

KCL homelessness webinar

Palliative Care for People Experiencing Homelessness

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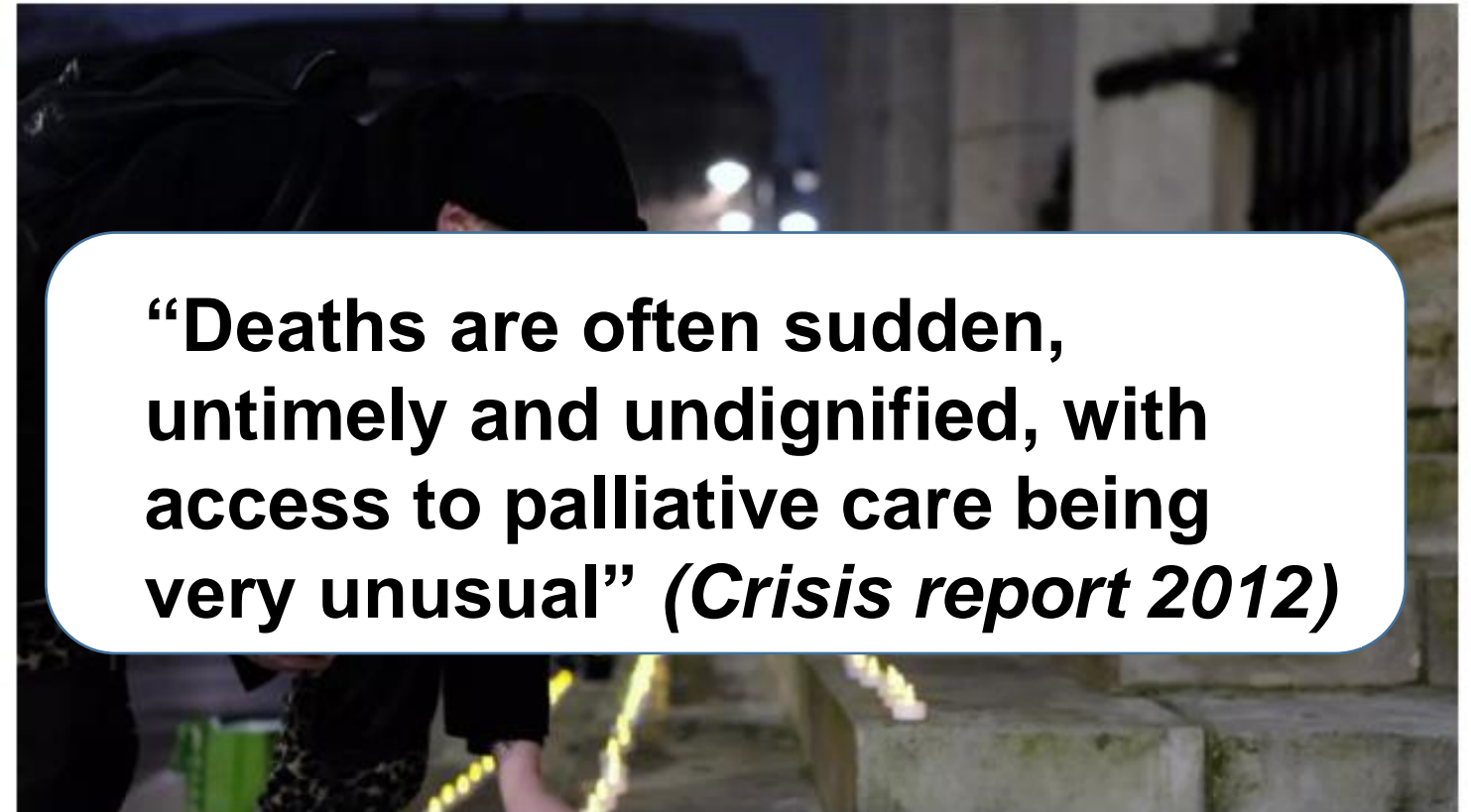
Today's Talk

- Why is palliative care relevant?
- What we know from research
 - Challenges and complexities around the support received by people with frailty and advanced ill health living in hostels
 - Why people are not accessing palliative care
 - What's needed to improve access to high quality trauma informed support for this population
 - What works - case example
- Resources

A person died while homeless every seven hours in the UK in 2021

The Museum of Homelessness's Dying Homeless Project recorded 1,286 deaths across the UK – the rise of a third in just one year is a 'hammer blow', the campaigners said.

LIAM GERAGHTY | 31 Mar 2022



“Deaths are often sudden, untimely and undignified, with access to palliative care being very unusual” (*Crisis report 2012*)

Carla Ecola, the director of the LGBTQ+ homeless shelter The Outside Project, was among the campaigners laying candles on the landmark in memory of homeless deaths.

Credit: Anthony Luvera

Museum of Homelessness
Dying homelessness project:
1474 people experiencing homelessness died in 2023

Office for national statistics
Mean age of death of people experiencing homelessness:
men 45
Women 43

<https://museumofhomelessness.org/dhp>
<https://www.ons.gov.uk>

What is Palliative Care?

Palliative care

- Is a holistic multidisciplinary approach in the care and support of people with a life limiting condition and advanced ill health
- It aims to prevent and relieve suffering through the early identification, correct assessment and treatment of pain and other problems whether physical, psychosocial or spiritual.
- Palliative care is not just for the end of life and can occur alongside active treatment

Gemma (age 28)

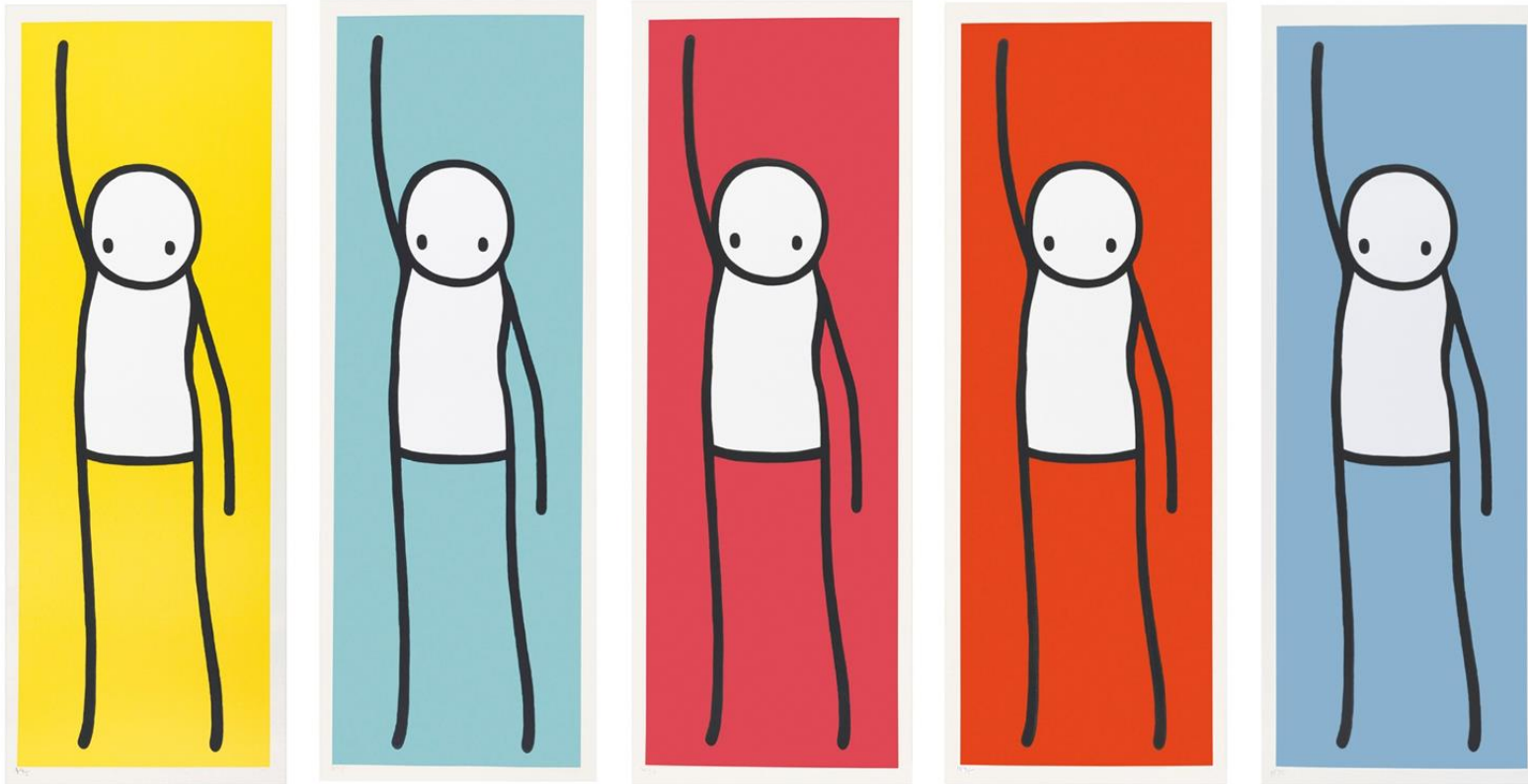


Nick (age 52)



**How can we
improve
palliative care
for people who
are homeless?**

What we know from research



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Frailty and multimorbidity in a homeless hostel

Hostel: 42 residents aged over 30

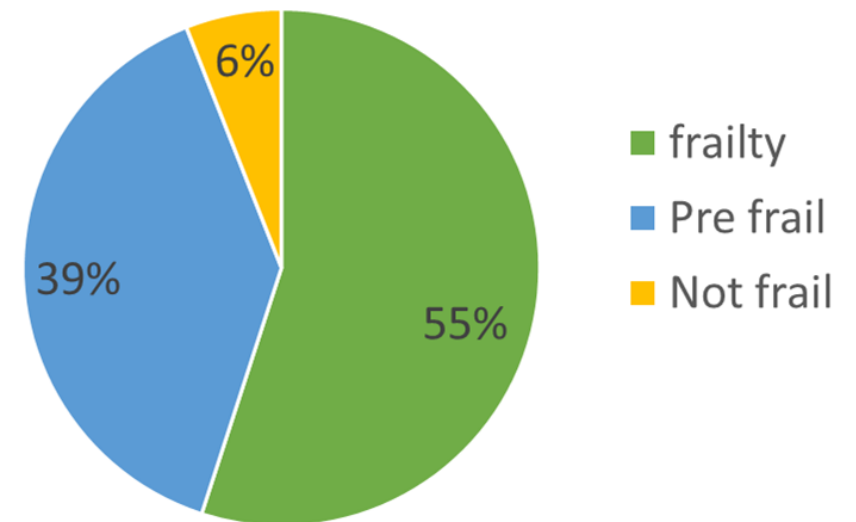
Findings

- **Average age: 55**
- 85% history of rough sleeping
- **Frailty scores equivalent to 89 year olds** in general population
- **Geriatric conditions:**
 - > 50% : Falls, Mobility problems, Low grip strength & Visual problems
 - Cognitive impairment 45%, Malnutrition 39% and Urinary Incontinence in 30%
- **Multimorbidity:**
 - Everyone had 2 or more long term conditions
 - Average number of long-term conditions per person > 7
- **Only 9% had any form of package of care**

Frailty (Fried):

Reduced strength; Reduced walking speed; Fatigue; Low physical activity; Unintentional weight loss: (3 or more = frail, 1 or 2 = pre-frail)

n=33 hostel residents (83% of eligible residents)



Rogans-Watson, R., Shulman, C., Lewer, D., Armstrong, M., & Hudson, B. (2020). Premature frailty, geriatric conditions and multimorbidity among people experiencing homelessness: a cross-sectional observational study in a London hostel. *Housing, Care and Support*.

Shulman, C., Rogans-Watson, R., Palipane, N., Lewer, D., Yeung, M., & Hudson, B. F. (2024). The Frailty, Health and Care Needs Assessment (FHCNA): development of the questionnaire and testing its feasibility in homeless hostel accommodation. *Housing, Care and Support*, 27(1), 34-48.

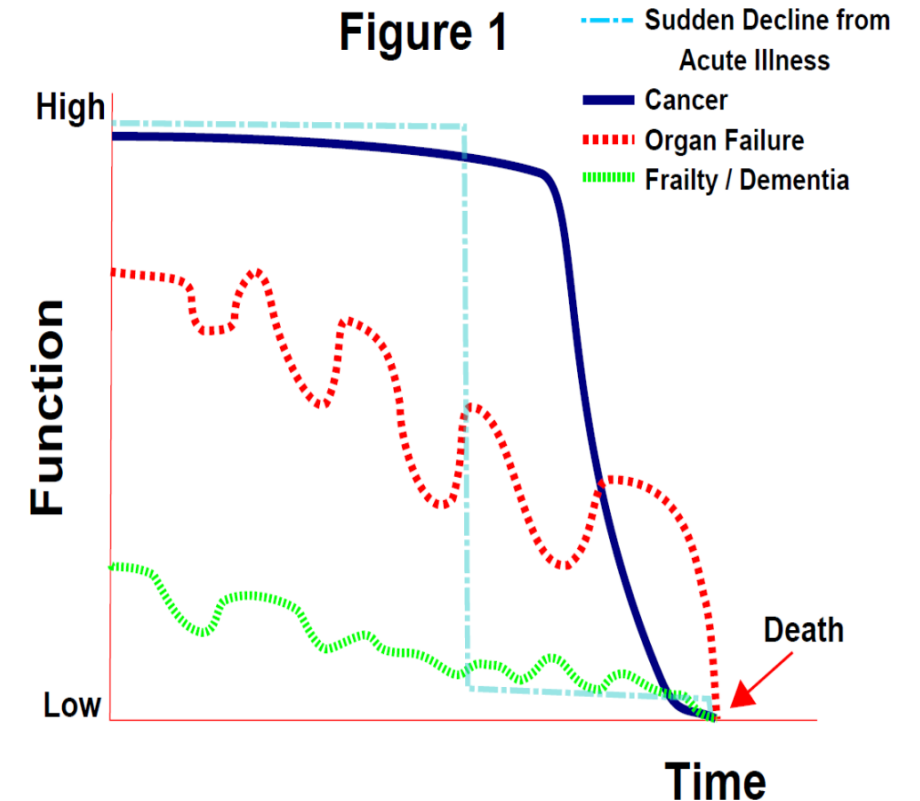
“I think that people are just resistant to the concept of them [people who are homeless] being palliative patients. You are dealing with people who are still relatively young...it's difficult”.

Specialist GP

KEY FINDINGS FROM RESEARCH

Lack of identification of who has palliative care needs

- Young age
- Uncertainty (disease trajectory)
- Complexity, related to trauma, substance use disorders
- Barriers to accessing mainstream services



Lunney JR, et al. Profiles of older medicare decedents. *J Am Geriatr Soc.* 2002 Jun;50(6):1108-12.



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Shulman C, Hudson BF, Low J et al. End-of-life care for homeless people: A qualitative analysis exploring the challenges to access and provision of palliative care. *Palliative Medicine.*2017



Gaps in current systems

Many people with very complex needs, at risk of dying, are in hostels or temporary accommodation

Gaps in current systems: Recovery model of homeless services

People with complex needs often remain in hostels and lack support

...we're trained to do recovery.... our hostel is commissioned to engage people with support and recovery... getting better, moving into jobs, whatever..

“At least three times a shift we check she’s okay. It’s hard... particularly on weekends and nights when we only have two staff... it’s a big hostel [60 residents]... this isn’t an appropriate environment, but it’s the best we have” **Hostel staff**

- Homelessness services role is to support people into recovery
- Hostels are designed to provide temporary accommodation
- Staff left to support people with increasing complexity
- Staff go way over and above their role
- Often struggle to get adequate medical support or support from social services
- High rates of staff burnout

Gaps in Current systems: Lack of options for place of care

"...In the past we have tried to put people into hospice ... one person [in his 40's] we did get in there. And he was asked to leave because of his behaviour when drunk. And in the end he died in the hostel, he had cancer"

Hostel staff

Most care homes are for people with dementia who are older; it's just, it's our patients just don't fit any of these like rigid things....the care homes themselves are like 'what?! 'We don't want this 29 year old"...

you know? **Specialist nurse**

Gaps in Current systems

- Lack of alternative places of care due to:
 - Young age
 - Mental health difficulties
 - Substance misuse

Findings: Lack of Planning

Lack of confidence

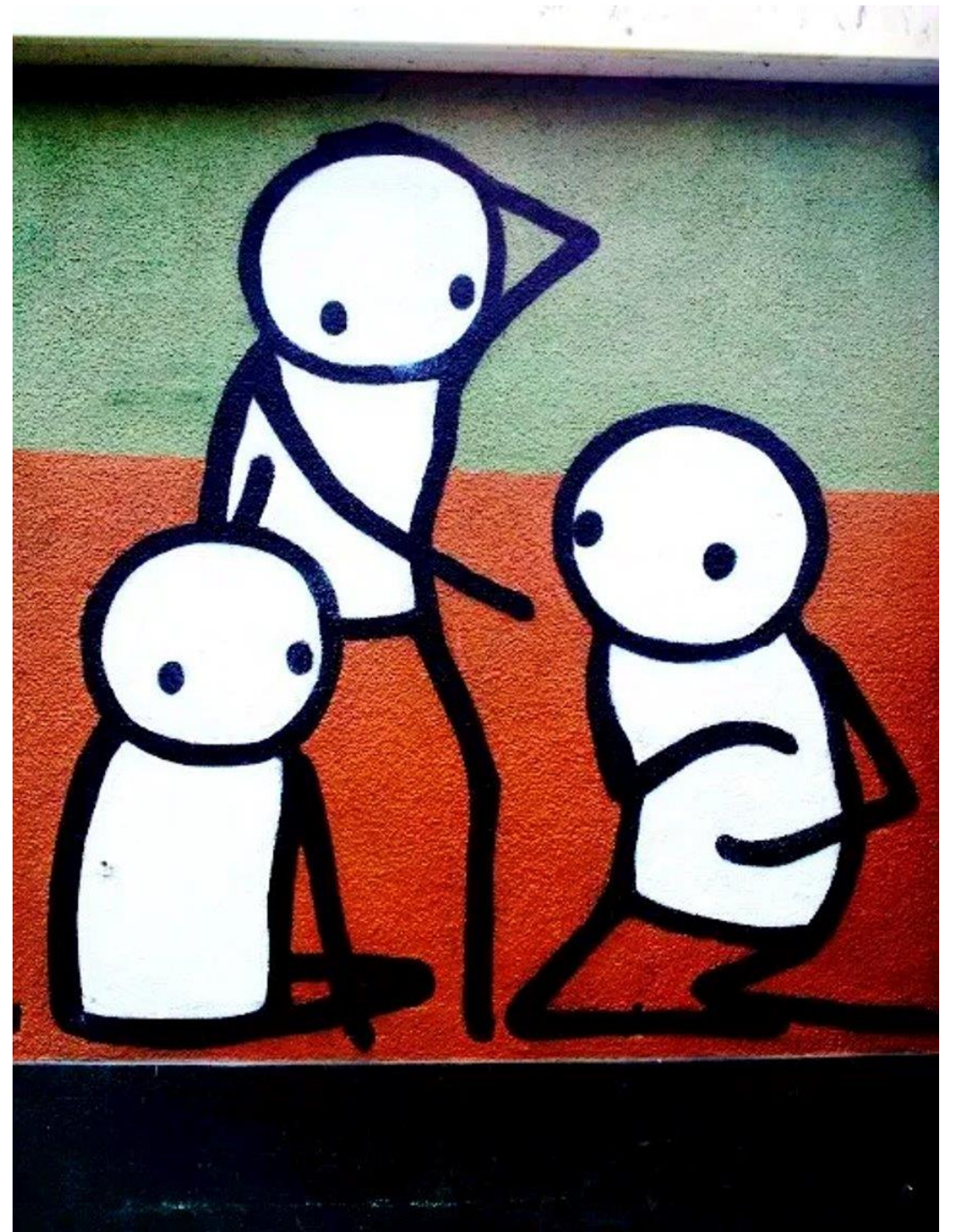
Denial - from all sides

Concern about fragility & removing hope

Uncertainty of prognosis

Lack of options to offer

Overcoming the challenges



What's can help / what's needed?

- Trauma informed services, valuing continuity with time to develop trust
- Improve identification of those that might benefit from palliative care
 - Listen to and involve frontline staff: who are they concerned about?
 - Shift our approach from *“is this person approaching the end of life”* to *“does this person have advanced ill health or deteriorating health”*
 - **Hope for the best while planning for the worst**
 - Shared understanding of palliative care approach and what it can offer: **not giving up on someone, active treatment can continue**



Shulman C, Hudson B F, Low J et al (2018). Palliative Medicine 32(1): 36-45

Hudson BF, Shulman C, Low J, et al (2017). BMJ Open 2017;7:e017502.

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What's can help / what's needed?

- Trauma informed services valuing continuity with time to develop trust
- Improve identification of those that might benefit from palliative care
- **Think differently about Advance Care Planning considering uncertainty and trauma**
 - **Person-centred, trauma informed exploration** of insights into illness, wishes and choices around **living well** eg **‘how I want to live, how I want to receive care’**
 - Early & repeated conversations
 - Not centred around giving warnings
 - Where possible respect and explore choices (*even if we feel they are unwise*)



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Shulman C, Hudson B F, Low J et al (2018). Palliative Medicine 32(1): 36-45

Hudson BF, Shulman C, Low J, et al (2017). BMJ Open 2017;7:e017502.

What's can help / what's needed?

- Trauma informed services valuing continuity with time to develop trust
- Improve identification of those that might benefit from palliative care
- Think differently about advance care planning considering uncertainty and trauma
- ***Choice in Place of Care and Care in Place of Choice***
- **Multidisciplinary support (including adult social care) taken to where people are – including in-reach into hostels**
 - Shared understanding and training for all professional groups
 - Collectively advocate for alternative places of care such as high support need facilities

Shulman C, Hudson B F, Low J et al (2018). Palliative Medicine 32(1): 36-45

Hudson BF, Shulman C, Low J, et al (2017). BMJ Open 2017;7:e017502.

Training and support

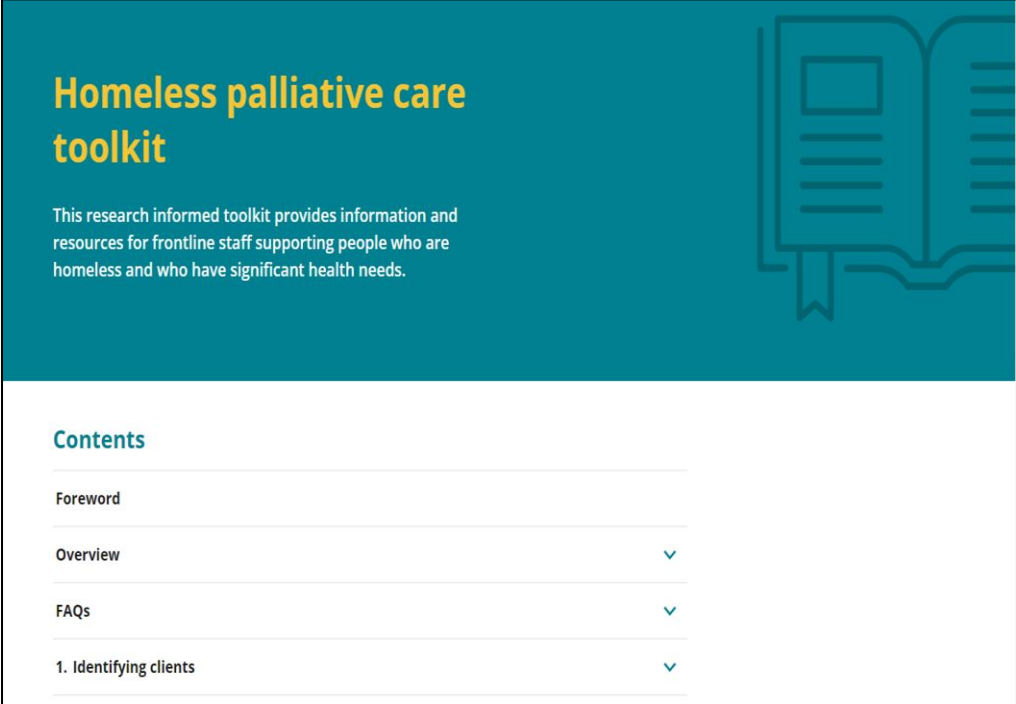
Homelesspalliativecare.com
toolkit

Training for hostel staff

-For lasting change, training needs to be
accompanied by

multi disciplinary, multi agency support

Shulman C, Hudson BF, Kennedy P, Brophy N, Stone P. Evaluation of training on palliative care for staff working within a homeless hostel. Nurse Educ Today. 2018 Dec;71:135-144. doi: 10.1016/j.nedt.2018.09.022. Epub 2018 Sep 29. PMID: 30286371.



Homeless palliative care toolkit

This research informed toolkit provides information and resources for frontline staff supporting people who are homeless and who have significant health needs.

Contents

- Foreword
- Overview
- FAQs
- 1. Identifying clients

www.homelesspalliativecare.com



Taking palliative care to where people are: The 'twinning project'

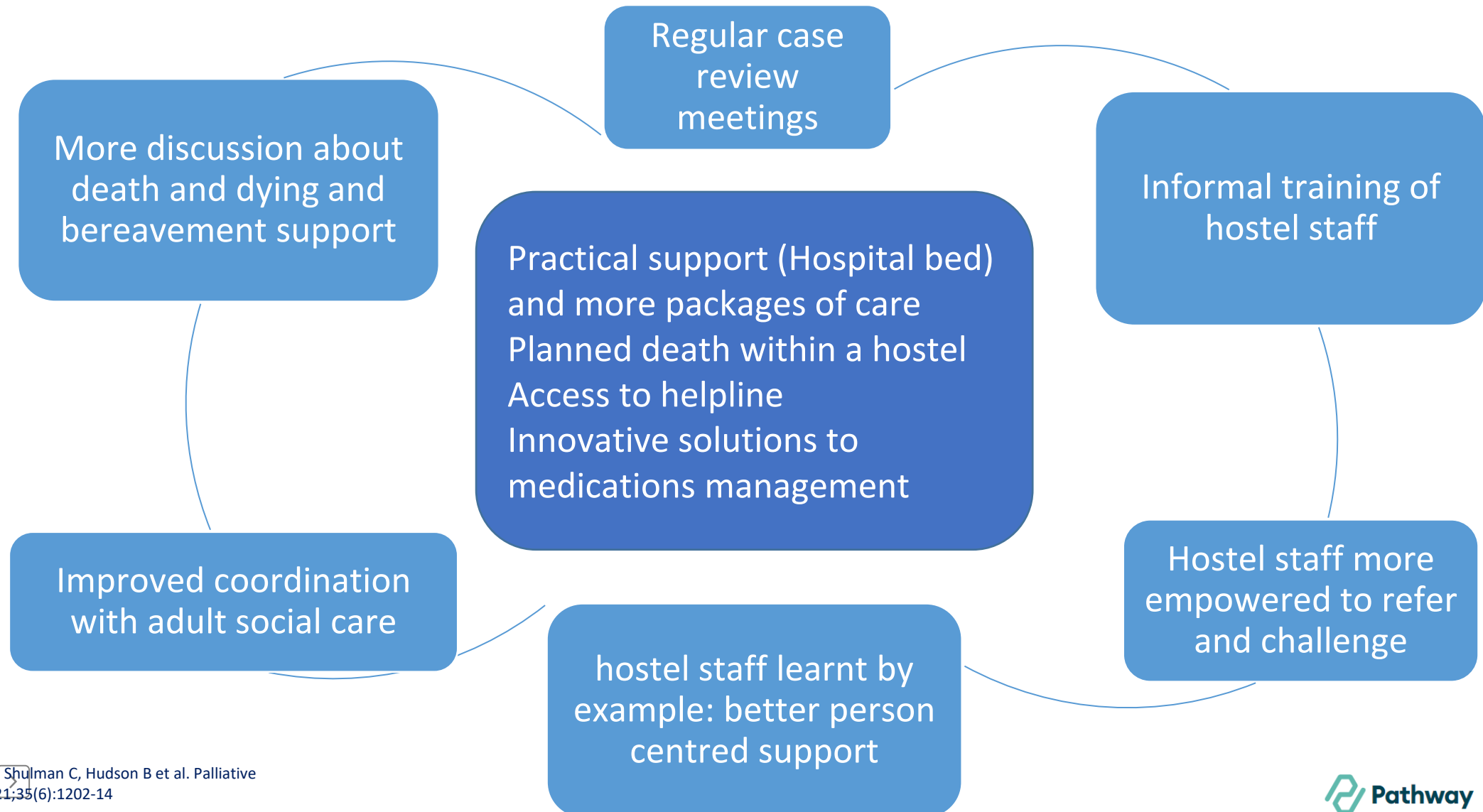
Project aimed to:

- Link hostels with community palliative care team in order to:
 - Improve access to high quality care and support for people with advanced ill health
 - Reduce burden on frontline staff by embedding training, support and an MDT approach into hostels



Armstrong M, Shulman C, Hudson B, Brophy N, Daley J, Hewett N, et al. The benefits and challenges of embedding specialist palliative care teams within homeless hostels to enhance support and learning: Perspectives from palliative care teams and hostel staff. *Palliative Medicine*. 2021;35(6):1202-14

How in-reach support can help



Abbie (age 42)

Overview

- Abbie was very unwell, in and out of hospital with decompensated liver disease, untreated Hep C, chest infections, episodes of unresponsiveness, underweight
- Self discharged as soon as able
- Alcohol and drug dependent
- No engagement with key worker or services
- Hostel staff had little knowledge of her life prior to being in hostel
- Placed Abbie in a room with glass windows in reception so they could keep an eye on her
- The palliative care nurse and social worker were called to help



Abbie (age 42)

Team explored what was important to Abbie.

She was

- Adamant she did not want to return to hospital (many friends had died in hospital)
- Did want to cut down from alcohol but struggled due to isolation and being in hostel environment
- Felt GP had given up on her but wanted assistance with managing Hep C
- Hated being in glass room as wanted her privacy
- Liked Art



Abbie (age 42)

Actions

- Abbie was referred to the hospice
 - Enabled palliative care team to continue working with her
 - Attended day centre to do art therapy
- Discussed with hostel staff *care vs control*
- Moved Abbie back to her room



Abbie (age 42)

Outcomes

- Abbie engaged with the hospice and recovered some of her independence, and physical and emotional wellbeing
- Abbie felt listened to and a plan was made in line with her priorities
- Improved engagement with her key worker and other hostel staff.
 - Commented to key worker – *‘you must really care to be going to this much effort’*.
- Basic teaching provided to hostel staff around Abbie’s health needs and how to monitor for a deterioration
- Hostel staff felt more supported and started working in a more person-centred trauma-informed way
- Palliative care team felt they better understood the difficulties hostel staff face regularly
- Abbie is still in the hostel (>3 years later) and is much more stabilised as far as her health and her substance use

The “Twinning Project”: hostel staff quotes

“..initially when we think that someone is going to die, we would have said “no,no,no, we need to move them on quickly” ..but then we started to change our way of thinking.. saying, well yes this is his home”.

“Previously when we have a death, you do ..the incident report ..just the general paperwork stuff. For this guy, we did something special. We did a vigil... We had these cards made for him. We had it in the canteen. His friends came and a little service”

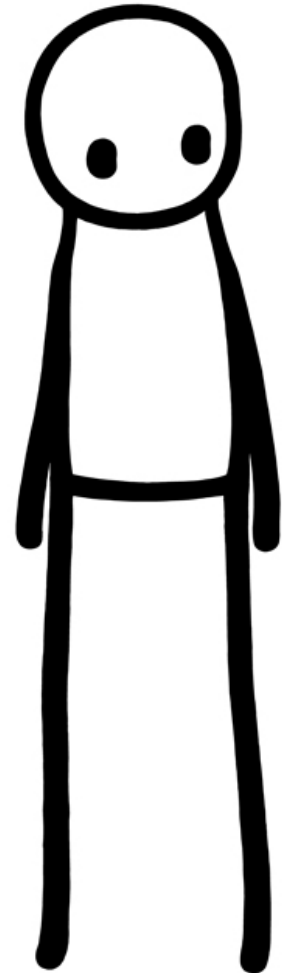
... And I’ve seen so many people die ..so much of it over the last 19 years...And its invaluable .. It should have been done years ago”. Hostel staff

Then COVID hit bringing:

Less ability to do inreach in person

More opportunities with online resources and meetings

We then went onto create online resources to support development of localised community of practice



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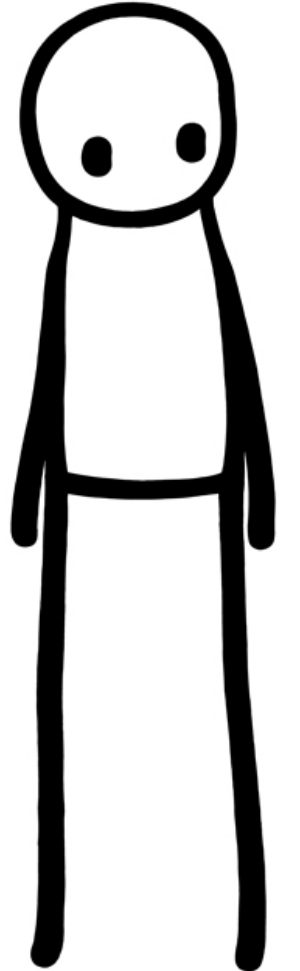


What is a community of practice?

Aim

To help facilitate building local, multidisciplinary communities to support each other and improve the care that people with advanced ill health who are experiencing homelessness receive.

- Programme includes 8 sessions including:
 - Short **video presentations** from a range of experts, with discussion points
 - Opportunity for people to **bring cases** for discussion to help frame conversations (suggest facilitators are prepared with cases if possible)
 - Supporting each other to explore **possible solutions** to current challenges & share what has worked
- Access to resources including guides for facilitators and attendees



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pathway
Building the pathway to better practice

UCL

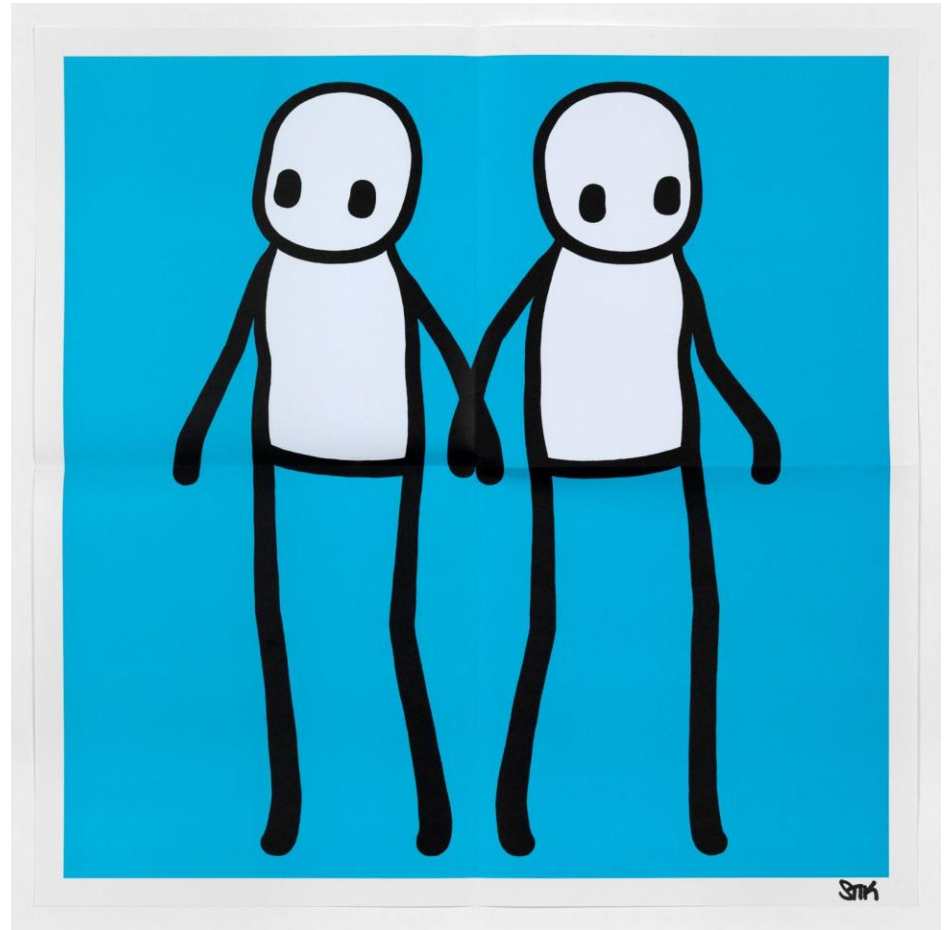


Session content

What will the community explore together?

Homelessness and health

- Complexity of need in hostels
- Complex trauma
- Neurodiversity
- Communication considerations
- Identifying people whose health is a concern
- Mental capacity and safeguarding
- Palliative care



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Where has it been used so far?

- Fifty-two people have now completed the facilitator training
- 10 communities of practice have been set up across the UK using these resources

Intervention to optiMise Palliative caRe for peOple with liVed Experience of homelessness (**IMPROVE**)

This project aims to find out how we can make IMPROVE as useful as possible by talking to people that have used the resources, making some changes and testing it in 6 places.

The programme has a new name: **IMPROVE**

Resources and getting involved



Inspired to get involved?

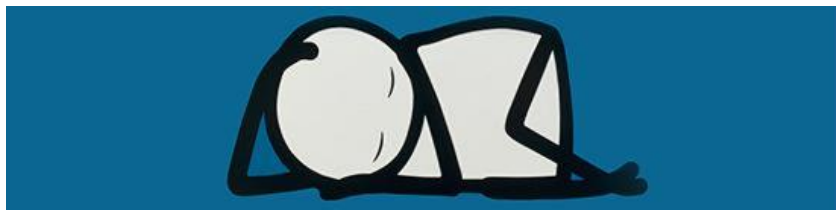
Join a national network on palliative care and homelessness:

- 1 hour monthly online meetings with opportunity to learn, share and connect.
- Scan QR code for more information and to register for the network



Paper outlining projects across the UK supporting people experiencing homelessness with palliative care needs;

<https://bmjopen.bmj.com/content/14/1/e075498.abstract>



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pathway
Building the pathway to palliative care

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Marie
Curie

Link to information about projects around the country

Involving people with lived experience of homelessness in research

Share best practice with professionals

Homelessness and palliative care projects by region

Homelessness and palliative care projects by region

Expand all +

North West ▾

North West research ▾

North East ▾

South West ▾

South East ▾

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<https://www.mariecurie.org.uk/research-and-policy/research/homelessness-palliative-care>

LESS?

A film of personal stories and journeys to health from people who have experienced and overcome homelessness

While the tone of the film is optimistic, it does contain references to depression and suicide.
If you need help please contact 111, or speak to Samaritans on 116 123.



<https://journeystohealth.co.uk/>



Useful Training & Resources

The TIFFIN recommendations for involving people with lived experience of homelessness in palliative care research

<https://journals.sagepub.com/doi/full/10.1177/02692163241259667>

Pathway & Faculty of Homeless and inclusion health: Standards for providers and commissioners, publications, network, local meetings, training : <http://www.pathway.org.uk>

Palliative care resources: <https://www.pathway.org.uk/issues/palliative-care/>

Fairhealth training: <https://fairhealth.org.uk/modules/> including on adverse childhood experiences and trauma

Training on trauma <https://www.carolynspring.com/online-training/>

Online courses in homelessness and mental health / trauma informed support / psychologically informed environment:

<https://www.aneemo.com/courses>

Queen's Nursing Institute for a range of resources & guidance <https://www.qni.org.uk/nursing-in-the-community/homeless-health-programme/homeless-health-resources/>

Other films on palliative care and homelessness:

Commissioned by St Ann's Hospice:

<https://www.sah.org.uk/homelessfilm/>

Tina: Commissioned by Kings College Hospital

<https://www.youtube.com/watch?v=pRHu1Cu1s8U>

Selected Publications

- James R, Flemming K, Hodson M, Oxley T. Palliative care for homeless and vulnerably housed people: scoping review and thematic synthesis. *BMJ Support Palliat Care*. 2023 Dec;13(4):401-413. doi: 10.1136/bmjspcare-2021-003020. Epub 2021 May 3. PMID: 33941575.
- Shulman C, Hudson BF, Low J, Hewett N, Daley J, Kennedy P, et al. 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.
- Hudson BF, Shulman C, Low J, Hewett N, Daley J, Kennedy P, et al. (2017) Challenges to discussing palliative care with people experiencing homelessness: a qualitative study. *BMJ Open* 2017;7:e017502. doi: 10.1136/bmjopen-2017-017502
- Armstrong M, Shulman C, Hudson B, Brophy N, Daley J, Hewett N, et al. The benefits and challenges of embedding specialist palliative care teams within homeless hostels to enhance support and learning: Perspectives from palliative care teams and hostel staff. *Palliative Medicine*. 2021;35(6):1202-14.
- Armstrong M, Shulman C, Hudson B, *et al* (2021) Barriers and facilitators to accessing health and social care services for people living in homeless hostels: a qualitative study of the experiences of hostel staff and residents in UK hostels *BMJ Open*;11:e053185. doi: 10.1136/bmjopen-2021-053185
- Hudson, B. F., Dzung, E., Burnett, A., Yeung, M., & Shulman, C. (2023). Palliative care, homelessness, and restricted or uncertain immigration status. *Palliative Care and Social Practice*, 17, 26323524231216993.
- Rogans-Watson R, Shulman C, Lewer D, Armstrong M, Hudson B. Premature frailty, geriatric conditions and multimorbidity among people experiencing homelessness: a cross-sectional observational study in a London hostel. *Housing, Care and Support*. 2020;23(3/4):77-91
- [Shulman, C.](#), [Rogans-Watson, R.](#), [Palipane, N.](#), [Lewer, D.](#), [Yeung, M.](#) and [Hudson, B.F.](#) (2024), "The Frailty, Health and Care Needs Assessment (FHCNA): development of the questionnaire and testing its feasibility in homeless hostel accommodation", *Housing, Care and Support*, Vol. 27 No. 1, pp. 34-48. <https://doi.org/10.1108/HCS-06-2023-0012>
- Shulman C, Nadicksbernd JJ, Nguyen T, Fantoni ER, Lally J, Bawden M, Hudson B. People living in homeless hostels: a survey of health and care needs. *Clin Med (Lond)*. 2023 Jul;23(4):387-394. doi: 10.7861/clinmed.2023-0075. PMID: 37524414; PMCID: PMC10541041.
- Crooks, J., Flemming, K., Shulman, C. & Hudson, B. F.(2024) Involving people with lived experience of homelessness in palliative and end of life care research: key considerations from experts in the field. *Research Involvement and Engagement* 10, 16. <https://doi.org/10.1186/s40900-024-00549-3>

With thanks to you for being here and

Everyone who has contributed to our work, particularly people with lived experience, amazing hostel staff and the palliative care teams involved in the this work

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