Marie Curie Response

Scottish Parliament's Local Government Committee Inquiry into Homelessness

Marie Curie believes everyone has the right to palliative care. We believe that there are homeless[1] people in Scotland 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, especially if the Scottish Government's 2021 vision that everyone gets the palliative care they need is to be achieved.

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.

Around 54,000 people approach their local authority for help with homelessness in Scotland each year[2]. Of these, just under 35,000 make a formal application for statutory homelessness support.

Homelessness and terminal illness

Homelessness is associated with poorer physical and mental health, and higher mortality rates[3].

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 homeless people with a terminal illness, deteriorating health, increasing isolation and poor mobility may make access to healthcare services, particularly specialist palliative care services, very difficult[4].

The Scottish Public Health Network published a report in 2015, *Restoring the Public Health Response to Homelessness,* which has provided a renewed focus on this area, including Health and Homelessness Standards[5]. The report noted the higher risk of death faced by homeless people and their comparatively worse health compared to the general population. For example, 41% of homeless people have a long term physical health problem compared to 28% of the general population. However, there was no reference in the standards set out in the document for support for those people who are homeless and living with a terminal illness, including palliative care.

[1] *Homeless people include those individuals living on the street, sofa surfing, temporary accommodation systems or hostels.*
[2] Scottish Government 2016
[3] Hetherington & Hamlet 2015, Homeless Link 2014).
[4] Hudson et al, BMC Palliative Care (2016)
[5] Restoring the Public Health Response to Homelessness

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 death for homeless people is between 43 (women) and 47 (men)[6]. This compares to the 81 (women) and 77 (men) in the general population.

A five year study in Glasgow found that being homeless 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 UK[7]. Chronic progressive illness such as cancer, liver or respiratory disease are also experienced earlier by homeless people[8].

Poor health is not only a consequence of homelessness but can also be an underlying cause. Scottish Government statistics published in June 2014 show that 34% of households assessed as homeless in 2013-14 were assessed as having one or more support needs. This included 13% of people with mental health needs, 14% requiring support or skills for independent living and 12% requiring support because of alcohol or drug dependency. Over 11% of homeless applicants had a recorded drug or alcohol dependency in Scotland. This can lead to chronic liver failure, also called end-stage liver disease, which is a terminal illness and requires a palliative care approach.

A Glasgow study 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 population[9]. A report by Crisis entitled *Homelessness Kills* looked at mortality rates and statistics for England, which although not covering Scotland, can provide a valuable insight until Scottish 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 deaths[10]. 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 diseases[11]. 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.

These statistics suggest that a significant proportion of those homeless people who die each year would be likely to benefit from some form of palliative care. However, there is little or no information out there to show that homeless people are actually accessing palliative care.

There is no evidence to show how many of these people, if any received any form of palliative care, and it is likely that they would have benefited from this care.

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

[6] 'Nowhere else will take him' – palliative care and homelessness, European Journal of Palliative Care, 2017
[7] Hudson et al, BMC Palliative Care (2016)
[8] Hudson et al, BMC Palliative Care (2016)
[9] Morrison DS. Homelessness as an independent risk factor for mortality: results from a retrospective cohort study. *International Journal of Epidemiology* 2009;38:877-883.
[10] Crisis Report
[11] Crisis Report

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.

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 also a clear link between homelessness and people who have been looked after, for example, in care, and those who have been subject to abuse earlier in their lives. Research in the US found that 92% of a racially diverse sample of homeless mothers had experienced severe physical and/or sexual violence at some point in their lives, with 43% reporting sexual abuse in childhood and 63% reporting intimate partner violence in adulthood[12]. As well as contributing to mental health issues and increased potential for substance abuse, this can alienate many homeless people from institutions, making it harder to provide services in a traditional way.

There is a need to identify the key primary care access points for homeless people across Scotland, 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.

[12] Goodman, L, Fels, K, Glenn, C (2006) No Safe Place: Sexual Assault in the Lives of Homeless Women http://vawnet.org/sites/default/files/materials/files/2016-09/AR_SAHomelessness.pdf

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 in line with the NHS Education for Scotland and Scottish Social Services Council Palliative and End of Life Care framework should be made available to hostel staff[13].

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 Partnerships 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 that are homeless nor do we know the cause of death for the homeless people in Scotland. These figures are not routinely collected or published by the Scottish Government or statutory partners.

There is also limited data available to show the number of people living with terminal conditions who are also homeless. It is therefore difficult to know how many homeless people each year need palliative care 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 needs to be more data collected around homelessness and palliative care to support understanding their needs and putting in place the services to meet them.

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 Scottish populations. Future research into access to palliative care should consider looking at homeless populations.

Conclusion

It is clear that 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.

[13] Enriching and Improving Experience: Palliative and End of Life Care Framework (2017) http://elearning.scot.nhs.uk:8080/intralibrary/open_virtual_file_path/i2564n4083939t/Palliative%20framework%20interactive_p2.pdf

There is no explicit mention of homeless populations in the Scottish Government's Strategic Framework for Action on Palliative Care and End of Life, but the framework does commit the Scottish Government to a vision that everyone should the palliative care they need by 2021, which would include those who are homeless.

All stakeholders must, at both national and local level, come together to establish the picture for homelessness and terminal illness and then develop an appropriate strategic and operational response.

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Care and support through terminal illness