



Care and support
through terminal illness

Routes to impact: end of life care for homeless people

The deaths of many homeless people are not planned for and occur following emergency admission to hospitals. Despite the high burden of disease and mortality in this population, they have poor access to palliative care. Reasons for this include the lack of positive interactions between homeless people and healthcare providers, challenges around alcohol and substance use, and methods and models of service delivery. Homeless people are less likely to have family members to advocate for them should their health deteriorate, thus the potential importance of advance care planning for this group has been raised.

In 2018, researchers at the Marie Curie Palliative Care Research Department at University College London published a study entitled 'End-of-life care for homeless people: A qualitative analysis exploring the challenges to access and provision of palliative care'¹.

Led by Dr Caroline Shulman, and published in Palliative Medicine, the study aimed to explore the views and experiences of current and formerly homeless people, frontline homelessness staff and health and social care providers, regarding challenges to supporting homeless people with advanced ill health, and to make suggestions for improving care. The team were awarded 'Research Paper of the Year' in the journal Palliative Medicine for the most outstanding publication in 2018.

The study found growing concern that many homeless people are dying in unsupported, unacceptable situations. It highlighted the complexities of identifying who needs palliative care and lack of appropriate places of care for people who are homeless with high support needs. It also found that due to the lack of alternatives, homeless people with advanced ill health often remain in hostels and suffer from a lack of person-centred care. It concluded that greater multidisciplinary working, extended in-reach into hostels from health and social services and training for all professional groups, along with more access to appropriate supported

accommodation are required to improve care for homeless people with advanced ill health.

The study concludes that greater multidisciplinary working, extended in-reach into hostels from health and social services and training for all professional groups, along with more access to appropriate supported accommodation, are required to improve care for homeless people with advanced ill health.

The study has helped advise commissioning, service provision and national government. In particular:

- In 2018, a free online toolkit was launched based on findings of this study. The aim of the toolkit is to help hostel staff feel confident in supporting homeless people get access to the care they need at the end of life².
- Dr Caroline Shulman is part of the All Party Parliamentary Group for ending homelessness, focusing on preventing deaths in homeless people throughout 2018 and 2019³.
- In 2018, the researchers involved in the study influenced the Faculty for Homeless Inclusion Health's publication 'Homeless and Inclusion Health standards for commissioners and service providers'⁴.

- In 2018, the Tackling Inequalities in End of Life Care for Minority Groups Voluntary Community and Social Enterprise Project Group, which includes Marie Curie, published a resource entitled ‘Care committed to me. Delivering high-quality, personalised palliative and end of life care for Gypsies and Travellers, LGBT people and people experiencing homelessness: a resource for commissioners, service providers and health, care and support staff’⁵. This resource cited this and other pieces of Marie Curie funded research on a range of issues, such as homelessness and end of life care for LGBT people.

Looking to the future, this research can have a far-reaching impact on improving access to end of life care for homeless people:

- Training more staff and volunteers within hostels, through the free online toolkit, has the potential to have an impact by improving the end of life experience for both the person who is dying and the staff and volunteers in the hostels.
- Exploring a topic which has received limited research interest to date has the potential for societal impact by highlighting this as a public health issue and encouraging action by the government and funding organisations to prioritise it.
- By providing information and training to staff and volunteers, the resource may also have an economic impact by reducing unnecessary hospital admissions of homeless people towards the end of life.

1. Shulman S. et al. (2018), End-of-life care for homeless people: A qualitative analysis exploring the challenges to access and provision of palliative care. Available at: ncbi.nlm.nih.gov/pmc/articles/PMC5758927/
2. Kennedy, P, Hudson, B.F, Shulman, C. & Brophy, N (2018). A toolkit for supporting homeless people with advanced ill health. Accessed at: homelesspalliativecare.com
3. All Party Parliamentary Group for Ending Homelessness Available at: crisis.org.uk/ending-homelessness/appg-for-ending-homelessness
4. Faculty for Homelessness Inclusion Health (2018), Standards for Commissioners and Service Providers. Available at: pathway.org.uk/wp-content/uploads/Version-3.1-Standards-2018-Final.pdf
5. Tackling Inequalities in End of Life Care for Minority Groups VCSE Health and Wellbeing Alliance Project Group (2018). Care committed to me. Delivering high quality, personalised palliative and end of life care for Gypsies & Travellers, LGBT people and people experiencing homelessness: a resource for commissioners, service providers and health, care and support staff. Available at: hospiceuk.org/docs/default-source/Policy-and-Campaigns/briefings-and-consultations-documents-and-files/care_committed_to_me_web.pdf?sfvrsn=0

Marie Curie is the largest charitable funder of palliative and end of life care research. The charity invests nearly £3 million each year into research to help inform better quality of care for people with any terminal illness, and the people who care for them.

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