



# How can we provide quality and personalised end of life care to Gypsy and Traveller communities?

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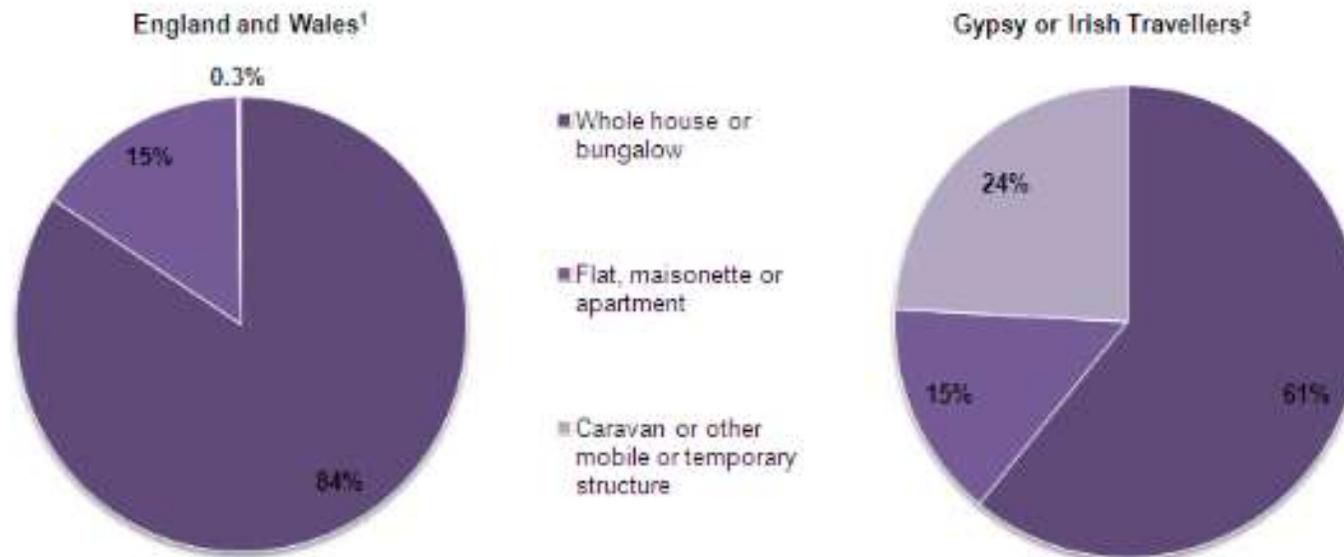
## Gypsy and Traveller communities in the UK

- There are an estimated 300,000 Gypsies and Travellers in the UK.
- There are a number of different groups who fall under the title of Gypsies and Travellers; Romany Gypsies, Irish Travellers, Scottish Gypsies and Travellers, Welsh Gypsies and Travellers, New Travellers, Liveaboard Boaters and Travelling Showpeople.
- Romany Gypsies and Irish Travellers are defined as ethnic groups and protected from discrimination under the Equality Act 2010.



## Nomadism – Census 2011

Figure 8: Accommodation type in England and Wales, 2011





## Accommodation

- 16% of caravans in the July 2017 national caravan count were on unauthorised land, largely as a result of a chronic shortage of sites.
- Families living on unauthorised sites may not have access to basic water and sanitation and may experience stigmatisation and discrimination.
- Repeated evictions are correlated with anxiety and depression but also can present issues around continuity of care.
- Many Gypsies and Travellers report decreases in wellbeing when forced to move into bricks and mortar accommodation.

# PEOPLE LIVE IN FEAR OF THE INVADERS

Police warn landowners over Blacks

**Jews bombed  
out by  
arsonists**

**Beware of working  
Irish warning**

**Knife wielding youths  
attack Jamaicans in  
Hyde Park**

**ASIANS  
LEAVE EVEN  
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**Pensioners breach  
caravan defences**

Gays need to clear off

**Winning the war against  
women**

**Fat people leave  
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**QUADRAPLEGICS DOG  
BIT ME ON THE ARM**

## PEOPLE LIVE IN FEAR OF THE INVADERS

Police warn landowners over travellers

**Beware of working  
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**Travellers breach  
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Travellers need to clear off

**Winning the war against  
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**Gypsies leave  
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**TRAVELLERS DOG BIT  
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## Overview of Gypsy and Traveller health

- Gypsy and Traveller communities are known to face some of the most severe health inequalities and poor life outcomes amongst the United Kingdom population, even when compared with other ethnic minorities.
- Data from the 2011 Census found that in England and Wales, Gypsy or Irish Travellers had the lowest proportion of people rating their general health as 'good' or 'very good' at 70 per cent compared to 81 per cent overall.



# Life expectancy – estimated 10 – 25 years shorter

Barry and Herity, 1987, (Ireland)

Census, 2011

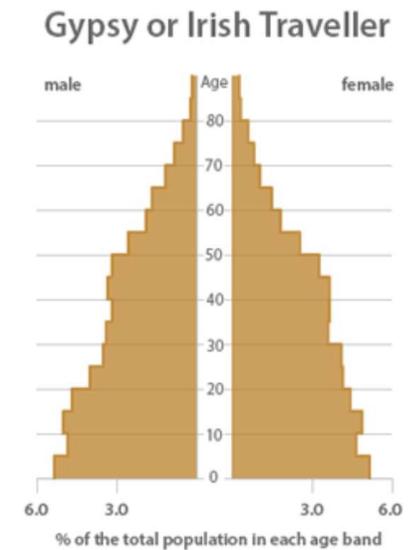
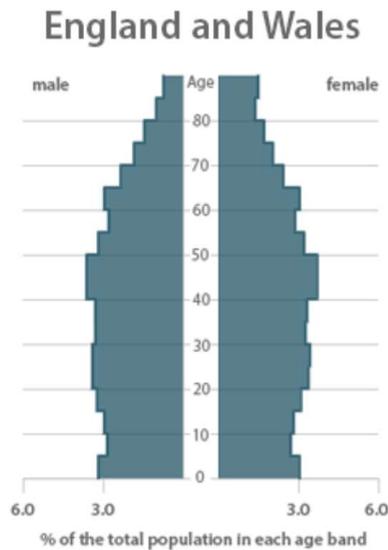
TRAVELLERS' VITAL STATISTICS 1987

TABLE 7  
LIFE EXPECTANCY AT VARIOUS AGES FOR TRAVELLERS  
AND THE IRISH POPULATION, 1987

Age	MALES		Traveller Deficit (Years)
	Travellers	Ireland	
0	61.7	71.6	9.9
15	48.9	57.4	8.5
45	21.3	28.8	7.5
65	10.1	13.1	3.0

Age	FEMALES		Traveller Deficit (Years)
	Travellers	Ireland	
0	65.3	77.2	11.9
15	52.1	62.9	10.8
45	25.1	33.6	8.5
65	10.4	16.4	6.0





## Disclaimer

- In attempting to establish how to provide personalised care to Gypsy and Traveller communities, we should recognise that these are not homogenous groups.
- Personalised care sees each person as a unique individual with their own views, values, aspirations, needs, lifestyles, social and family circumstances.



## General principles

- Ensure that you are communicating in the best way for the individual and family you are working with – both when you're in their presence and when you're not in their presence.
  - Literacy
  - Speak in language people can understand – plain language, no jargon
- Build trust – this may take some time.
- If you're unsure of culture or traditions, ask people who you have built trust with.
- Don't make assumptions.



## Preferences around end of life care

- The extended family is important, especially during illness or crisis.
- Most families care for their own family members.
- Family members will stay with their loved one while in hospital and will even take meals into hospital if their loved one will not eat hospital food.
- Home care for the terminally ill is often preferred to hospital care. Families will usually opt for home care for as long as the health condition will allow.
- Gypsies and Travellers may have preferences around the gender of the person caring for them.



## Supporting the extended family involvement

- It is common for extended family to travel to the place where their loved one is to offer support and pay respects.
- Health professionals can feel unsure about how to support this tradition. They may find it difficult to communicate amount and times of visits and may feel reluctant to speak to the family and resolve problems if they do arise. You should anticipate this and make plans to accommodate the extended family where possible.
- There may be practical considerations if the extended family don't have anywhere to stop.
- Try to find one family member who can act as a contact person for the wider family.



## Cleanliness

- Gypsies and Travellers tend to maintain very high levels of cleanliness to prevent cross contamination. For example:
  - One bowl for washing up, one bowl for cleaning trailers etc., another for washing the body and some people keep another bowl for washing the face too.
  - Animals and other domestic pets would not normally be housed with the family - they would live outside.
- Gypsies and Travellers may worry about not being able to stick to such standards in a hospice or other accommodation.
- Gypsies and Travellers generally have high standards of cleanliness, and, for example, may use bleach in washing up, which can cause problems with other residents.



## Providing quality end of life care at home

- Ensuring continuity of care for mobile communities.
- Addressing lack of confidence in dealing with Gypsy, Traveller and Boater populations.
- Ensuring people are tapping into the specialist services and support organisations they are entitled to or may benefit from.
- Addressing fear around visiting sites or towpaths.



## Fear around visiting sites

Allen and Riding (2018) asked social workers to imagine they had to carry out an initial home visit following a reported domestic disturbance. They showed the participants pictures of two different scenes; one of a typical bricks and mortar street and one of a Traveller encampment and asked them to describe how they felt about carrying out the visit.

The practitioners described feeling comfortable in response to the image of the street, but scared and out of their depth when asked to imagine visiting the Traveller encampment. This suggests that there is a degree of prejudice and fear amongst some social workers who are normally confident and capable in other settings.





## Preference around carers

- Gypsy and Traveller communities often have a strong preference for carers from within the same community.
- Gypsy and Traveller carers who have had to move into bricks and mortar accommodation can often feel isolated.
- Many Gypsy and Traveller carers would not identify themselves as 'carers' and may not be aware that they can receive support.
- Many Gypsy and Traveller carers will not attempt to access support if they do not feel the service being offered is culturally appropriate.



## Lady-Jacqueline's story – Liveaboard Boater

“I’ve got to the point now where I need carers, and they are all boaters. I employ them myself using the budget provided by my social worker. They know how things work on a boat. It’s a completely different way of living to being in a house; you have to be careful not to use too much water or power. And emptying the chemical toilets . . . I can’t see an agency carer going 150 yards down the towpath with my bicycle and trailer and a plastic bucket of poo. There are jobs where you need to know what you are doing, like cleaning all the ash out of the stove and filling the coal scuttle up; carers have to be prepared to lift a bag of coal, and not mind if their hands get a bit dirty.”



## The role of faith

- According to the 2011 Census, the majority of people who identified as Gypsy or Traveller identified were Christian (64 per cent).
- Many members of Irish Traveller communities are Roman Catholic.
- This can be a source of source and hope during pain, suffering and bereavement.
- Members of Roman Catholic communities may be interested in taking pilgrimages in the hope of healing.
- Roman Catholics will usually call a priest to read the last rites and confession just before death.





## Traditions around death and bereavement

- When a member of the Gypsy community is dying or has died, the family will want to take the person or body home.
- A vigil is kept over the body by family members. White sheets are often hung on the walls in which the deceased's body is laid out in. The deceased is never left alone.
- Irish Travellers will often light candles near the bed of the dying person and candles are kept illuminated until after the funeral.
- After death there will continue to be a constant flow of visitors who come to pay their respects to the deceased and their family.



## **Interview with Ivy Manning, Romany Gypsy**

**Do you think the rituals help with the bereavement process?**

Yeah, I think it does. It's a respect thing, we have a fire and we like as many people to come to show respect. There'll always be food, tea and coffee available, there'll be a team of women or girls, mucking in. I don't think it gives much time to grieve, but that's what you initially do and then once they're buried that's when you can shy away and pull yourself back in.



## Traditions around death and bereavement

- During the vigil, the deceased usually lays in an open coffin so that family can see their loved one for the last time and pay their respects.
- Irish Traveller communities often wish to have a funeral quite quickly – within a space of a few days.
- Close family members will wear black following a death in the family. Typically this will be for a year following the death of close family members. Women will often wear completely black and men will often wear a black tie or band.



## Lady-Jacqueline's story – Liveaboard Boater

“I have asked for regular scans so I can be prepared, and at some point I’m going to look at a scan and know I haven’t got long. I’ve got it all sorted, and I’ve had some laughs planning my funeral with family and friends. I will be supported to die at home, and then I want to do things the old fashioned way: I want my body to be kept on the boat for a few days. I will go down the canal on my friends’ beautiful wooden launch to trumpets played by musicians from the community and a procession down the towpath. I have friends who are performance artists and who have a hearse covered with skeletons and green lights, and that will take me from the canal to the burial ground. I can have it exactly how I want it.”



## Gypsy and Traveller funerals

- Gypsy and Traveller funerals can attract people from all over the country and floral tributes are usually on a grand scale. The funeral cortege is often very long.





## Gypsy and Traveller burial

- Once a loved one has been buried it is customary for the grave to be attended regularly by the family and graves are impeccably kept.
- Some Travellers will visit the grave on a daily basis, particularly if the death was sudden or the person was young.



## Useful resources

- Online Gypsy and Traveller Cultural Awareness Training – [available here](#).
- Travellers Times magazine (both online and print) – [view here](#).
- Article in British Medical Journal on End of Life Care on the Water – [view here](#).
- Extended version of this presentation from St. Ann's Hospice Vulnerable Population Lecture Series – [view here](#).
- Friends Families and Traveller Services Directory of Gypsy, Roma and Traveller voluntary sector organisations – [view here](#).
- 'The end of the road – learning to have difficult conversations about death, bereavement and grief' – [view here](#).
- Email us – [sarahsweeney@gypsy-traveller.org](mailto:sarahsweeney@gypsy-traveller.org) and [avril@gypsy-traveller.org](mailto:avril@gypsy-traveller.org)



**Thank you!**

**Keep in touch:**



**@GypsyTravellers**



**@FriendsFamiliesandTravellers**