



Gofal a chefnogaeth
drwy salwch terfynol
Care and support
through terminal illness

RS 16
Ymchwiliad i gysgu ar y stryd yng Nghymru
Inquiry into rough sleeping in Wales
Ymateb gan: Marie Curie
Response from: Marie Curie

Marie Curie believes everyone has the right to palliative care. We believe that there are homeless¹ people in Wales living with a terminal illness who are not getting the palliative care that they need throughout their illness and at the time of their death. This must change and more needs to be done to identify and care for homeless people living with a terminal illness.

Background and introduction

The main focus of the committee's inquiry is naturally into the causes of, problems created by and solutions to Wales' rough sleeping community. Marie Curie would like the committee to explore the lack of a palliative care provision with this community as this is an issue which is often overlooked.

According to the Welsh Government 313 people were sleeping rough in Wales between 10th and 23rd October 2017.² Very little is known regarding the health and wellbeing of these people.

Someone has a terminal illness when they reach a point where they, or their medical team, carers or loved ones, understand their illness is likely to lead to their death. Palliative care aims to treat or manage pain and other physical symptoms. It will also help with any psychological, social or spiritual needs. Treatment will involve medicines, therapies, and any other support that specialist teams believe will help their patients. It includes caring for people who are nearing the end of life. This is called end of life care.

Whilst this inquiry is focusing on rough sleeping, we are also concerned about a wider homelessness problem across Wales and the barriers homeless people who are not rough sleepers face in accessing palliative care.³ Broadly speaking, the law defines someone as being homeless if they do not have a legal right to occupy accommodation, or if their accommodation is unsuitable to live in⁴. This can cover a wide range of circumstances and not just rough sleepers.

Homelessness and terminal illness

Rough sleepers are some of the most vulnerable people in our community and rough sleeping is associated with poorer physical and mental health, and higher mortality rates⁵.

Chaotic lifestyles and the lack of a permanent address, which means people are unable to register with a GP can severely limit access to services. Research suggests that for people with a terminal illness, deteriorating health, increasing isolation and poor mobility may make access to healthcare services, particularly specialist palliative care services, very difficult⁶.

¹ Homeless people include those individuals living on the street, sofa surfing, temporary accommodation systems or hostels.

² <http://gov.wales/statistics-and-research/national-rough-sleeping-count/?lang=en>

³ Not all homeless people are rough sleepers, homelessness people include people of no fixed abode and those living in hostels.

⁴ Shelter

⁵ UK Government 2002 - http://www.fph.org.uk/uploads/r_rough_sleepers_2002.pdf.

⁶ Hudson et al, BMC Palliative Care (2016)

Rough sleepers and homeless people have a much higher risk of death from a range of causes than the general population. It has been well established that the health of people who are homeless is often poor. The average age of death for homeless people is between 43 (women) and 47 (men)⁷. This compares to the 81 (women) and 77 (men) in the general population.

In Scotland a five year study in Glasgow found that being homeless (not specifically sleeping rough) trebles the risk of death from chest conditions and doubles risk from circulatory conditions. Many of the health conditions that homeless people develop in their 40s and 50s are more commonly seen in people decades older. Substance and alcohol abuse contribute to a third of deaths in the homeless population in the UK⁸. Chronic progressive illness such as cancer, liver or respiratory disease are also experienced earlier by homeless people⁹. The study also suggested that homeless people were almost 5 times more likely to die from alcohol-related causes and two and half times more likely to die from circulatory diseases than the general population¹⁰.

The findings from the study in Glasgow suggest that a significant proportion of those people who die each year would be likely to benefit from some form of palliative care. However there is no evidence to show how many (if any) received any form of palliative care.

Following on from this study in Scotland, Marie Curie's hospice in Edinburgh is currently exploring ways in which they can work with local hostels, shelters and charities to identify people requiring palliative care.¹¹

A report by Crisis entitled *Homelessness Kills* looked at mortality rates and statistics for England, which although not covering Wales, can provide a valuable insight until Welsh data can be established. Drug and alcohol abuse was a particularly common cause of death amongst the homeless population, accounting for over a third of deaths¹². Looking at causes of death for homeless people, cancer accounted for 10%, 8% for respiratory disease, nearly 20% for cardiovascular disease, over 14% for alcohol, 22% for drugs and a 11% for other diseases¹³. Homeless people have a greater chance than the rest of the population of dying from HIV and hepatitis, three times more likely to die of chronic respiratory diseases, twice as likely to die of chronic heart disease.

Whilst not specifically looking at people sleeping rough a partnership was established in 2008 between Marie Curie and St Mungo's Palliative Care in London to develop services for terminally ill hostel residents.¹⁴

Barriers to palliative care for homeless people and recommendations for change

Homeless people often die in crisis and with little or no advanced planning. For many homeless people it can be very difficult to identify their palliative needs. Many of the conditions which homeless people suffer from do not have a clear trajectory or pathway, making it difficult to assess when palliative care might be appropriate. The chaotic nature of a homeless lifestyle can also add another layer of complexity to providing palliative care.

There are a range of barriers that can prevent a homeless person receiving palliative care:

Housing – A lack of stable housing or family connections to support the care of someone with a terminal illness is a significant barrier. Homeless people may not be able to register with a GP, and it may be very difficult, or impossible, to get an advanced care plan in place for them. An advanced care plan is a process that enables people to make plans about their future health care and treatment, and any advance decision to refuse a treatment in specific circumstances, including those where they may have lost capacity in the future.

⁷ 'Nowhere else will take him' – palliative care and homelessness, European Journal of Palliative Care, 2017

⁸ Hudson et al, BMC Palliative Care (2016)

⁹ ibid

¹⁰ Morrison DS. Homelessness as an independent risk factor for mortality: results from a retrospective cohort study. *International Journal of Epidemiology* 2009;38:877-883.

¹¹ This project is in its very early stages and no commitments or recommendations have been agreed as of Jan 2018.

¹² Crisis Report

¹³ ibid

¹⁴ <https://www.mariecurie.org.uk/professionals/working-in-partnership/current/st-mungos-palliative-care>

It is also important to note the distinction between homeless families and single homeless people. Where children, and safeguarding, are involved there is often more chance of ensuring access to services. However, this is not the case for adult single homeless people.

There needs to be a 'Housing First' approach for those homeless people living with a terminal illness with fast tracked support, which is appropriate to their needs. Wherever this is possible, and is appropriate, this should include permanent accommodation. A full package of health and social care should be in place from the point of need following the introduction of housing support. Neither should be an add-on to the other, but must work together. Any housing used to support someone with a terminal illness must be of a high quality in order to ensure that the person can receive the care that they need there in an appropriate environment.

Chaotic lifestyles – Alcohol and substance misuse, chaotic living, especially around accommodation. The Crisis report highlights problematic access to healthcare services in general for homeless people, as well as maintaining a treatment regime. Poor access and intermittent care can also exacerbate conditions in homeless people, as can limited advanced care planning.

There is a need to identify the key primary care access points for homeless people and rough sleepers across Wales, and to ensure people have appropriate access to general and specialist community nursing support. This can be offered in a flexible way to meet the needs of homeless people who have palliative care needs.

Identifying a terminal illness – Many homeless people will have advanced liver disease, where prognosis is uncertain, with numerous acute episodes over the course of the disease trajectory, which sees a significant deterioration in the patient before a partial recovery. Managing such a complex trajectory for someone that is homeless is incredibly challenging both in terms of diagnosing them as terminal and then putting in place service support to meet those needs.

Accessible services – Access to hospices and care homes is very rare for homeless people living with a terminal illness. A lack of any fixed abode makes it difficult, if not impossible for community palliative care teams to meet the needs of homeless people. The only possibility may be through a hostel, a setting in which can be very difficult to deliver care and not necessarily set up for end of life and palliative care. Many staff in hostels will not have the training and support they need to support someone at the end of life, despite in many reported instances of going 'above and beyond' in their roles. Education and support should be made available to hostel staff.

Health and social care integration – There needs to be greater links and work between health and social care services, housing services and hostels in health and social care partnerships to support people who are terminally ill and in need of palliative care. Primary care plays a key role in supporting homeless people with health needs, and particularly those who may have a terminal illness and approaching the end of life.

Health and Social Care Partnerships need a robust evidence base in order to commission appropriate services which can meet the needs of local populations, and this must include homeless people living with a terminal illness. Health and Social Care providers need to identify the palliative care needs of their localities and ensure that there are services available to support them.

Training and support for staff – Staff in all health and social care setting need to be able to identify homeless people with palliative care needs – this will require training and support for staff and volunteers. Trust between health and social care staff needs to be improved.

Inadequate Data – We do not know how many people die each year who are rough sleepers or have been sleeping rough. These figures are not routinely collected or published by either the Welsh Government or The Office of National Statistics.

There is also limited data available to show the number of people living with terminal conditions who are homeless whether they are sleeping rough or have recently moved from sleeping rough into a shelter or hostel. It is therefore difficult to know how many people each year need palliative care who have spent time sleeping rough and how many do not get the care and support they need as their terminal illness progresses and they reach the end of life.

There has been very limited research carried out in this area too with very few academic papers and studies published. There has been very little research done looking at either Welsh or UK wide populations in this area. Future research into access to palliative care should consider looking at homeless populations.

Conclusion

It is clear that providing both specialist and general palliative care for homeless people is complicated and challenging and at present not every homeless person living with a terminal illness is getting the care they need.

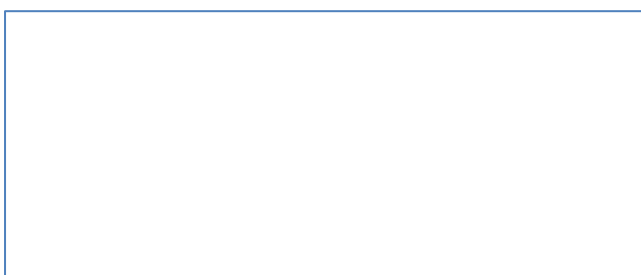
There is no explicit mention of rough sleepers (or homeless) in the Welsh Government's End of Life Strategy (Published March 2017)¹⁵.

Amongst the population as a whole there is a significant and well known unmet need^{16,17} in terms of accessing end of life care and this will be further complicated and more challenging for individuals who are homeless and/or sleeping rough.

We believe that all stakeholders must, at both national and local level, come together to establish the picture for rough sleepers and the homelessness in terms of terminal illness and then develop an appropriate strategic and operational response.

Further reading

The committee may also be interested in the following academic study:



¹⁵ <http://gov.wales/docs/dhss/publications/170327end-of-lifeen.pdf>

¹⁶ <http://www.who.int/mediacentre/news/releases/2014/palliative-care-20140128/en/>

¹⁷ <https://www.mariecurie.org.uk/globalassets/media/documents/commissioning-our-services/publications/understanding-cost-end-life-care-different-settingspdf>

