

Dying in the Cold: Being Homeless at the End of Life in Scotland

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Abbreviated abstract: Despite people experiencing homelessness having significantly worse health than the general population, higher death rates and more complex health needs, they have much poorer access to palliative care. *Dying in the Cold* explores the multiple and intersecting challenges when accessing and providing palliative and end of life care to people experiencing homelessness and makes recommendations for urgent system reform to support improved and more dignified end of life experiences for people experiencing homelessness and terminal illness.

Related publications: Rafferty, J. (2018). Dying without a home: Meeting the palliative care needs of people who are homeless in Glasgow and Edinburgh: What is the best way forward?



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Homelessness in Scotland; a bleak picture

- Over 200 people die in Scotland each year while homeless (highest death rate per million population in UK), with an average age of death of just 39 for women, and 43 for men
- Terminal conditions e.g. cancer and liver disease happen more frequently and at a younger age in people experiencing homelessness, and **many are living with tri-morbidities**; physical health, mental health & problem substance/alcohol issues
- But it is often unknown what, if any, palliative care support they have received

Report aims

- To evidence the scale of the issue surrounding challenges of access and provision of palliative care for people experiencing homelessness, and why reform is needed
- To inform future palliative care models to reflect the needs of people experiencing homelessness and other forms of disadvantage
- To shape and integrate national and local policy on homelessness and palliative care

Method

- Review existing homelessness and palliative care literature
- Use participant feedback from a homelessness and end of life care summit attended by multi-disciplinary health and social care teams, allied health professionals and homelessness organisations

Physical health

Those experiencing homelessness have significantly worse health than the general population^{25, 26}:

80%

have at least one physical health problem.

12

times more likely to have epilepsy²⁷.

20%

have at least three health issues.

6

times more likely to have heart disease.

29

times more likely to have hepatitis.

4

times more likely to have cancer.

Death rates are around **four times** that of the general population.

Mental health²⁸

45%

of those experiencing homelessness have a mental health diagnosis.

80%

have self-reported mental health issues.

Problem substance/alcohol use^{30,31}

More than
60%

of people experiencing homelessness have a history of problem substance use.

36%

have used drugs in the last month.

27%

are recovering from an alcohol problem.



Care and support through terminal illness



Making every 40 years of moment count

Key challenges for access and provision

1. **Frequently moving location**; people experiencing homelessness are a transient population and often move between Local Authority boundaries
2. **Complex trauma**; overlap between adverse childhood events, psychological trauma, homelessness and multiple exclusion can make it difficult to trust others, leading to inconsistent engagement with services, if at all
3. **Multiple, complex health issues**; many experience tri-morbidities (physical health, mental health and problem substance/alcohol use) and may fall through the cracks of public services which are often set-up to address 'single issues'
4. **Challenges with identification, engagement and delivery of services**; opportunities to be ***identified*** for palliative care support are significantly reduced as explained in points 1, 2 and 3; many have fears of needing care, losing control, dying alone or being forgotten after death impacting willingness to ***engage*** with services, many frontline homelessness also have few direct links with specialist palliative care providers including the third sector and hospices; lack of options for palliative care ***delivery*** for people experiencing homelessness as many are often too young for care homes, community hospitals and mainstream services may struggle to cope with complex needs in 1,2 and 3.

This puts huge pressure on A&E/acute hospital services, and means people die in hospital where end of life wishes may not be fulfilled



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40 years of making every moment count

What needs to happen?

- 1. The Scottish Government and Health and Social Care Partnerships must support improved access and provision of palliative and end of life care for people experiencing homelessness including;**
 - Facilitating specialist palliative care teams who can work with existing services supporting people experiencing homelessness and use this expertise to **support** new models of palliative care which are trauma informed and flexible to be delivered in all care environments
 - More awareness and proactive identification of those experiencing homelessness admitted to hospital with advanced ill health through a multi-disciplinary approach involving palliative care teams
 - Additional funding to facilitate partnership working between palliative care providers and homeless accommodation to provide community palliative and end-of-life care beds within these settings as an alternative to hospital admission
- 2. Palliative care training should be made available for those delivering homelessness services to help identify people who could benefit from palliative care much earlier to support them**
- 3. The Scottish Government should fund the development and delivery of bereavement support specifically for those experiencing homelessness and other disadvantage, in partnership with those with lived experience, homeless organisations and existing bereavement services.**



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This poster is part of
the SPPC Poster
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The logo for the Scottish Partnership for Palliative Care features a stylized blue 'C' shape with the text "Scottish Partnership for Palliative Care" written inside and around it.