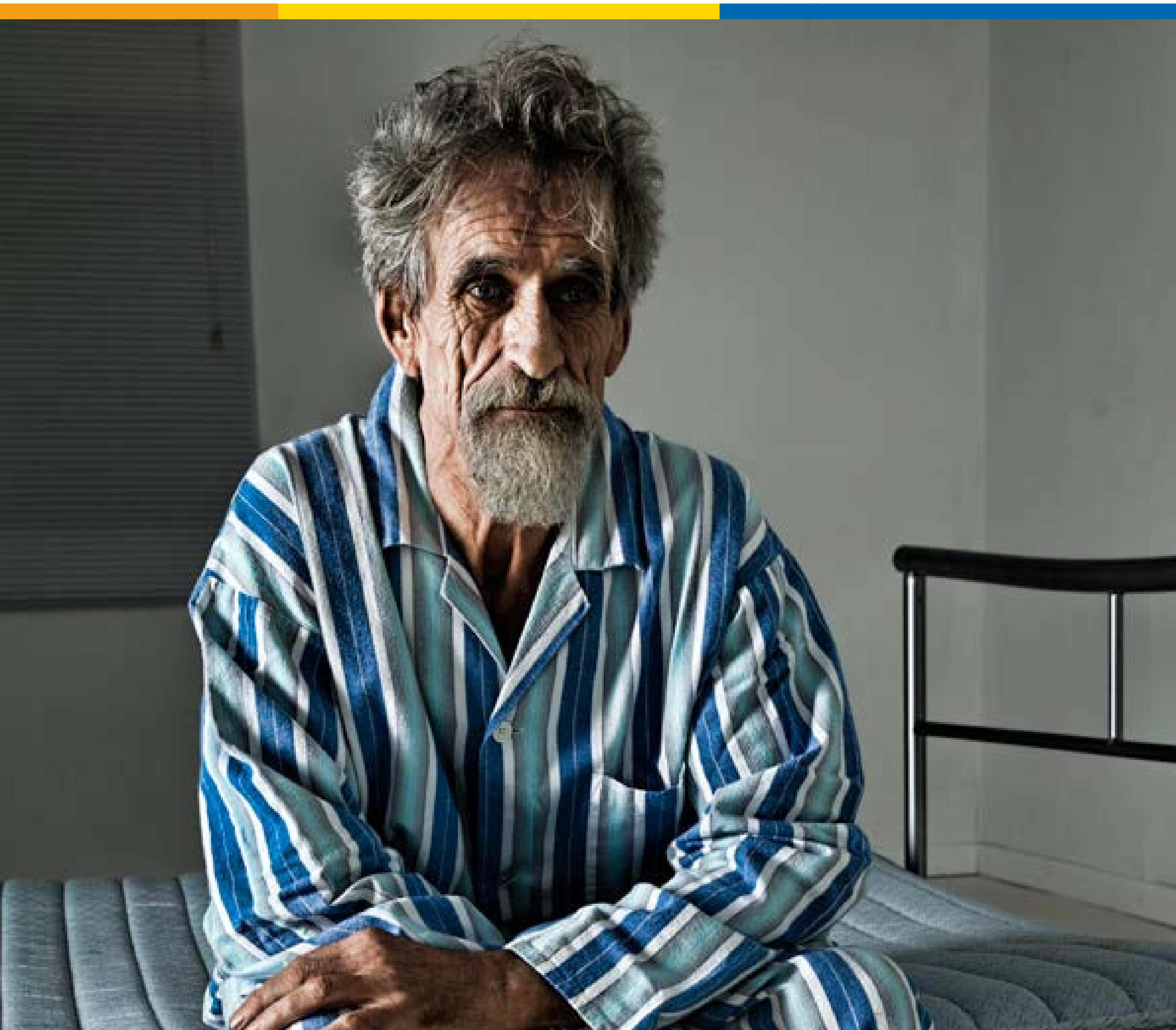
Marie Curie

Care and support
through terminal illness

Dying in the cold

Being homeless at the end of life



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Introduction

Everyone will be affected by dying, death and bereavement at some stage of their lives and everyone has the right to die well with dignity, and in a way that reflects what's most important to them. But people experiencing homelessness are often denied that right. Facing staggering levels of inequality in health and social care, they're often unable to access palliative and end of life care when they need it the most.

Palliative and end of life care supports people who have a terminal illness - by which we mean a disease or condition which will likely lead to a person's death. Marie Curie research has shown that around 90% of the general population who die each year in Scotland (almost 53,000 in 2019[1]) would benefit from palliative care, and increasing amounts of people are dying with at least two terminal conditions (multi-mortality)[2].

A significant proportion of people who die when homeless have palliative care needs and are likely to be dealing with multi-morbidities at the point of their death. Many people don't access palliative care services for reasons which will be explored in this report.

While coronavirus (Cov-19) has acted as a catalyst for some changes from the Scottish Government in tackling homelessness, these primarily relate to accommodation. There's still significant progress to be made in breaking down existing barriers that prevent people experiencing homelessness from accessing the palliative and end of life care they need, including bereavement support.

Marie Curie and Dr Joy Rafferty, a Specialty Doctor in Palliative Care at Strathcarron Hospice, have co-authored this report to examine the significant challenges faced by those experiencing homelessness in accessing palliative care and the detrimental impact on their quality of life, alongside issues faced by those providing homelessness support and palliative care.

The narrative and recommendations in this report are based on existing research and feedback from a homelessness and end of life care summit which Marie Curie hosted in October 2020. This summit included keynote addresses from palliative care and Deep End clinicians, gender specialists and frontline third sector homelessness support services.

Palliative care and homelessness

Someone is terminally ill if they're diagnosed with a condition that will lead to their death. Depending on the condition, this could be years, months, weeks or days.

Those who are terminally ill can be supported with a palliative care approach. The aim of palliative care is to support a person to have a good quality of life, which means living as well as possible in the time they have left. It can involve:

- managing physical symptoms such as pain
- emotional, spiritual and psychological support
- social care, including help with things like washing, dressing or eating
- support for family and friends.

A person can receive palliative care at any stage of their illness. It can be delivered alongside treatments, therapies and medicines aimed at controlling the illness, such as chemotherapy or radiotherapy.

Palliative care can be provided in different places, including a person's home, a hospital, a care home or nursing home, or a hospice. It can be delivered by generalist health and social care professionals – such as GPs, district nurses and social care teams – as part of the day-to-day care they provide. A person may also receive support from specialist palliative care professionals who might be involved in managing more complex care needs. They will often work in partnership with other professionals to provide co-ordinated and personalised care[3].

People experiencing homelessness often have complex health needs and many will need palliative care when living with terminal conditions, such as liver disease and cancer, which occur more often and at a younger age in people who are homeless[4,5]. Many of those experiencing homelessness will also experience tri-morbidities, consisting of a physical condition, mental health issue and alcohol/ substance dependency which has a significant impact on life expectancy[6]. A palliative care approach could benefit and improve the quality of life for a significant number of people who are experiencing homelessness.

However, providing care, palliative or otherwise, for people experiencing homelessness is extremely challenging. They can face many barriers in accessing and benefitting from services, meaning that their physical and mental health needs and concerns aren't always met[7].

Philip Hardman/Marie Curie

Definition of homelessness, trends and landscape

Being homeless means not having suitable accommodation to live in, which takes different forms across street and statutory homelessness. It includes rough sleeping, staying in a hostel or B&B, staying in temporary accommodation and sofa surfing (moving around friends or family without a stable base)[8].

For many of the terminally ill people Marie Curie supports, being able to receive palliative and end of life care – and ultimately being able to die – in their home surrounded by family is their preferred choice. Similarly, those experiencing homelessness prefer to die somewhere comfortable where people know them[9].

Official figures show that homelessness has continued to increase steadily since 2017/18[10], with the number of households assessed as homeless in Scotland rising for the third consecutive year to 31,333 in 2019/20. This translates to 51,365 people – up 4% on the previous year, which was up 3% from 2017/18. However, it's likely that the number of actual people who are experiencing homeless is significantly higher than those recorded[11].

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Why are people homeless?

The reasons behind homelessness across the country vary depending on age, gender and ethnicity, and are often the result of a complex combination of structural factors (including poor housing, welfare provision and social determinants of health) and individual circumstances (including relationship breakdowns, trauma, mental health issues and alcohol or substance use)[12].

In 2019/20, the three most common reasons recorded by local authorities for becoming homeless in Scotland were:

- being asked to leave (24%)
- relationship breakdown/non-violent dispute (19%)
- violent/abusive dispute (13%)[13].

Age

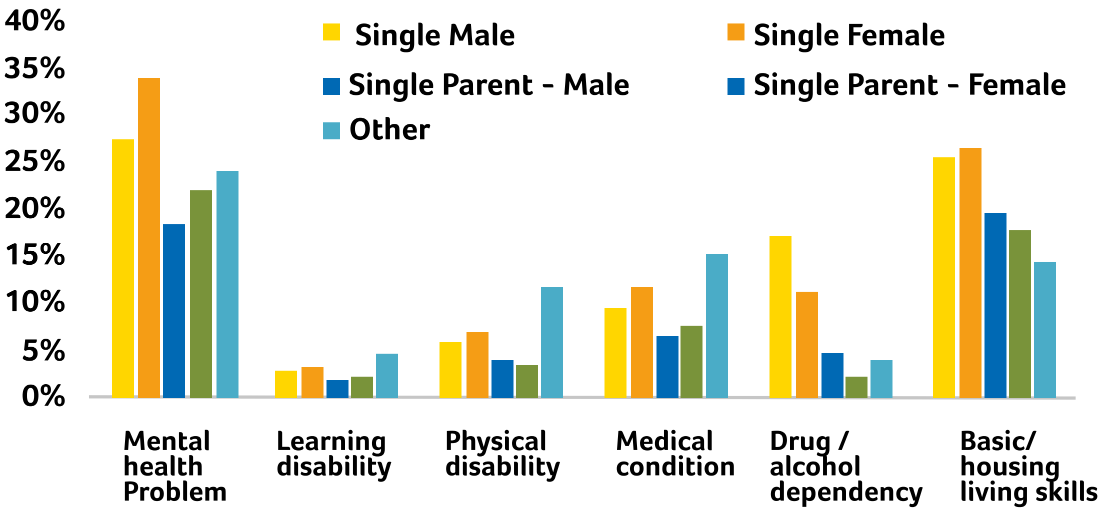
In 2019/20, young people aged 16–24 cited 'being asked to leave' as the primary reason for being homeless, highlighting 'lack of support from family' as additional reasons for becoming homeless from the family/parental home[14].

Older people, however, were more likely to cite a 'physical health reason' and reasons unrelated to the household for becoming homeless[15]. Those over 65 also required the most medical and physical disability support, but substance and alcohol dependency was most prevalent among those aged 35-49[16].

Gender

Research suggests that women often stay in more unstable accommodation when they are homeless – for example, sofa surfing. As such, they may not be captured in official statistics and, more importantly, may not be known to third sector organisations supporting people in these circumstances[17]. This means much remains unknown about the causes and impact of homelessness on women[18], including access to palliative and end of life care, with current responses/ interventions often being ineffective and 'ungendered', meaning existing inequalities are repeated[19].

Support needs by household type percentage (2019/20)[14]



In 2019/20, women were more likely to become homeless as a result of a violent household dispute, and more single females reported mental health as an additional reason for becoming homeless compared to males[20].

Drug and alcohol dependency, however, was highest in single male households[20].

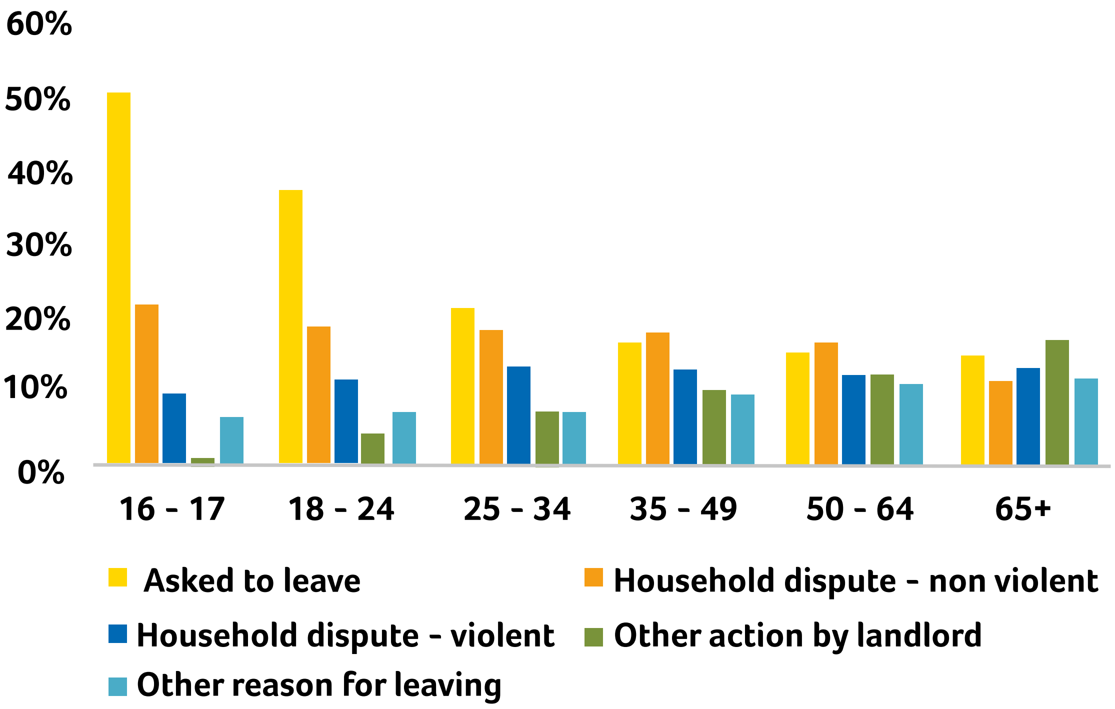
> *'Drug and alcohol dependency, however, was highest in single male households[20].'*

Ethnicity

Population diversity across Scotland is also an influential factor when it comes to homelessness. While 86% of homeless people in Scotland are white[21], a significant proportion are from other ethnic groups. It's also necessary to highlight the impact on non-UK nationals who account for a notable proportion of urban populations in Scotland's largest cities[22].

Reasons for homelessness vary by age[22]

Reasons for homelessness by age, percentages (2019/20)



Tri-morbidities: what are they and what is their impact?

Many of those experiencing homelessness have tri-morbidities, consisting of a physical health condition, mental health issue and alcohol/substance dependency, which has a significant impact on their quality of life and life expectancy[23]. In Scotland in 2019, the average age at death for those experiencing homelessness was just 39 for women and 43 for men[24].

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 epilepsy[27].

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 health[28]

45%

of those experiencing homelessness have a mental health diagnosis.

80%

have self-reported mental health issues.

Mental health issues in people experiencing homelessness are also likely under-diagnosed meaning many don't get the support they need[29]. Mental health is often further affected by being homeless, contributing to tri-morbidities.

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.

Problem substance/alcohol use is both a cause of homelessness – accounting for 14% of homeless applications in Scotland – and a result of homelessness, through use of alcohol and/or drugs to cope with loss in multiple forms (including bereavement), mental and physical conditions and general life on the streets[32].

Deaths among people experiencing homelessness in Scotland in 2019[33]

In Scotland in 2019, there were an estimated 216 deaths of people who were homeless, an 11% increase on the estimate of 195 in 2018[33]. Scotland had the highest rate of homeless deaths per million population aged 15–74 (52.2) in the UK in 2019. This figure is almost three times that of England (18) and more than three times that of Wales (14.3)[34].

National Records of Scotland: Homeless Deaths 2019 data showed that:

- Over half of deaths (54%) in 2019 were drug related.
- The average age at death was 39 for women and 43 for men.
- When cause of death was broken down by ICD-10 codes, the most common included:
    - external causes, including drug-related deaths, accidents, suicides and assaults (70%)
    - circulatory diseases, including heart disease and stroke (7%)
    - cancers (5%)
- Inverclyde, South Ayrshire and North Ayrshire had the highest rates of homeless deaths per million population aged 15–74 in 2019, with rates of 213.2, 120.3 and 111.8 respectively.

The above data suggests that a significant number of people experiencing homelessness will have died with a palliative care need. However, there is no way of telling if, or when, they received any specialist or generalist palliative and end of life support.

Even adjusting for the deprivation and health conditions that they are more likely to have, people experiencing homelessness are still at higher risk of death than would be expected. As such, homelessness can be classed as an independent risk factor for mortality[34]. This has led some to pose the question whether **homelessness itself could be considered a life-limiting condition**.

For those needing palliative and end of life care, early intervention is crucial to maximise the opportunity for a person to receive good care and ensure they get the best outcomes and quality of life. However, many people who would benefit from a palliative approach aren't identified early enough, which can have a significant impact on their outcomes and experience. For those from more vulnerable groups, including those experiencing homelessness, the chances of being identified are significantly reduced[35].

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Severe and multiple disadvantage

When considering end of life care for those experiencing homelessness, it is also essential to remember that homelessness is often about more than just housing. It is a very visible manifestation of severe disadvantage, complex need and deep social exclusion which can be present throughout a person's life.

There is significant overlap between homelessness and other forms of severe disadvantage. The Hard Edges Scotland[36] report explores the extent and nature of severe multiple disadvantage (SMD) in Scotland[36], finding that over a year:

156,700
adults experience one of three core forms of SMD (homelessness, offending or substance dependency)

28,800
experience two of these three

5,700
experience all three.

This means that over 190,000 people in Scotland have experienced these three disadvantages in a year, and the report highlights the impact of the overlap between multiple forms of disadvantage (including homelessness)[37].

It's important this wider understanding of issues is considered in the context of palliative care. For those affected by terminal illness who experience homelessness, it can be likely that they are also experiencing at least one other form of disadvantage and may not be getting the support they need. This may be due to challenges faced by the public sector and charitable services which are often set up to address 'single issues', meaning there is potential for people to fall through the cracks[38].

It highlights the need for a collaborative approach between local authorities, health and social care partnerships, multi-disciplinary clinical teams and homelessness support organisations, among others, to ensure appropriate support is accessible and can be delivered flexibly to reflect individual needs.

Understanding the barriers to accessing palliative and end of life care

For many people experiencing homelessness, there are significant barriers – both personal and institutional – that prevent them from accessing the palliative and end of life care they need. This next section explores these barriers and makes recommendations to mitigate them.

Lack of awareness

One of the key barriers is a lack of awareness of the palliative care needs of people who are experiencing homelessness. They tend to die young and of conditions that may have uncertain trajectories. They may have multiple crisis admissions to hospital before dying in a way that is often perceived to be sudden and unexpected. Many have illnesses with degrees of potential reversibility (such as alcoholic liver disease) and professionals don't want to give up hope or take away the possibility of rehabilitation.

Furthermore, those working with people experiencing homelessness may not recognise that someone has palliative care needs or be aware of the barriers to accessing services. We support the recommendations made in Caroline Shulman, Niamh Brophy and Briony Hudson's work around implementing the concept of 'parallel planning' for people who are homeless with deteriorating health[39]. This approach involves hoping for the best, but planning for the worst, and suggests that palliative care and advanced care planning is carried out alongside plans for rehabilitation and recovery, where appropriate.

Staff working in homeless accommodation and homelessness support projects often have good relationships with people experiencing homelessness and have experience and expertise in providing trauma-informed care. A number of projects in England have looked at providing palliative care support and training to staff working in homelessness. Increasing staff knowledge and awareness can equip them to recognise palliative care needs and better advocate for these needs to be met[40]. St Mungo's and Marie Curie have developed a **palliative care toolkit** to help staff working with homeless people who have advanced ill health[41].

Project ECHO, a knowledge-sharing network model providing remote learning and support at multiple sites, is already used by some hospices in Scotland to provide training and support to care home staff and health professionals. A 2020 project led by St Columba's Hospice in Edinburgh used this model to provide palliative care training and support to staff working in homelessness services in Edinburgh. This could be rolled out across the country to continue building knowledge and skills in addressing the palliative care needs of those experiencing homelessness.

A number of services may already be involved in working with people experiencing homelessness, thus there is a need to ensure a co-ordinated approach to palliative and end of life care. Teams which understand homelessness and the extent of severe multiple disadvantage, are trauma-informed and able to work flexibly and across geographical boundaries will be able to provide the best possible person-centred care.

Recommendation 1

Health and Social Care Partnerships to facilitate the provision of specialist palliative care teams including Clinical Nurse Specialists and Link Workers with medical support who can work collaboratively with existing services caring for people experiencing homeless and other severe multiple disadvantages (SMD).

This would include working with housing services, homeless health services, social work, drug and alcohol recovery services, primary care, bereavement services and relevant third sector organisations to help identify and support people with palliative care needs.

Recommendation 2

The Scottish Government to support a roll-out of Project ECHO in collaboration with Health and Social Care Partnerships, work with key stakeholders to facilitate palliative care knowledge exchange, and support training specifically for those delivering services to those experiencing homelessness and other SMD, with a focus on early identification of people with advanced ill health and palliative care needs.

We welcome the Scottish Government and Healthcare Improvement Scotland's new project referenced in the Housing 2040 Strategy to better integrate homelessness and problem substance/alcohol services and connect people experiencing homelessness with the vital health support they need (amongst other services). However, this approach must include palliative care services to support people experiencing homelessness who are living with terminal conditions to get the right care they need. The inclusion of palliative care expertise must also be reflected in the Scottish Government's proposed National Learning Network between Health and Social Care Partnerships and rapid rehousing co-ordinators to ensure terminally ill people in these circumstances are fully supported based on their care needs.

Complex trauma

There is a high degree of overlap between adverse childhood events, complex psychological trauma, homelessness, contact with the criminal justice system and multiple exclusion.[42]

Trauma impacts both a person's symptoms and their ability to access and benefit from homelessness and palliative care services. For those specifically with post traumatic stress disorder PTSD, evidence has shown that a terminal diagnosis can echo the original or previous trauma a person has experienced, that severe distress can be caused when looking back at their lives, and that symptoms of PTSD can ultimately prevent a peaceful death.[43]

Significant trauma can make it hard to trust others, including homelessness and palliative care support, because of past experiences of abuse and/or not having their needs met. Some people actively avoid services, which makes it hard for professionals to establish and maintain relationships with them, resulting in inconsistent engagement with palliative care, if any at all.

There is existing guidance and principles on trauma-informed practice (TIP) in Scotland produced by NHS Education for Scotland (NES). But feedback from clinicians and third sector support teams at Marie Curie's homelessness and end of life care summit highlighted that despite a TIP approach being used in some healthcare settings, there are inconsistencies in TIP delivery across mainstream health services. These findings show that improvements need to be made to increase the accessibility of palliative and end of life care for those experiencing homelessness.

Recommendation 3

Use expertise from the specialist teams in recommendation one and/ or homeless/inclusion health services, third sector support teams and people who have lived experience of homelessness and SMD to inform the development of new models of palliative care which are trauma informed, and flexible to be delivered in all care environments.

Bereavement and grief

People experiencing homelessness often experience profound loss, such as bereavement and the loss of many aspects of ‘normal’ life[44]. Bereavement contributes heavily to people becoming homeless[45], and the death of someone experiencing homelessness can have a significant impact on other service users, bringing up old losses[46]. Those experiencing homelessness often have repeated bereavements and may deal with these in self-destructive ways, putting them at increased risk of loneliness, depression, isolation and suicidal ideas[47].

Also, people working in the homeless sector are often exposed to the deaths of those they care for, sometimes in difficult circumstances[48]. As a result, they are at high risk of secondary trauma and burnout[49]. Bereavement support should be a component of providing a holistic palliative care service for people affected by homelessness.

Eighty-five percent of UK born people with multiple-exclusion homelessness have experienced childhood trauma[42].

The lifetime prevalence of post-traumatic stress disorder (PTSD) in those experiencing homelessness is **79%**[43].

Recommendation 4

The Scottish Government to fund the development and delivery of bereavement support specifically for those experiencing homelessness and other SMD, in partnership with those with lived experience, homeless organisations and existing bereavement services.

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Case study: James

James had been experiencing severe multiple disadvantages since his early teenage years, developing problem substance (drug and alcohol) use that continued throughout his life and led to homelessness.

In summer 2020, James was admitted to hospital and diagnosed with end stage liver failure. Following treatment, he was discharged from hospital to a recovery care facility, then to his temporary homelessness accommodation. But by late 2020, James had been readmitted to hospital as a result of his terminal condition worsening. He was due to be discharged before Christmas 2020, but a care package not being in place meant this was delayed until early 2021.

Cyrenians, James's homelessness support organisation, had been trying to secure a housing tenancy for months but had been unsuccessful due to demand for properties and the complexities of James's condition. Before James was admitted to hospital in late 2020, he was finally offered a housing tenancy, but had been too unwell to view it. Cyrenians did this on his behalf and got it ready for his discharge from hospital as James's preference was to die at home.

James was allocated a care package but the carers struggled to provide the support required in the allotted time. The carers were not experienced in providing care to patients with the complexity of needs that James had, and were also unable to handle methadone which James required, leading to increased symptoms and distress.

James continued to quickly deteriorate and an ambulance was called to his tenancy on the advice of a GP at a homeless health practice. But not wanting another hospital readmission, James refused. There were serious concerns about James's safety by leaving them alone and the possibility he would die overnight, having specifically expressed to Cyrenians that dying alone was his biggest fear.

When Cyrenians returned the following day, James's health had significantly worsened and after consultation with a GP from a homeless health practice, a non-urgent ambulance was called and James was readmitted to hospital.

James received palliative and end of life care while in hospital, and died there in early 2021.

James had waited several years for his own tenancy to be able to die at home, and wanted to do everything possible to avoid dying in hospital. This highlights the urgent need for a whole-system approach to enable palliative care in the community.

Name has been changed for patient confidentiality

Coronavirus (Covid-19)

The pandemic has shown the distressing impact dying, death and bereavement can have on anyone at any time, not least **in socio-economically deprived Scottish communities where the coronavirus death rate has been 2.1 times higher** than the least deprived areas[50]. It has intensified complexities associated with terminal illness, which will affect many people for years to come. The need to identify terminally ill people who would benefit from palliative support as early as possible to ensure the best quality of life has never been greater.

Existing research has demonstrated that even before coronavirus, access to and proactive engagement with palliative and end of life care services for those experiencing homelessness was typically poor, which coronavirus is likely to have exacerbated. Throughout the pandemic, usual Deep End GP practice activities such as routine consultations were reduced, with some, like home visits, significantly reduced and others forced to stop altogether[51].

Deep End GP Practices support the 100 most deprived patient populations in Scotland[52]

The transition to primarily remote consultations brought digital poverty in Scotland to the forefront for many of those experiencing homelessness (and/or other forms of disadvantage) because they're unable to access devices or use remote consultations effectively[52]. Many of those experiencing homelessness are unlikely to have devices which are compatible with appointment platforms, so there's significant concern among Deep End GPs for patients who have been missed during the pandemic and the status of their conditions, including terminal illnesses.

The backlog that has built up in chronic disease management, screening, immunisation and cancer referrals is also a huge cause for concern for Deep End GPs, with the impact of this still unknown on patients' health[52].

Initiatives such as Simon Community Scotland's Get Connected Pilot, which focused on digital access for people experiencing homelessness during coronavirus, have been essential in helping move towards digital inclusion. Throughout the pandemic, the pilot connected people experiencing homelessness with a range of services, including health, to ensure they could access the support they needed and felt confident doing so.

Recommendation 5

The Scottish Government must close the digital poverty gap by increasing access to up-to-date digital devices to help facilitate remote consultations, particularly targeting those who are experiencing homelessness.

Community link workers are non-clinical social prescribers linked to GP practices. They

work with patients to achieve their goals and help them connect with community resources and support. Aiming to improve health and wellbeing and tackle health inequalities, they have been described as invaluable during the pandemic in contacting patients who are vulnerable, making connections and helping meet their needs[53]. They can have particular benefit in working with people experiencing socioeconomic deprivation and reducing health inequalities.

Recommendation 6

We support the recommendations in the GPs at the Deep End report that provision of Community Link Workers should be increased from 50% to 100% of Deep End GP practices to maximise outreach with vulnerable patients[54].

Hospitals and homelessness

People living in the most deprived settings, including those who are homeless, are 33% less likely to die at home and more likely to die in hospital[55]. Many of those experiencing homelessness may die in hospital by default when they have spent their lives actively avoiding it, likely resulting in a significantly more distressing end of life experience.

Common illnesses associated with homelessness, such as liver disease, can have unpredictable trajectories and result in a significant amount of crisis admissions to hospital and/or use of other unscheduled care services. Competing priorities, stigma and concerns about management of alcohol/substance withdrawal often results in people who are homeless self-discharging early from hospital[56].

Research from Marie Curie and the University of Edinburgh has shown that people from the most deprived communities make up one of the largest proportions of unscheduled care interactions that require emergency services and/or hospital admissions. These often require multiple readmissions to emergency or acute facilities, and come at a total cost of £190m to the NHS each year[57].

There is evidence to show that people experiencing homelessness are considerably more likely to use unscheduled care facilities. When compared to those living in deprived communities with similar levels of health, **those experiencing homelessness are five times as likely to have an emergency readmission and A&E visits after discharge from hospital[58]**. The deaths of many people experiencing homelessness from a crisis admission to hospital are often perceived as sudden or unexpected, but in fact many are predictable when looking at their health over the preceding months to years.

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Case study: John

John was referred for palliative care in 2020 with end stage liver disease. John (and his partner) were alcohol and heroin dependent, experiencing homelessness and had formerly been in prison. John's partner had recently been released from prison and they both became homeless again during the coronavirus pandemic, subsequently being moved into a hotel.

The couple's transient life circumstances made it difficult to follow-up on john's condition as they were out of the GP and hospice catchment areas, which led to ongoing concerns around vulnerability and the potential for drug diversion. John did not want to go to hospital or be in a care environment but had multiple hospital admissions, which also caused his partner severe distress. A request was made for a hospital palliative care team referral, and John also eventually registered with a new GP and was referred to a local hospice.

John died peacefully in hospital in 2020, but there were multiple complexities with his terminal condition and access to palliative care, including precarious social circumstances, potential for continued substance misuse, illness behaviour, the coronavirus pandemic, health literacy and location.

Name has been changed to keep patient anonymity

This poses the question whether current palliative care models are suitable for those experiencing homelessness and who have a severe and multiple disadvantage background.

A recent report by Marie Curie and the University of Glasgow also found that despite examples of good practice, hospitals are still not identifying enough patients on admission who could benefit from palliative care, meaning there are people who are unfairly missing out on the right care at the end of their life[59].

Although the report doesn't state this specifically, it's likely that this will include people experiencing homelessness. This is likely to have worsened as a result of coronavirus pressures and severely impacted the opportunities to engage with people early and provide palliative support to people experiencing homelessness with a terminal illness.

This will discourage self-discharge, enable the patient to understand palliative care and treatment options, support their care wishes and help primary and secondary care teams understand their priorities. This approach has been successful in some English hospitals through Pathway's[44], which have specific hospital teams to support homeless patients.

In Scotland, a hospital inreach programme by Cyrenians in Edinburgh has supported patients who are experiencing homelessness. The service supports improved health outcomes and reduced re-admissions to hospital through facilitating patient engagement in treatment, discharge planning and ongoing community support.

Recommendation 7

More awareness and proactive identification of those experiencing homelessness who are admitted to hospital with advanced ill health through a multi-disciplinary approach involving palliative care teams. This will support anticipatory care planning and address palliative care and deteriorating health needs.

Challenges with engagement and palliative care delivery

A large proportion of the practical and emotional support provided for people experiencing homelessness is undertaken by specialist third sector homelessness organisations and temporary accommodation providers such as hostels and shelters. Yet many organisations have few direct links with specialist palliative and end of life care providers, including the third sector and hospices, despite the high rates of advanced ill health and premature mortality demonstrated in the data above.

End of life care wishes also remain poorly understood for people experiencing homelessness, despite research having shown a fear of needing care, losing control, dying alone or being forgotten, as well as spiritual and practical concerns, as common in people experiencing homelessness at the end of life[60].

Palliative care can be complex when aiming to meet many individual palliative and end of life care needs. But for those experiencing homelessness, this complexity is greatly enhanced, both by their past and present experiences. Hospices and acute settings are often engaged at crisis point when the conditions of people experiencing homelessness are at an advanced stage[61]. While distressing for the patient themselves, it also places intense pressure on these services and can leave them less able to holistically meet the patient’s needs.

Providing palliative and end of life care for those experiencing homelessness can be challenging. Services are traditionally designed to provide care to patients who live in a stable setting, such as their home, a care home or a hospital, but for those in non-traditional settings, such as hostels, B&Bs or shelters, palliative care providers can face significant difficulties[62].

As mentioned above, living in transient accommodation when services work in specific geographical areas can be a barrier to identifying and maintaining a relationship with people experiencing homelessness in order to provide palliative and end of life care. A traditional inpatient at a hospice often has a stable family and friends support network, a stable residence, a reasonably indicative disease trajectory and access to other health and social care. But for people experiencing homelessness, most or all of these circumstances are completely reversed[63].

For many people experiencing homelessness, individual accommodation and personal circumstances, coupled with existing fears and concerns about receiving care, often results in difficulties engaging with services and maintaining relationships. This impacts the physical, emotional and spiritual support patients receive and negatively affects their quality of life.

There is also a lack of options for people experiencing homelessness at the end of their life[64]. They may be too young for care homes and community hospitals, and mainstream services may struggle to cope with those who experience complex trauma, problem substance/alcohol use and poor mental health. Research shows that many experiencing homelessness want to remain in their homeless accommodation if their health deteriorates[65]. Those working in homelessness services usually have experience of working with people with complex trauma, challenging behaviour, mental health problems and substance misuse, and as a result may be better placed than hospitals to meet peoples’ emotional needs[66].

However, there are challenges with providing palliative care within homelessness accommodation. Staff typically have no medical or care training and when a resident is unwell or has high care needs, a serious burden can be placed on them, which also impacts other residents[67]. There are also practical challenges around storing and administering medications in homelessness accommodation[68].

In Scotland, there are currently no palliative care beds within homelessness accommodation. Deaths do occur in these settings, and planning for this may improve care and provide another option for those experiencing homelessness with palliative care needs who don't want a hospital admission.

Recommendation 8

Additional health and social care partnership funding to facilitate partnership working between palliative care providers and homeless accommodation in order to provide community palliative and end of life care beds within these settings as an alternative to hospital admission.

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Conclusion

It is clear that palliative and end of life care support for those experiencing homelessness is currently in crisis. Many people are not being identified early enough or receiving palliative care at the end of their lives.

People experiencing homelessness have significantly worse health than the general population, with homelessness itself increasing the risk of death. Over 210 people who are homeless are estimated to be dying in Scotland each year, a death rate much higher than the rest of the UK. The average age of death for someone who is homeless in Scotland is just 44 for men and 39 for women.[33]

There are many barriers to accessing palliative care for people experiencing homelessness, including tri-morbidities, a lack of awareness and the way services are designed. Complex trauma is a common thread amongst those experiencing homelessness, yet trauma-informed practice (TIP) is largely absent from health and palliative care models. Although this report specifically focuses on people experiencing homelessness, we recognise that there is significant overlap of experience and need with others experiencing severe and multiple disadvantage and deep social exclusion.

We are calling for the implementation of all the recommendations in this report to help those experiencing homelessness who have palliative care needs. This would help them to easily access the support they need, allowing them to have a positive end of life experience and to live well until they die.

Acknowledgements

We'd like to extend our thanks and appreciation to **Dr Joy Rafferty** for co-authoring this report with us, and for permitting findings from her public health master's dissertation to be used as part of the content and recommendations of this report.

Access to Dr Rafferty's full dissertation on homelessness and palliative care can be found here.

We'd also like to thank **Dr Andrea Williamson** for sharing her expertise in severe and multiple disadvantage and deep social exclusion, which helped to highlight the prevalence and importance of these issues in a palliative care context, as well as for reviewing this report.

We would also like to thank all of the speakers at our homelessness and end of life care summit in October 2020 who shared first-hand experience of working with and advocating for those experiencing homelessness from a range of perspectives:

- Birgit Thaysen-Goodman, Cyrenians
- Jan Williamson, Simon Community Scotland
- Emma Ritch, Engender
- Dr Shaun Peter Qureshi, Speciality Trainee in Palliative Medicine

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For more information:

Ellie Wagstaff
Policy and Public Affairs Manager
ellie.wagstaff@mariecurie.org.uk

Dr Joy Rafferty
Specialty Doctor in Palliative Care
joy.rafferty@nhs.scot

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