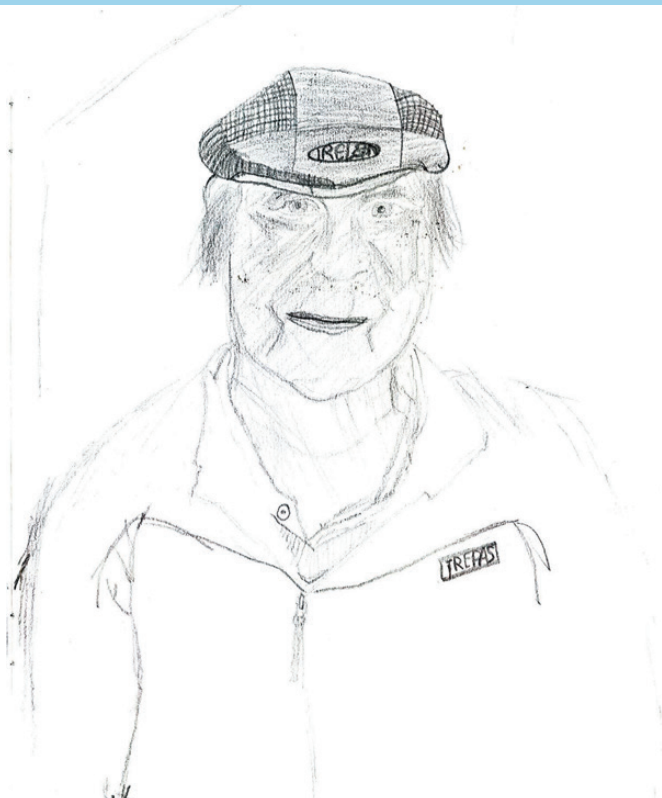
Yours sincerely,

A handwritten signature in black ink, reading "Vaughan Gething". The signature is written in a cursive style with a small dot at the end of the last word.

Vaughan Gething AC/AM

Ysgrifennydd y Cabinet dros Iechyd, Llesiant a Chwaraeon
Cabinet Secretary for Health, Well-being and Sport

Dementia in Gypsies and Travellers



a brief guide
for commissioners and providers



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

With special thanks to Leeds GATE Chair Kim Moloney and her family

Cover illustration by Paddy Hanrahan: drawing of his Old Daddy

Photos: Merlo Michell, Claire Graham, Pete Saunders, Ciara Leeming, and Leeds GATE Archives collection.



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 cardiovascular 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.

(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).

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).

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.

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

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.

growing numbers of families caring for older relatives with dementia, and increasingly, supporting people with young-age dementia.

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



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.

The shortage of sufficient, decent Traveller sites adds to the stress of caring for somebody with dementia.

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.



Dementia - a guide for commissioners/providers

- 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).



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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.

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