

A SECOND CLASS ENDING

Exploring the barriers and
championing outstanding
end of life care for people
who are homeless

The Care Quality Commission

Our purpose

The Care Quality Commission is the independent regulator of health and adult social care in England.

We make sure that health and social care services provide people with safe, effective, compassionate, high-quality care and we encourage care services to improve.

Our role

- **We register** health and adult social care providers.
- **We monitor** and inspect services to see whether they are safe, effective, caring, responsive and well-led, and we publish what we find, including quality ratings.
- **We use** our legal powers to take action where we identify poor care.
- **We speak** independently, publishing regional and national views of the major quality issues in health and social care, and encouraging improvement by highlighting good practice.

Our values

Excellence – being a high-performing organisation

Caring – treating everyone with dignity and respect

Integrity – doing the right thing

Teamwork – learning from each other to be the best we can

The Faculty for Homeless and Inclusion Health

The Faculty is the UK's first independent, multi-disciplinary network organisation for nurses, doctors, allied medical professionals, social workers, public health experts, health advocates and support workers, commissioners, researchers and people with a lived experience of exclusion.

Our primary purpose

To re-affirm the fundamental rights of homeless people and other excluded groups to be treated with dignity, compassion and respect.

Our aim

We aim is to improve the quality of health care for these groups of people by setting standards and supporting services so that generosity, kindness, and compassion combine with a passionate commitment to professional quality to become the defining characteristics of health services for homeless and multiply disadvantaged people.

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Introduction

There is huge variation in the quality of care that people receive at the end of their life. In 2016, the Care Quality Commission (CQC) published its review **A different ending: addressing inequalities in end of life care**, which found that this was often because of a person's diagnosis, age, ethnic background, sexual orientation, gender identity, disability or social circumstances. In that report, CQC called on leaders of local health and care systems and to commissioners and providers of care to ensure that every person gets fair access to care at the end of life.

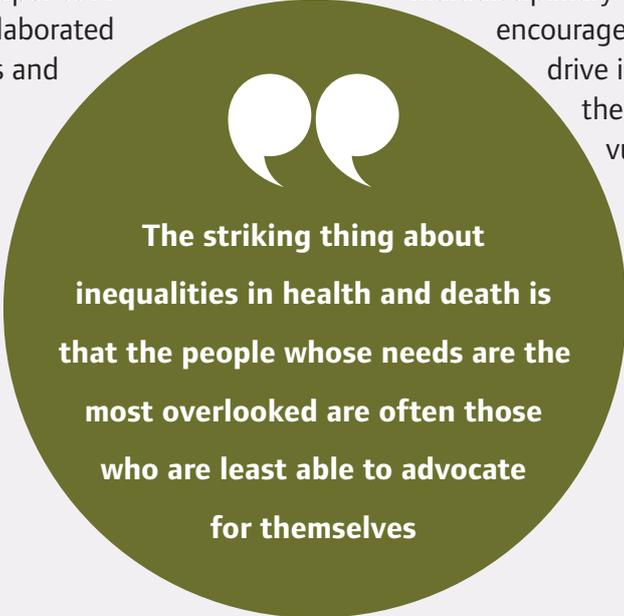
The striking thing about inequalities in health and death is that the people whose needs are the most overlooked are often those who are least able to advocate for themselves. This is particularly true for people experiencing homelessness. Homeless people face significant health inequalities: the average age of death is just 47 years. Their end of life care needs and preferences also differ considerably from the rest of the population.*

In this follow-up discussion paper to *A different ending*, CQC has collaborated with the Faculty for Homeless and Inclusion Health, and other experts in end of life care for homeless people, to further explore the barriers for this

particularly vulnerable group. Voluntary sector organisations, such as Pathway and St Mungo's, as well as GP practices, housing projects and hospices, have provided specialist input and case studies that highlight the issues.

This collaborative discussion paper has also been informed by the findings of a recent, large qualitative study. This explored the current challenges in supporting homeless people with advanced ill health, from the perspective of homeless and ex-homeless people, hostel and outreach staff and health care professionals from a number of disciplines.¹

Using the key recommendations in *A different ending* as a framework and the findings of the research, together we explore in more depth the many and complex reasons why people who are homeless do not experience good care at the end of life. We also celebrate organisations that are often crossing traditional boundaries to deliver innovative and outstanding care, as seen in CQC's inspections. As a group, we intend for this paper to stimulate cross-sector and multidisciplinary conversations and ideas, encourage innovation, and ultimately drive improvement to address the inequalities faced by this vulnerable and excluded group.



The striking thing about inequalities in health and death is that the people whose needs are the most overlooked are often those who are least able to advocate for themselves

* In this briefing, we use 'end of life care' and 'palliative care' interchangeably.

Qualitative research exploring the challenges to palliative care for people who are homeless

This paper refers to the findings of a recent collaborative qualitative research study conducted by Pathway, Marie Curie, UCL, St Mungo's and Coordinate My Care, which explored the challenges to palliative care for homeless people in London. As part of this research, focus groups and interviews were conducted with currently homeless people, formerly homeless people, hostel and outreach staff and a range of health and social care providers, to explore their views and experiences of palliative care and to find out what they believe may improve support for this group if their health deteriorates.

In summary, the research revealed that because of the lack of acceptable alternatives, homeless people with advanced ill-health often remain in hostels as their health deteriorates. The burden of supporting sick residents is often left to hostel staff who have no medical experience. Uncertainty around the prognoses of common illnesses, the impact of behaviours related to complex trauma and substance misuse and gaps in existing provision contribute to the difficulty and complexity in accessing and providing palliative care for this population.

The research proposes that conversations with homeless people about their future and health should begin earlier. The trigger for action should shift away from identifying a person who is dying, towards identifying an individual whose health is a concern. Discussions should help people explore their insights, aspirations, health and choices for the future, and not just end of life issues.

The research also suggests a need for greater multidisciplinary working, extended in-reach into hostels from health and social care services and training for all professional groups. In addition, access to appropriate, supported accommodation is required to improve care and quality of life for homeless people with advanced ill health.

End-of-life care for homeless people: A qualitative analysis exploring the challenges to access and provision of palliative care, Shulman, Hudson and others, July 2017



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Summary of key discussion points

The needs of homeless people are not well understood or taken into consideration by different health and care services. As a result, the standards in their care at the end of life vary considerably. Where services do exist, they are often fragmented and work in relative isolation. The result is that homeless people experience little continuity of care so that signs of deterioration in their health or circumstances are often missed and effective interventions are few and far between. When they are in their last weeks and days of life, there are few genuine options for where they can be appropriately looked after.

These issues are exacerbated by a lack of training and support for frontline staff who work regularly with this vulnerable group. This is particularly true for staff in hostels, who are often the only ones left to explore residents' insights and care preferences, yet feel unable to do so without training on how to meet their needs.

Identifying homeless people who may be dying is difficult, so care and support may be better focused on any homeless people whose health is a major concern. To involve homeless people in decisions about their treatment and care means striking the right balance between continuing to support them and, at the same time, respecting their individual choices. It means considering the difficult backgrounds they may have survived, the negative experiences of care they may have received, and the sometimes chaotic nature of their lives.

The separation of existing health care, social care, housing and voluntary services appears to have an impact on the quality of care for homeless people; but actively linking these may improve the care options available. The research by Shulman, Hudson and others looked at the challenges around end of life care for homeless people. It suggests that comprehensive, standardised and

multidisciplinary training for staff on how to meet their needs would enable them to deliver these services more effectively.

Working together will facilitate better continuity of care. One way of enabling this continuity is to record information about the health needs of homeless people in a way that makes it available to hostel and outreach staff, GPs, hospital teams, palliative care staff, out-of-hours and emergency services. This would involve a significant shift in the way health services are currently delivered, and would require a collaborative effort across different services.

To ensure that everybody gets good care in the last phase of their life it is essential to have a strategic, equality-led approach at a local level, which prioritises the delivery of personalised care. Some commissioners, services, and health and care staff are already doing this well, and others can learn from them. CQC has found pockets of excellent primary care and specialist community services for homeless people, often supported by voluntary sector organisations, which we now share.

Hospices and primary care organisations in particular can play a key role in championing an equality-led approach by engaging local communities, delivering care based on individual need, and supporting others to do the same. However, bringing down the barriers that homeless people face will involve a concerted collaborative approach across health, social care, housing, justice and voluntary sector organisations.

Reducing inequalities for homeless people

A recommendation from CQC's end of life care review was to encourage commissioners and providers to fulfil their duties under the NHS Constitution, the Health and Social Care Act 2012 and the Equality Act 2010, to reduce inequalities, eliminate discrimination and advance equality when developing, arranging or delivering end of life care.

People who are homeless experience significant inequality and discrimination when they need access to care and support while they are very unwell, and indeed, at the end of their life. In this section, we explore some of the major barriers that they face – in particular the lack of awareness in a local health economy about the extent of homelessness in an area, inflexible and fragmented services that do not allow for continuity of care, and the absence of any real palliative care options for this vulnerable group.

Lack of awareness of the extent of the problem

To address inequalities, providers and commissioners of care must first be aware of them. But local awareness of the extent of homelessness itself is a major barrier to understanding the level of need of this group.

In *A different ending*, CQC reported that many healthcare professionals and commissioners were unaware that there were homeless people in their area, even where an area's statutory homelessness rate was twice that of the national average.

Awareness at local and regional levels depends to some extent on the quality of information

available at a national level. For example, although some national data is available about the number of homeless people at any one time in an area, this is usually restricted to 'statutory homelessness', and does not give a full picture or take into account the 'hidden homeless', for example those who may be constantly sofa-surfing but don't sleep rough or end up in hostels. The demographics of hidden homelessness are different, and include more women and young people.²

The needs of homeless people are almost certain to be overlooked if those who commission and provide health and care services aren't even aware of them and if there is inconsistent information available at a national level on the scale of the problem.



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Poor continuity of care

Inflexible and fragmented services

Homeless people, more than others, experience fragmented care in many settings. Although they can present to health services through different routes, it is mainly through repeated visits to accident and emergency departments.³

People without a fixed address can find it difficult to register with a GP, or find a primary care service that meets their needs. Guidance from NHS England states that "*inability by a patient to provide identification or proof of address would not be considered reasonable grounds to refuse to register a patient*".⁴ Despite this, it remains difficult for many people to register with a GP practice without a fixed address.

Inappropriate discharge from secondary care

As well as taking highly variable routes into hospital services, the research by Shulman, Hudson and others found that homeless people are often discharged from hospital without taking into account the environment that they are going to. They may be discharged without being linked into support services in the community or without accommodation to return to.

On top of this, outpatient clinics often discharge homeless patients for failing to attend appointments without offering any additional support to attend, which can be particularly challenging for them and for those supporting them.

Another challenge related to discharge from hospital is when a homeless person leaves before investigations or treatment are completed. To understand the reasons why people self-discharge, staff need to firstly understand how people's current situations can conflict with the way care is delivered. For example, for patients with an opiate addiction, the slow process of getting admitted onto a ward and the long delay before being prescribed an adequate dose of methadone can be extremely challenging. This is the same for patients who are dependent on alcohol who fear alcohol withdrawal, and so leave the A&E department or ward before being discharged.⁵

Furthermore, self-discharge compounds problems with communication as no discharge letter is sent to the GP, which leads to increased work to investigate and liaise with teams on the ward in order to understand what the diagnosis and management plans were.

Difficulties in sharing information between services

Joined-up working is essential for all agencies that work with homeless people so they can get to know people's needs and recognise any changes in their health or circumstances. However, poor communication between health professionals and

with hostel or outreach staff exacerbates existing problems with fragmented care.

The research by Shulman, Hudson and others found that hostel and outreach staff often have difficulty giving and receiving information from a hospital, as they are not considered next of kin and healthcare professionals don't view them as experts in the person's care needs. Without any formal communication, hostel staff may be unaware of a person's condition, its treatment or its severity.

Problems in communication are further compounded by the fact that the homeless person may not be able to advocate for themselves. Without social support, a homeless person admitted to hospital in crisis may have nobody to speak on their behalf or give their history and background. Their ability to self-advocate can also be hampered by language barriers, substance misuse, emotional volatility, social anxiety and other mental health issues – including the overlapping disorders of personality and neurodevelopment such as autistic spectrum disorder and attention deficit and hyperactivity disorders – which are over-represented in this population.⁶ As a result, ill-informed decisions are made about their care and discharge.

Few options available at the end of life

The environment in hostels and supported accommodation projects is often not appropriate to care for someone at the end of their life: it can be noisy and chaotic without access to a private bathroom or there may not be enough space for necessary medical equipment, such as hospital beds and hoists.

However, the reality is that there are very few suitable alternatives available. CQC reported in *A different ending* that homeless people find it difficult to access services other than hostels.

Alison's story

Alison* is 31 and has been intermittently homeless since she left care at 18. She is a long-term heavy drinker and intravenous substance user. By early 2015, Alison had developed end-stage liver failure and was regularly admitted to hospital.

Alison finds it difficult to take her prescribed medications; she regularly misses doses or attempts to take more than the prescribed dose, and is prone to disruptive behaviour, making it difficult at times for others to engage with her. She continues to drink and has a fluctuating level of insight about the severity of her illness.

Following one admission to hospital, hostel staff raised concerns about their ability to manage Alison's care. They were anxious that she was near the end of life and might die in a hostel environment. A case review meeting was arranged by the palliative care coordinator upon discharge, which involved hostel staff, Alison's GP and the community-based addiction services supporting her. They now meet regularly to review her progress.

Over time, an open and honest dialogue has developed between Alison, her GP, the palliative care coordinator and the palliative care nurse about the severity of her illness. Together, they have been able to discuss the implications of her continuing to drink and her expressed wishes and preferences for care. With regular meetings, they have been able to plan her current and anticipated needs.

Although Alison's health continues to deteriorate, St Mungo's has provided stable and consistent support to Alison, which has enabled her chaotic behavior to subside and has reduced hospital admissions. With the help of the coordinator and keyworker, she has also reconnected with her family, from whom she had been estranged for more than half her life. They are now playing an important role in her care.

Name has been changed. Case study from **St Mungo's*

For example, the recent research from Shulman, Hudson and others has identified that many hospices find it challenging to support people with active addictions on an inpatient basis, which limits the access of many homeless people to these services. The young age at which many homeless people may benefit most from nursing home support is also problematic, as access to such services often requires patients to be at least 65 years old.

The research found that the lack of specialist provision of end of life care for homeless people means that many are cared for in hostels, where staff are not equipped to deal with their often substantial needs, and have little access to palliative care support. As a homeless person's health deteriorates, hostels struggle to provide the level of care and support that people need. The research found that clients often see the

hostel as their home and express a wish to remain there. Staff-to-client ratios can be very low, often with only two members of staff working at night in hostels with up to 60 beds. This means that it is often impossible to attend adequately to someone with high needs.

The result is that many homeless people have inadequate support as their health deteriorates and are frequently admitted to hospital in the last months of their life. Indeed, St Mungo's own data found that just under half of their residents who die, do so in hospital. They found that most of the health care they accessed in the last six months of life was from secondary care services, rather than from their GP or a community hospice. This was echoed in the findings of research commissioned by St Mungo's and Marie Curie.⁷

Promoting access and continuity in care

Some organisations are making strides in improving the continuity of care for homeless people. One example is **Pathway**, which provides a model of integrated healthcare for single homeless people and rough sleepers. The charity aims to share and spread its models, to train and support a new cohort of healthcare practitioners and care navigators for homeless people, and to challenge the health service to deliver better quality healthcare to the most excluded.

Pathway's work, which CQC has seen on its inspections, also champions multidisciplinary team working that crosses traditional boundaries. The Pathway team supports and advocates for homeless patients, liaising directly with hospital teams to ensure that communication is up-to-date and of a high quality, as well as with community teams to ensure a safe and successful discharge. Although this model has a much broader remit than just end of life care, it is an example of how barriers can be brought down by improving communication and continuity, and therefore the quality of care at the end of life. Services across health, social care, housing and justice could learn from the projects' successes.

Manchester Pathway (MPath)

Urban Village Medical Practice is a GP surgery in Manchester that caters for the needs of homeless patients. CQC rated the GP surgery as outstanding in 2015. Based on the Pathway model, it has been commissioned to reduce A&E attendances and re-admissions for homeless people and to provide an effective discharge service for inpatients. The three main elements to the service are:

1. **Acute hospital rounds** led by an Urban Village GP and Specialist Case Manager. They regularly visit every homeless patient admitted to a hospital to coordinate all aspects of their care while they are an inpatient. They offer specialist advice where required and work with hospital and community staff to facilitate an appropriate discharge, including for patients at the end of life.
2. **Primary care follow-up**, which the service offers to all homeless patients that it identifies. It includes access to existing primary care services such as a weekly multi-disciplinary drop-in session offering access to GPs, practice nurses, drug and alcohol services, mental health services, a dentist and dedicated GP/nurse clinics for homeless people throughout the week.
3. **Community follow-up and support** from Specialist Case Managers who work proactively and flexibly to engage patients with complex needs who are discharged from hospital and A&E in the community. They support them with issues including housing, benefits and accessing appropriate healthcare such as palliative care, and work closely with other local agencies, such as hospices, to ensure their needs are met.

In the first six months alone, MPath was able to demonstrate a reduction in unplanned patient activity at the hospital, improvements in individuals' housing and financial status and an increase in access to primary and community health services.

Few homeless people with complex physical health problems have an identified person to improve the coordination of their palliative care needs. St Mungo's therefore pioneered the role of the palliative care coordinator for homeless people in 2007. St Mungo's is a homelessness charity and housing association that provides a bed and support to more than 2,600 people every night who are either homeless or at risk, and works to end homelessness and rebuild lives. The charity has been able to demonstrate clear improvements in outcomes and experiences of care for homeless people at the end of life since the palliative care role was implemented.

Some services take the approach that respecting people's decisions, for example to continue to drink alcohol, can empower them and ultimately lead to more trusting and open relationships. CQC has seen examples where this approach is successfully meeting the needs of homeless people, such as the Anchor Centre in Leicester. The centre, like others designed to improve access for vulnerable and excluded people, adopts a 'low threshold' approach. This means removing certain barriers, such as requiring clients to be free from alcohol or other substances, before they are allowed to use certain services.

St Mungo's palliative care coordinator role

St Mungo's developed an end of life care service in partnership with Marie Curie, led by a palliative care coordinator. Over the last three years, on average, 60 people have died each year while living in St Mungo's accommodation or using outreach services. Since the service was established in 2007, 180 residents have received one-to-one support across 100 accommodation projects, with 300 staff receiving support and training in end of life care.

The service supports people to come to terms with and prepare for death, and to make informed choices about future needs and wishes. It also supports staff to deliver this. It coordinates care with other services, which involves close working with primary and secondary healthcare providers, specialist palliative care service providers and other relevant health and social care agencies.

Referral criteria and an assessment protocols help staff to identify residents who may benefit from the support available, and a flexible pathway supports a diverse range of people both in a hostel or accommodation setting and in medical settings.

The service has also set up a volunteer-led befriending service to support people who are at the end of their life and those dealing with bereavement, including staff.

St Mungo's has been able to demonstrate an impact:

- residents stay longer at home with some planned deaths at home*
- there are greater links with supportive and specialist end of life care services
- communication between hospitals and hostels is improved.
- staff are more confident when engaging with primary and secondary care services about residents' needs.
- staff are more prepared for both anticipated and sudden death, leading to reduced anxiety about death and improved psychological wellbeing.

* *In this context, 'home' means hostel or semi-independent accommodation.*

The Anchor Centre

This 'wet' centre is run by a partnership between **Inclusion Healthcare** and Rutland Probation Trust. Inclusion Healthcare was rated as an outstanding GP practice in 2015. It aims to provide a safe environment for street drinkers and homeless people with alcohol dependency issues as an alternative to drinking on the street. The service uses a harm reduction approach to encourage individual clients to achieve specific goals related to their alcohol consumption.

When people are identified as being particularly unwell or deteriorating, they are referred to the primary care service, where they can be registered and cared for under a multidisciplinary team approach, which includes an end of life care lead.

The team has been able to demonstrate reduction in alcohol use among the people who use the service, as measured by a reduction in 'alcohol use disorders identification test' (AUDIT) scores.

These organisations are demonstrating innovative approaches that have a positive impact on homeless people who are at the end of their life, with some funded by local clinical commissioning groups. They provide inspiration for commissioners and providers, who may be able to use the learning from the work in different sectors to improve the design of services and deliver better care for their homeless population. These case studies demonstrate how partnership with existing organisations can provide comprehensive, multidisciplinary pathways of care that meet the specific needs of homeless people.

Summary discussion points

In summary, reducing inequality of care and eliminating discrimination for homeless people centres around a number of key areas.

- Firstly, because of the difficulty in identifying a homeless person who is dying, a more successful approach may be a shift towards focusing care on all homeless people who have advanced or deteriorating health problems. Meeting this demand will require action by commissioners and providers to be aware of, and understand, the scope and needs of the homeless population in their local area.
- Continuity of care and support is particularly important when coordinating end of life care needs. Homeless people often have complex care requirements, yet don't have access to the continuity or quality of care services that they need. This is the case in hospital, when discharged into the community and in terms of options at the end of life.
- Health services are not adequately communicating with each other, or with those who are often in contact with homeless people, so opportunities to intervene are missed. A multi-disciplinary approach would enable healthcare staff to improve the frequency and quality of communication with homeless people and others involved in their care, and to build a more holistic picture of their needs.
- There is a clear need to develop genuine options for homeless people who have deteriorating health or are approaching the end of life, so that they can be cared for in an environment that is comfortable and appropriate to their needs. This could be a hostel-based hospice that is able to provide 24-hour care, supported by health, housing and social services.

Knowledge, skills and support

CQC's end of life care review encouraged commissioners and providers to ensure that staff who care for people who may be approaching the end of life have the knowledge, skills and support they need.

The health needs of homeless people are complex, and even more so when they are very unwell and potentially approaching the end of their life. We explore the many obstacles they face to having their needs recognised, explored, communicated and met, and the importance of training staff who work with homeless people to understand these barriers in order to surmount them.

Lack of recognition or action on deteriorating health

A key barrier to good end of life care for homeless people is that any deterioration in their health is not recognised and responded to early enough. Identifying homeless people with advancing ill health early would allow time to plan appropriate care and support and may help to avoid crisis-driven hospital deaths.

There are many reasons why deterioration is not recognised promptly in this group. As well as the lack of continuity of care discussed in the previous section, homeless people can have very complex health needs, often combining physical conditions such as HIV, hepatitis and liver disease, with substance misuse issues and poor mental health.⁸ They also die from different conditions compared with the rest of the population, which may contribute to why deterioration is less readily identified. For example, the majority of deaths for people receiving care from St Mungo's in 2009/10 were associated with multiple organ failure, mostly liver disease.⁹ Whereas, for the rest of the population in England, cancer claims the most lives prematurely, and dementia overall.¹⁰

Homeless people are also three times more likely to die as a result of traffic accidents or falls, and twice as likely to die from infection. They are over nine times more likely to commit suicide than the general population.¹¹

Death is often seen as sudden in this group, but in reality it is usually not unexpected. There are usually missed signs of deterioration in physical and mental health which, if recognised, would enable services and support to be discussed and put into action earlier. This requires a thorough understanding of the often multiple health problems in order to recognise when things begin to change. For example, liver failure is a major cause of death for homeless people, yet because of the unpredictable course that decompensated liver disease takes, it is difficult for staff and carers to judge when a person is approaching the end of their life and this prevents initiating conversations about end of life in secondary care settings.¹²

In response to the challenges of identifying when a homeless person may be approaching the end of their life, Shulman, Hudson and others suggest that planning should be incorporated in parallel with the care of homeless people:

“Parallel planning – planning for the worst while still hoping for the best – is a way of working with the uncertainty surrounding health and illness for people who are homeless. This means that the trigger for multidisciplinary intervention will be when concerns are raised about someone's deteriorating or advancing ill health, rather than needing to know for certain if they are reaching the end of their lives.”

By lowering the threshold of what determines the 'end of life' and instead recognising any deterioration in health, more timely interventions could be achieved as well as earlier conversations about a person's preferences and wishes.

John's story

John* was a 66 year old man who had been homeless for many years. When he moved to Oxford he was staying in a hostel and drinking heavily. Staff at Luther Street Medical Centre found him a challenge to engage with, as he would often aggressively demand sedative medication. His self-care in the hostel was very poor.

The Luther Street team worked closely with the hostel team to help him understand that it was not safe to take sedatives if he was drinking. He was accompanied to appointments and progress was made to help John slowly improve his self-care.

John's health gradually deteriorated until he was admitted to hospital with liver failure. On discharge, he remained very unwell, so the GP team decided to involve the palliative care team from the local hospice and they were able to get hold of John's next of kin. John accepted an admission to the hospice where his liver improved and he remained off alcohol, which allowed him to take appropriate psychiatric medication. His mood improved and a while staff were looking to secure a residential placement for him, John passed away peacefully from complications of liver failure.

Name and some identifying details have been changed. **Luther Street provides primary health care services for homeless people over the age of 16 and people vulnerably housed in Oxford. CQC rated the service as outstanding in 2016.*

Lack of understanding of a person's individual context and needs

Homeless people who are approaching the end of their life need support to help them explore their wishes and make personal choices. This helps to understand their needs and involve them in their care. By appreciating an individual's unique personal situation, services can respect the choices they make.

Many homeless people have survived difficult backgrounds, experienced abuse and violence, served time in prison or with the armed forces, and frequently have a broken support network.¹³ This exposure to complex trauma can make it difficult to build trusting relationships and is often associated with alcohol or substance misuse.

Furthermore, life is often chaotic for homeless people: managing appointments, medications and decisions about care can be particularly difficult.

Some services that require people to be alcohol or substance-free may not be available to those with addictions.

Discrimination is also common, so homeless people can feel excluded from society, and may have had negative experiences of health and care services in the past.

All these factors, combined with the lack of continuity of care, can affect their ability to build trust with anyone offering support. It can mean homeless people are less likely to access or be willing or able to engage with health and care services about their care needs. People who work with homelessness must therefore be offered the training that is necessary to understand these complexities and be supported to help and advise homeless people about how to access services.

Inclusion Healthcare Social Enterprise CIC

Inclusion Healthcare holds GP and nurse clinics for homeless and people in vulnerable circumstances at four sites in Leicester city centre to manage acute and chronic healthcare, in the style of a mainstream GP practice. It provides specialist alcohol and drug management services and works towards integration with statutory and voluntary services to provide seamless care. CQC rated the service as outstanding.

Inclusion's staff receive training to understand and support their patients to help them get the help that they need, such as by accompanying them to secondary care appointments.

End of life care is coordinated by a GP and nurse team following assessment and face-to-face discussion with the patient, supported by friends or a relative if requested. In the final stages of life, community services are linked to deliver care with 24-hour support. The team uses documentation that has been tailored for those living a hostel environment.

Bevan Healthcare Social Enterprise Community Interest Company

Bevan House in Bradford provides primary medical services for homeless people, people in temporary or unstable accommodation, refugees or those seeking asylum and others who find it hard to access health care and support. CQC inspected and rated the service as outstanding.

The practice offers a 'one stop shop' by being co-located alongside other services, including the homeless team, benefits services, refugee support teams, rape crisis, housing, midwifery and health visiting teams.

CQC saw that outcomes for patients were improved as a result of a respite service, developed alongside a social housing provider. This offered accommodation for homeless patients who need medical care after they are discharged from hospital. There is also a Street Medicine Team, which holds outreach clinics in city centre locations to improve people's access and also offers advice and healthcare to people who are not registered with the practice. Clothing, food, oral and personal hygiene packs and cold weather packs are offered to patients in urgent need.

These initiatives led to a demonstrable reduction in the use of acute healthcare, A&E admissions and days spent in hospital. The intermediate respite facility has enabled Bevan to deliver intensive end of life care for a number of homeless patients, through a multi-disciplinary partnership that has meant a radically improved quality of life for patients who need palliative care.

Challenges of exploring end of life wishes with homeless people

To understand a person's needs and preferences in poor health, there must be timely and sensitive discussions.¹⁴ Many people struggle to let others

know their wishes as they approach the end of their lives. For people who are homeless, additional obstacles make it even harder for them to talk about their thoughts, as well as for those who are trying to help and support them. It is essential to understand these barriers to identify how to overcome them.

Poor physical and mental health may affect people’s ability to communicate their wishes. Problems with memory can affect those with severe alcohol dependency or liver disease. For most of the population, the end of life is a time when friends and relatives can help advocate, but homeless people are often estranged from their family. Their friends may have chaotic and challenging lives of their own. Furthermore, many homeless people who may be approaching the end of their life are still young, often with potentially preventable or treatable conditions, and this can be another barrier to initiating a conversation about end of life.¹⁵

It is therefore important for health services to recognise the many obstacles that people face and work flexibly and persistently with homeless people to build a trusting relationship and allow them to be meaningfully involved in planning for care at the end of their life. This includes ensuring that they have the benefits they are entitled to and receive a holistic assessment of their needs.

“We found a conflict between the recovery-focused nature of many services and the realities of illness experienced by homeless people with advancing poor health. This made staff apprehensive to explore the wishes of homeless people with worsening health.” (Shulman, Hudson and others, 2017)

A big gap in support and training

To tackle inequities for homeless people, those who work with them must have the knowledge, skills and support to enable them to meet their needs. However, CQC has found a lack of sustainable training for staff on many issues, including end of life care.¹⁶

Hostel staff are often best placed to recognise when a resident’s condition is deteriorating and to have a sensitive discussion about future wishes

and preferences with residents who have advanced ill health. But they rarely receive formal training on this. They also have insufficient access to support and advice about palliative care.

Shulman, Hudson and others found that without the appropriate training and support, staff can be afraid of the impact of a resident dying in their hostel. Hostel staff also need support when a resident dies – as do the other residents.¹⁷ It is not generally considered appropriate for residents to die in hostels; deaths are therefore often investigated and staff are left feeling worried and unsupported.

Because homeless people do not have the opportunities to discuss their health and future, few have the chance to be involved in personalised care and support planning, which we know to be pivotal in coordinating meaningful care, especially at the end of life.¹⁸

In recognition of this training gap for all staff that come in contact with homeless people, Marie Curie and St Mungo’s developed comprehensive guidance in a Homelessness and End of Life Care Resource Pack. This aims to enhance the skills and knowledge of managers and frontline staff working with homeless people, including those working in supported accommodation, assertive outreach, drug and alcohol services, and homeless day centres.¹⁹

The pack describes effective ways to recognise and meet the physical, psychological, spiritual and social needs of homeless people as they approach the end of their life. The findings of the qualitative research conducted by Shulman, Hudson and others are being used to update this resource pack and develop training for hostel staff and health care professionals.



Supporting homeless people with advanced liver disease who are approaching the end of life

Marie Curie and St Mungo's found in their research that most of their homeless patients died of advanced liver disease. The trajectory of liver failure can be difficult to predict so it may be harder to recognise the end of life. They identified a need for guidance for healthcare professionals and other staff looking after homeless people on **identifying signs of deterioration in liver disease**, and published this in 2011.

They found that homeless people with liver disease display a combination of physical, psychological and behavioural signs and symptoms as their health deteriorates and the end of life approaches. They noted that death for these patients is often not anticipated and appears to occur suddenly, despite key signs of deterioration that are frequently missed.

Summary discussion points

In summary, to recognise deteriorating health and provide the appropriate care, staff in all agencies that work with homeless people need the necessary education, training, supervision and support.

- The inequalities that homeless people face in life and in death are compounded by a lack of recognition of their health needs and wishes. Staff who work with them are rarely given the training and support necessary to overcome the barriers they face and improve the quality of care they receive at the end of life. Currently, there is an over-reliance on hostel staff to meet the needs of people who are homeless. Rather than having to provide this care alone, they should have the support and resources of a multidisciplinary approach.
- This includes training and support to explore people's current insights into their health, and their wishes and aspirations for the future. Staff also need access to information, advice and support on end of life issues, and specialist palliative care input where appropriate.
- Adequate training would allow staff to develop personalised care and support plans together with homeless patients and in conjunction with the relevant multidisciplinary teams. In line with NHS England's guidance, plans should address their physical, mental, psychological, social and spiritual needs. We also highlight a reciprocal need for staff and residents in hostels and other accommodation settings to have access to bereavement support when a homeless person has died.

The role of hospices in championing equality

In *A different ending*, CQC encouraged hospices to champion an equality-led approach, engage communities, deliver equitable end of life care for homeless people, and support others to do the same.

Many hospices, as they are currently designed, are unable to cope with the needs of homeless people at the end of life. The behaviour of people who are homeless may be difficult, including that related to complex physical and mental health conditions such as personality disorders, as well as learning disabilities, poor literacy and substance misuse problems. As discussed in the previous chapters, there is rarely a straightforward pathway for homeless people to access hospice services,

particularly as an inpatient, and their specific care needs are not always addressed.

However, CQC has also seen some examples of outstanding care in hospices, where the staff take an individual approach to personalised care, enabling them to meet a homeless person's needs and preferences. In some hospices, staff provide training and support to those working with homeless people in different settings, and work with other agencies (including in the voluntary sector) to support the development of end of life care options in the community for homeless people. Through this work, they are helping to address the inequalities that homeless people experience at the end of life.

Hospice, primary care centre and housing association team up to provide a medical bed for homeless people

St Luke's Hospice in Cheshire West teamed up for an innovative project with St Werburgh's Medical Practice for the homeless and Forum Housing Association. They secured funding to install a medical room for end of life care for Forum's residents in Richmond Court, a local homeless hostel. The Extra Care Room has a medical bed, disabled access, kitchenette and en-suite bathroom. It is also used to provide respite care when a homeless person is discharged from hospital.

A palliative care nurse from St Luke's provided the expertise and training needed to develop this project. The ongoing medical and palliative care is provided by St Werburgh's to most of the residents in Richmond Court.

St Luke's continues to offer support and training to Richmond Court staff where needed. By having strong links with partnership agencies, St Luke's team has ambitions to develop a "compassionate community model" to support this marginalised group of people. This would include having a counsellor in two of the local hostels, and being able to advocate for the needs of homeless people at the end of life.

St Luke's Hospice provides specialist care to people over 18 who have advanced life-limiting illnesses. St Werburgh's provides primary care services for the homeless population in Chester. Both services were rated as good by CQC in 2016.

Artur's story

Artur* was diagnosed with end-stage lung cancer in September 2016. He was initially street homeless but was offered a bed in Richmond Court. Over the following months he was looked after by an integrated team: he had weekly consultations at St Werburgh's Medical Practice with his GP, his keyworker from Richmond Court, the Macmillan nurse and the district nurse. His key worker attended hospital appointments with him, and the ambulance and out-of-hours services were informed of his care plan.

Artur's condition deteriorated in February 2017. He stabilised during a hospital admission but was discharged to Richmond Court's Extra Care Room. There, he received regular pain relief administered by the district nurse, and the rest of the team remained involved in his care. He passed away in the room with his family, whom his key worker had helped him to contact. The team and facilities allowed Artur to have a dignified death in a place of his choosing with those around him that he wished for.

**Name has been changed. Case study provided by St Werburgh's Medical Practice*

Because of their expertise in delivering excellent, individualised care at the end of life, hospices are well placed in the community to engage other services and champion an equality-led approach to delivering palliative care for homeless people. The examples of good practice demonstrate how effective they can be in supporting others to do the same.

There are inspiring examples of hospice staff training others, particularly staff in hostels. But some hospices are also taking the lead and bringing together organisations across voluntary services and health and social care to share learning and drive improvement for vulnerable people.

For example, in response to CQC's recommendations in *A different ending*, a team of doctors, nurses and social workers from Royal Trinity

Hospice organised an event to bring together professionals from across 15 different voluntary, health and social care organisations to address the issue of access to services for homeless people.

There are also examples where hospices are working together across areas to upskill staff by teaching additional skills and expand their capabilities to develop innovative new roles to support their particularly vulnerable patients.



Hospices are well placed in the community to engage other services and champion an equality-led approach to delivering palliative care for homeless people

Hospices working together to upskill staff who work with homeless people

Dorothy House Hospice Care provides specialist palliative and end of life care for adults in parts of Bath and North East Somerset, and parts of Somerset and Wiltshire. CQC rated the service as outstanding in January 2017.

CQC found that Dorothy House had carried out exceptional work to improve equity of access to end of life care services for hard to reach groups, including homeless people. A working group was set up to look at the issues faced by some marginalised groups, and partnerships were developed with relevant statutory and charitable organisations to enhance their end of life care.

For example, Dorothy House Hospice Care took part in a project with St Peter's Hospice in Bristol to provide a series of training sessions for homelessness organisations in the Bath and North East Somerset and Mendip areas in 2015, and with Prospect and Salisbury's Hospices in Wiltshire in 2016/17. The project was funded by Health Education South West. The approach was to upskill the staff who were already working with those they are trying to reach.

The courses provided a two-way learning opportunity. They allowed networking between agencies, a growth in confidence around the subject of end of life and, in particular for Dorothy House Hospice Care, they enabled the development of direct clinical relationships with providers offering direct support to people who are homeless.

As part of the working group, Dorothy House had also developed a nurse specialist role to explore the needs of homeless people, originally funded by Burdett Trust for Nursing. The nurse was able to establish closer partnership working with health, police and housing and voluntary organisations providing services directly for people who are homeless.

Michael's story

Michael* was a middle-aged man who was homeless and had advanced liver disease. He was living in a hostel where all staff attended an education and training session on end of life care delivered by a palliative care nurse from the local hospice. The staff mentioned this resident several times during the training session as they were worried he was approaching the end of his life. The hospice nurse used his case to illustrate how to approach personalised care and support planning.

When the nurse returned to give further training, the staff told her that the training had changed their perceptions, and they had spent time with Michael talking about what was important to him. They established that he wanted to write a letter to his estranged family and were able to support him to do this. Staff had managed to track down his family's address through a charity service. A few months later his condition deteriorated rapidly and he died. The staff expressed their gratitude that they had been supported to meet his wishes before he died.

**Name has been changed. Case study provided by St Luke's Hospice, Cheshire West*

Summary discussion points

In summary, hospices are ideally placed to champion an equality-led approach to end of life care for homeless people, and engage and support staff and others in the community to do the same.

- If staff who work in hospices have access to the necessary training and support, they will be better equipped to champion equality.
- What is particularly inspiring about the examples is how organisations that traditionally offered specific services independently have teamed up to work in partnership with other agencies to share expertise and deliver more holistic care for people who are homeless. These examples of multidisciplinary education, working and support could be hugely beneficial in sharing learning and innovation to improve end of life care for homeless and other marginalised groups.

CQC celebrates outstanding primary care services for homeless people

Regulation of primary care services includes GP services that provide care specifically for homeless people and other marginalised groups. CQC's comprehensive inspection programme found that many of these services are providing good and outstanding care. Not all GP practices have a large homeless population, but all primary care services can learn from the approach and ethos of specialist primary care services for homeless people.

CQC has seen some truly inspiring practices, highlighted in this report. Services that provide outstanding care have some common features:

- they have carried out robust local needs assessments
- their services are highly accessible to excluded and vulnerable groups
- they have highly motivated teams with a clearly articulated underlying philosophy
- there is a strong multidisciplinary and cross-agency approach to working
- they have a commitment to demonstrating impact, often with academic links to outcome data, demonstrating improved life expectancy or reduced hospital admissions as a result of their interventions.



If you do not have a roof over your head, there is no dignity at the end of life

Delegate at QNI Homeless and Inclusion Health Conference 2016

Putting the discussion into action

The most vulnerable people in our communities are being let down at a time when they need help and support the most: when they are dying.

In this paper, we have explored the multiple reasons why homeless people do not experience good care at the end of life. However, we show that there are many opportunities to improve standards of care.

We have highlighted the importance of working collaboratively across traditional boundaries to build relationships and trust, design flexible end of life care options, and educate and support one another to break down the barriers that prevent equal access to compassionate care for all.

Many of the challenges in meeting the needs of homeless people who are at the end of their life are the same for other marginalised and vulnerable groups. The learning from one group should be shared and applied to others.

We have been inspired by the joint working that preceded, and has emerged, following *A different ending*, but there are still many hurdles to overcome. We now call on all those involved to make the changes needed to ensure that homeless people have the same rights as others: to die with dignity, how and where they wish to.



We now call on all those involved to make the changes needed to ensure that homeless people have the same rights as others: to die with dignity, how and where they wish to

References

1. Shulman C, Hudson B F, Low J, Hewett N, Daley J, Kennedy P, and others, **End-of-life care for homeless people: A qualitative analysis exploring the challenges to access and provision of palliative care**, *Palliative Medicine*, 2017;0(0):0269216317717101, July 2017
2. Crisis, **The hidden truth about homelessness**, 2011
3. Homeless Link, **The unhealthy state of homelessness**, 2014
4. NHS England, **Patient Registration Standard Operating Principles for Primary Medical Care (General Practice)**, 2015
5. Homeless Link, **Improving hospital admission and discharge for people who are homeless**, 2012
6. Fazel S, Khosla V, Doll H, Geddes J, **The Prevalence of Mental Disorders among the Homeless in Western Countries: Systematic Review and Meta-Regression Analysis**. *PLoS Med* 5(12): e225. doi:10.1371/journal.pmed.0050225, 2008
7. St Mungo's and Marie Curie Palliative Care Research Unit at University College London, **Supporting homeless people with advanced liver disease approaching the end of life**, May 2011
8. Homeless Link, **The unhealthy state of homelessness**, 2014
9. St Mungo's and Marie Curie Palliative Care Research Unit at University College London, **Supporting homeless people with advanced liver disease approaching the end of life**, May 2011
10. Office for National Statistics, **Deaths registered in England and Wales: 2015**
11. Crisis, **Homelessness: A silent killer**, 2011
12. St Mungo's and Marie Curie Palliative Care Research Unit at University College London, **Supporting homeless people with advanced liver disease approaching the end of life**, May 2011
13. Fitzpatrick S, Bramley G and Johnsen S, **Multiple Exclusion Homelessness in the UK, Briefing Paper 1**, 2012
14. National Council for Palliative Care and Dying Matters, **Dying – doing it better**, 2011
15. Shulman C, Hudson B F, Low J, Hewett N, Daley J, Kennedy P, and others, **End-of-life care for homeless people: A qualitative analysis exploring the challenges to access and provision of palliative care**, *Palliative Medicine*, 2017;0(0):0269216317717101, July 2017
16. Care Quality Commission, **A different ending: addressing inequalities in end of life care**, May 2016
17. Shulman C, Hudson B F, Low J, Hewett N, Daley J, Kennedy P, and others, **End-of-life care for homeless people: A qualitative analysis exploring the challenges to access and provision of palliative care**, *Palliative Medicine*, 2017;0(0):0269216317717101, July 2017
18. NHS England, **Personalised care and support planning handbook: The journey to person-centred care**, 2016
19. St Mungo's and Marie Curie, **Homelessness and End of Life Care Resource Pack**, 2013

How to contact us

Care Quality Commission

Call us on > 03000 616161

Email us at > enquiries@cqc.org.uk

Look at our website > www.cqc.org.uk

Write to us at >

Care Quality Commission
Citygate
Gallowgate
Newcastle upon Tyne
NE1 4PA

 Follow us on Twitter >
[@CareQualityComm](https://twitter.com/CareQualityComm)

The Faculty for Homeless and Inclusion Health

Call us on > 020 3447 2420

Email us at > info@pathway.org.uk

Look at our website > www.pathway.org.uk/faculty

5th Floor, East Block
250 Euston Road
London
NW1 2PG

Please contact us if you would like a summary of this report in another language or format.

