

Challenges to accessing palliative care for people experiencing homelessness: Working together to overcome them

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Today's Talk

- Background on homelessness and health
- Research findings: challenges and complexities around the support received by people experiencing homelessness who have advanced ill health
- Recommendations from this research
- Training for hostel staff: evaluation and resources
- Pilot intervention
- Other ongoing projects
- Outputs and impact
- Conclusion and implications

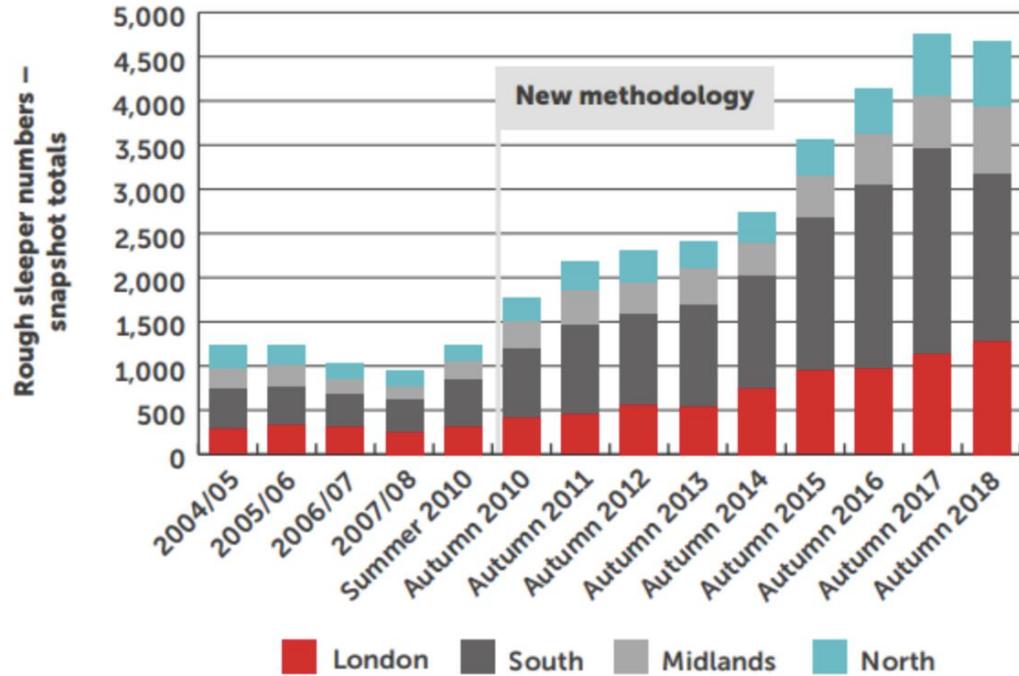
Homelessness background



“A home provides roots, identity, a sense of belonging and a place of emotional well-being. Homelessness is about the loss of all these things “

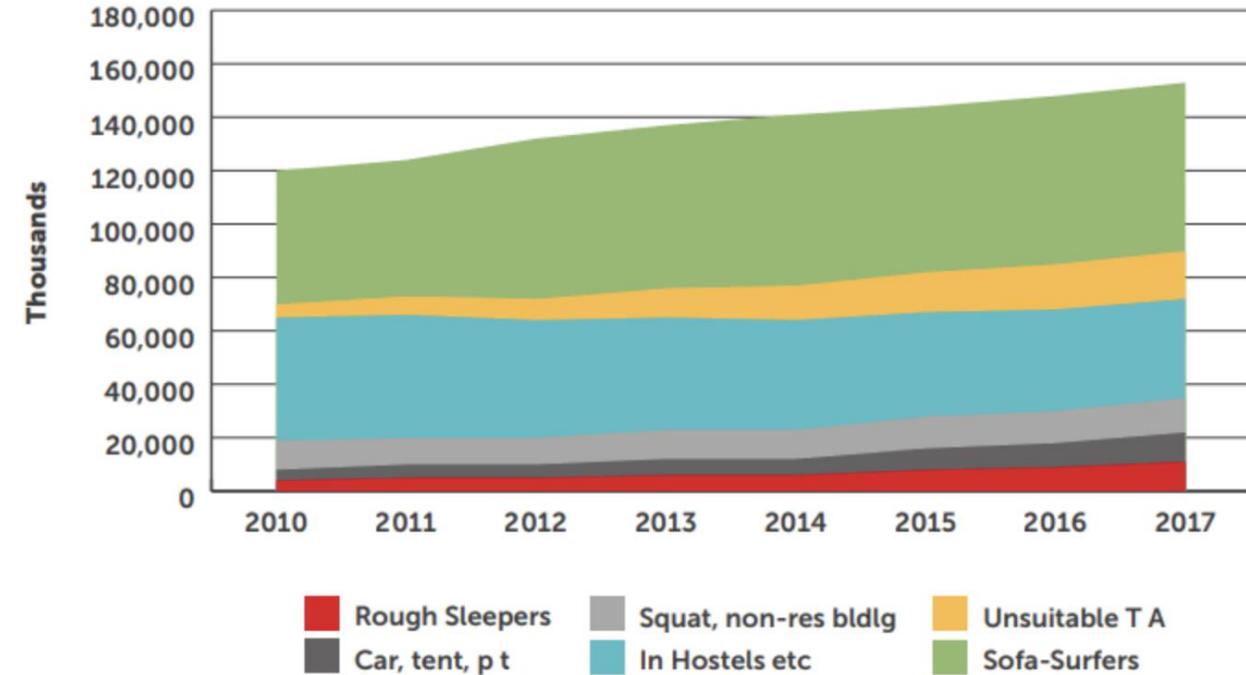
Homelessness is increasing nationally

Figure 4.1 Trends in local authority rough sleeper estimates by region, 2004-2018



Source: 2004/05-2007/08 – collated from Audit Commission Best Value Performance Indicators returns; Summer 2010 onwards – MHCLG

Figure 4.4 Core Homelessness by Category in England, 2010-17

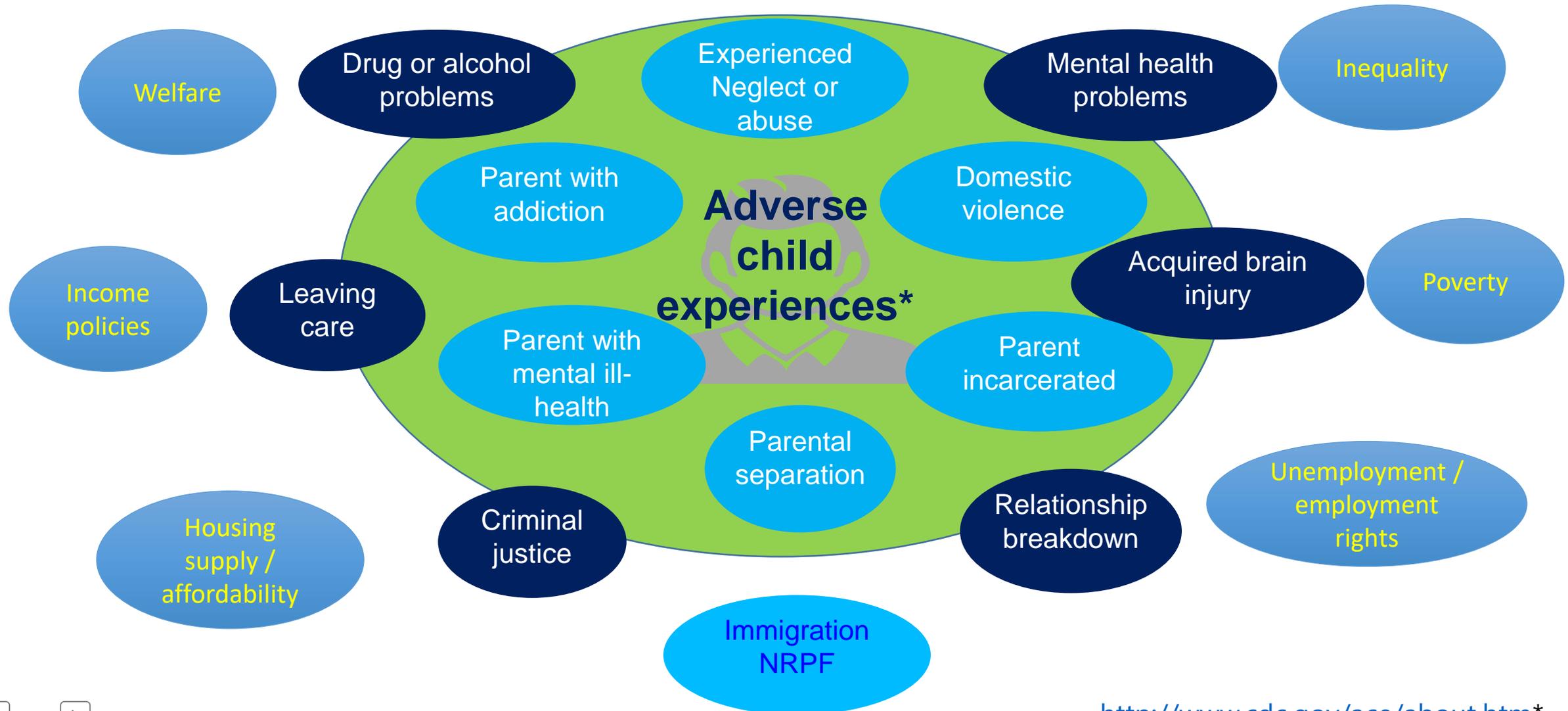


The homelessness monitor: England 2019, Crisis

Suzanne Fitzpatrick, Hal Pawson, Glen Bramley, Jenny Wood, Beth Watts, Mark Stephens & Janice Blenkinsopp

Risk factors for homelessness

Many routes to homelessness – Structural causes and Individual vulnerabilities



A.C.E. → Homelessness



ACE Score and Relation to Adult Homelessness

Impact of trauma on adults



A child's exposure to multiple traumatic events can have wide ranging and long term implications for how they think, feel and behave



Impact

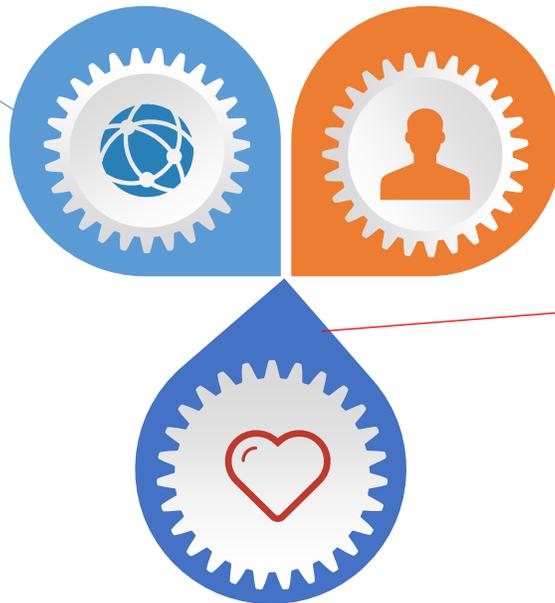
- Low self esteem
- Feeling unsafe, Difficulty trusting
- Mental health issues, self harm
- Self medicating with substances
- Hypersensitive, hyper vigilant
- Chaotic lifestyle

Homelessness is a Health Issue

Complex needs & Tri-morbidity

Substance Misuse

> 60% history of substance misuse



Mental Health

70% reach criteria for personality disorder

Physical Health

>80% at least 1 health problem,
20% > 3 health problems

Hepatitis C – 50 x higher

TB – 34 x higher

Heart disease 6x higher

Stroke 5x higher

Epilepsy 12x higher

High rates of multimorbidity and early onset frailty

St Mungos (2010), Homelessness, it makes you sick, Homeless Link Research (n = 700)

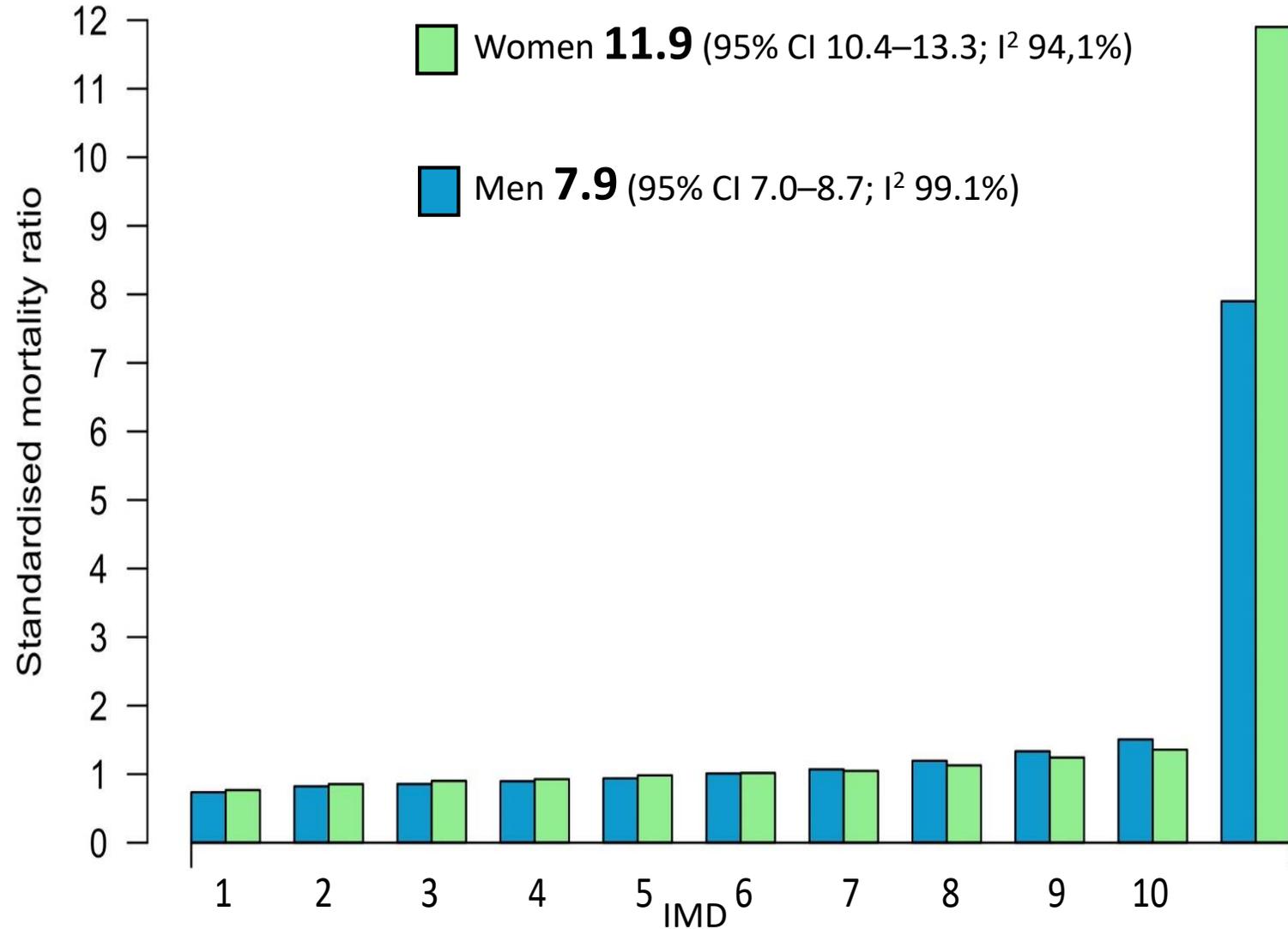
Suzanne Fitzpatrick et al (2010) Census survey multiple exclusion homelessness in the UK (n= 1268)

Story, A. (2013) Slopes and cliffs: comparative morbidity of housed and homeless people. The Lancet. Nov 29. Volume 382. Special issue. S1-S105

Homeless people are dying young

Average age of death in the UK (ONS 2018):

45 for men (88%)
43 for women (12%)



Morbidity and mortality in homeless individuals, prisoners, sex workers, and individuals with substance use disorders in high-income countries: systematic review and meta-analysis. R Aldridge, A Story, S Hwang et al, The Lancet Nov 2017

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsofhomelesspeopleinenglandandwales/2018>

Office of National Statistics 726 deaths in 2018

Homeless deaths rose by a record 22% last year, says ONS report

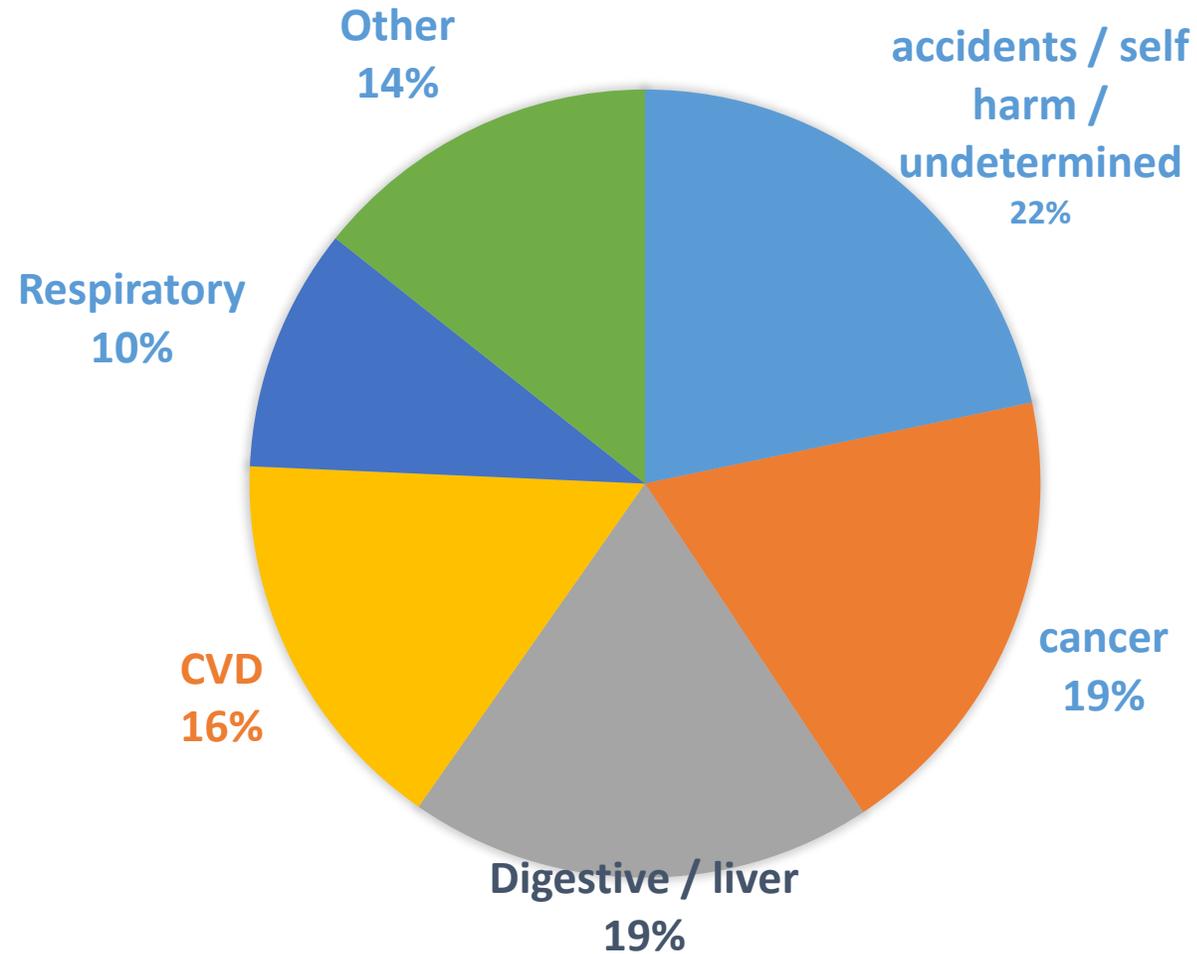
Charities demand action after estimated 726 homeless people die in England and Wales



726 deaths in
2018

▲ Jon Sparkes from Crisis said homeless people 'should not be dying unnoticed and unaccounted for'. Photograph: Yui Mok/PA

CAUSE OF DEATH AMONG PEOPLE EXPERIENCING HOMELESSNESS



Aldridge, R. W., Menezes, D., Lewer, D., Cornes, M., Evans, H., Blackburn, R. M., ... & Hewett, N. (2019). Causes of death among homeless people: a population-based cross-sectional study of linked hospitalisation and mortality data in England. *Wellcome open research*, 4.

Dying as a homeless person

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

Gemma



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

What are the challenges to palliative care access for people experiencing homelessness and what can be done to improve care?

Systematic review

- Synthesize previous research on challenges to palliative care access for people experiencing homelessness (PEH)

Qualitative study

- Explore the challenges to supporting homeless people with advanced ill health in London

Systematic review and thematic synthesis

Inclusion criteria

- Qualitative studies exploring the views on palliative and end-of-life care of:
 - PEH
 - Hostel workers
 - Health and social care professionals who work with PEH

Search method and results

- Six databases searched in Sept 2016
- Key stages undertaken by two reviewers
- 13 studies identified

Study characteristics

- Published between 2005 and 2016
- Participants:
 - 93 PEH
 - 52 hostel staff
 - 103 professionals
- Conducted in:
 - USA (6), Canada (4), Australia (1), Sweden (1), UK (1)

Qualitative Study: Explore the challenges to supporting homeless people with advanced ill health in UK

Method

- Focus groups and semi-structured interviews conducted between October 2015-Oct 2016

127 participants from 3 London Boroughs

49 health and social care professionals

28 PEH

10 previously PEH

40 hostel and outreach staff

Analysis

- Thematic analysis

Findings

Complex behaviours in mainstream services

Who

How

?

Where

What

Uncertainty and complexity

Gaps in current systems

Main Findings 1: Uncertainty and Complexity

...around who is palliative due to:

disease trajectory

substance misuse / complex behaviour

access to and utilisation of health care

young age

Many deaths are sudden,
but not unexpected



“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

*“I think everyone knew she was very, very sick. But... I sort of have an informal list of people...a **“this isn’t good list”**. But actually, then a third of them probably move up to my **“this is really bad”** list. But....how do you know out of those...”*

In-reach nurse

They sort of...could be classed as palliative but they are also reversibly palliative. So if you don’t stop drinking, if you don’t stop doing these things, then you are probably going to die in 6 months. And it’s a little bit difficult sometimes to class them as palliative, when you have a reversible cause to it.

Healthcare professional

This uncertainty results in people not being considered for referral to palliative care services

Main Findings 2: Barriers to access

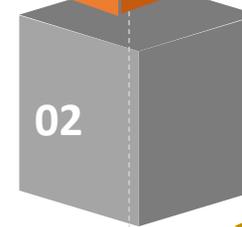
Difficulties accessing and delivering care

"...one problem is that hospitals are so busy... if someone is repeatedly coming back in...popping off the ward for a couple of cans, they just discharge them.... But.... if that's going to be the pattern for the last 6 months of someone's life, you want to try and actually use it"

General Practitioner



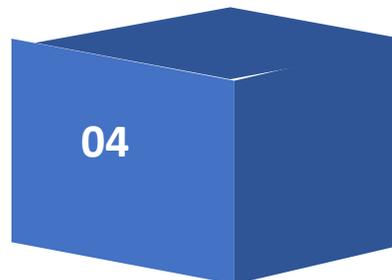
Complex behaviours & priorities



Fear of judgement / lack of trust



Inflexibility & fragmentation



Resulting in: late presentation, self discharge, exclusion from services and unsafe discharge

“I think there’s a stigmaand some professionals see it as a choice, you choose to pick the can up and put it to your mouth, rather than you being mentally and physically sick ... So they just think “You’re wasting our time” but there’s so much more behind it than just picking up the drink”

Person who was previously homeless

“We've had a guy who was in a lot of pain from a spinal abscess... he was injecting and wasn't on a script so ...massive fear of the amount of time it was going to take to go through A&E and get on a ward and be prescribed and titrated up [with methadone] ..and the amount of withdrawal he was going to experience...”

Specialist homeless nurse

“We find it really hard to get people registered with the local GP’s. When I went with a new client they said “we’ve got too many of yours – you can go to xxx practice [further away]. Also they won’t see people without a key worker which can be really difficult”

Hostel staff

Main Findings 3: Gaps in Current systems & Lack of Options in Place of Care

Many people with very complex needs, at risk of dying, are in hostels or temporary accommodation with inadequate support & care.



Main Findings 3: Gaps in Current systems

“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**

“...it was really hard to get that [social services] support. It was really really hard, and to begin with they only wanted to give us two hours a week” **Hostel Staff**

we’re trained to ...engage people with support and recovery.... getting better, moving into jobs ... **Hostel staff**

- Hostels taking burden of supporting people who are very unwell / “young olds” / people with cognitive impairment
- Lack of alternative places of care due to:
 - Young age
 - Mental health difficulties
 - Substance misuse

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 with people with dementia who are older; it's just ... 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”... **Specialist nurse***

Gaps in Current system: Challenges for hostels as a place of care

- Hostels are designed to provide temporary accommodation
- Their remit is to support people into recovery
- Hostels have been left to support people with increasing complexity at a young age, with limited resources
- Difficulty accessing social services & adequate medical support including palliative care
- Felt by many staff to not be an appropriate place for people who are sick
 - planned death in hostel not an option
- High rates of staff turnover and burnout

Main Findings 4: Barriers to Advance Care Planning

Lack of confidence

Denial - from all sides

Concern about fragility & removing hope

Uncertainty of prognosis

Lack of options to offer

“For people who aren’t engaging... Self-discharging, in and out of hostelsnobody feels they completely know that person...and having those... very difficult conversations, well ...sometimes...no one feels qualified...” Health care professional

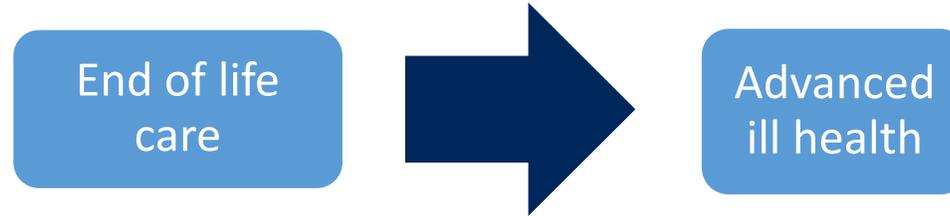
Overcoming the challenges



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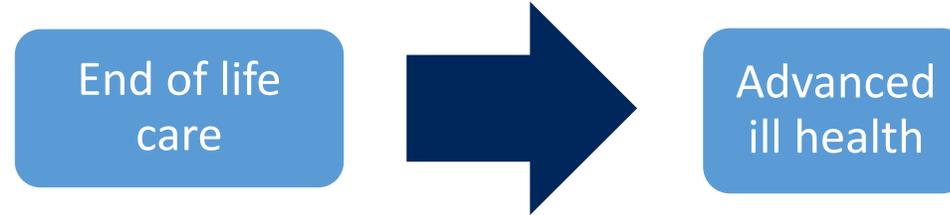
Our research – recommendations

1. A Shift in Focus: (parallel planning)



Our research – recommendations

1. A Shift in Focus: (parallel planning)



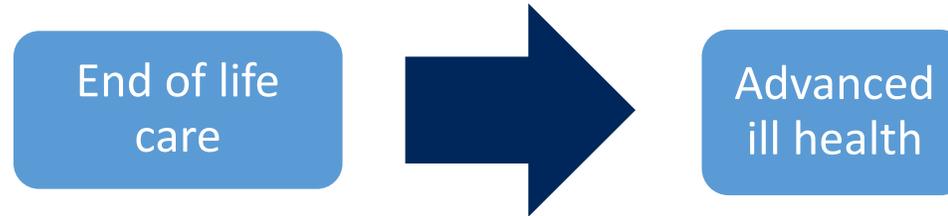
...as a way of working with **Uncertainty**

Supporting decisions, while keeping options open

- Identify people whose health is a concern
- Person-centred exploration of insights into illness, wishes and choices, not just giving warnings– but how to live well
- Respecting choices even if we feel they are unwise
- Early & repeated conversations
- Not just issues for the very end of life, but about living well.

Recommendations around palliative care

1. A Shift in Focus: (parallel planning)



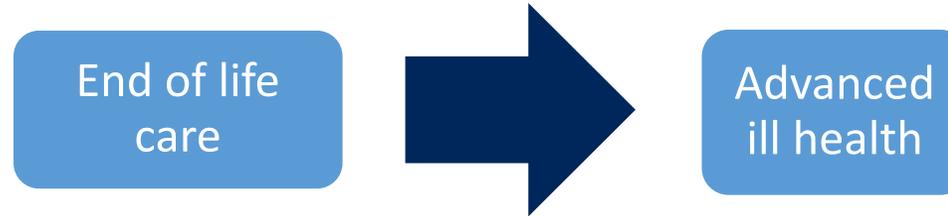
2. **Choice in Place of Care and Care in Place of Choice:**

a) Care in own home – eg Housing First

- Housing first / floating support models need to include comprehensive long-term wrap around support

Recommendations around palliative care

1. A Shift in Focus: (parallel planning)



2. Choice in Place of Care and Care in Place of Choice:

a) Care in own home – eg Housing First

b) High support need facility that

- Understands the needs of people who are homeless
- Acts as a step up from hostel/street & a step down from hospital
- Could provide adequate 24 hour support
- Offers respite AND/OR a comfortable place to live until the end of life

Example in
Ottawa and
Toronto

But what if the hostel is seen as their home?

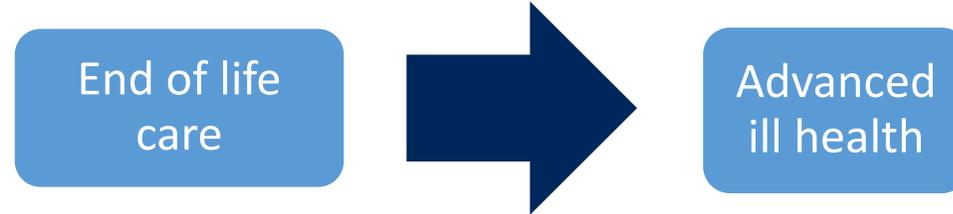
*It was his desire to remain here, he wanted to remain here, and ...for me personally...I don't think we should go against that....***Hostel staff**

There's been a few guys that were in hospital, told they were dying ... they didn't want to go to any hospice, they didn't want to ... stay in hospital, they wanted to die in the homeless hostel... **Person who was previously homeless**



Recommendations around palliative care

1. A Shift in Focus: (parallel planning)



2. Choice in Place of Care and Care in Place of Choice:

a) Care in own home – eg Housing First

b) High support need facility

c) More in-reach (into hostels / day centres)

- Greater multi agency working - regular meetings to discuss clients of concern)
- More training and support for all groups

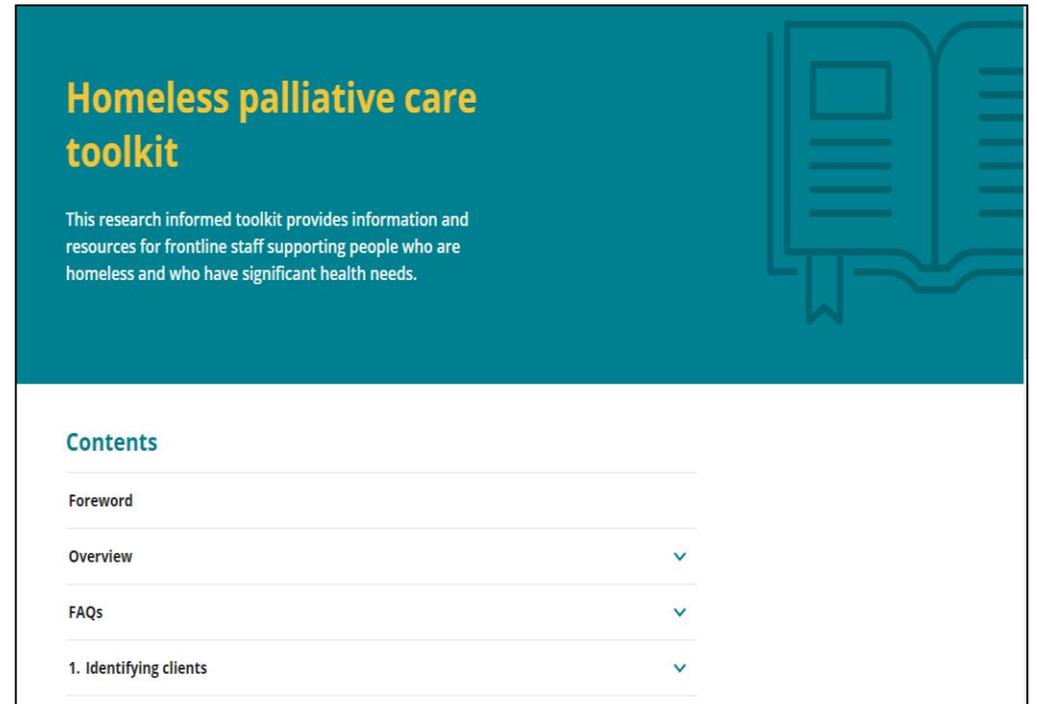
Training and Support



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Homeless palliative care toolkit

- **Identifying Clients**
- **Assessing Needs**
- **Sharing Care**
- **Communication**
- **Bereavement**
- **Practicalities after a death**
- **Self Care**



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 

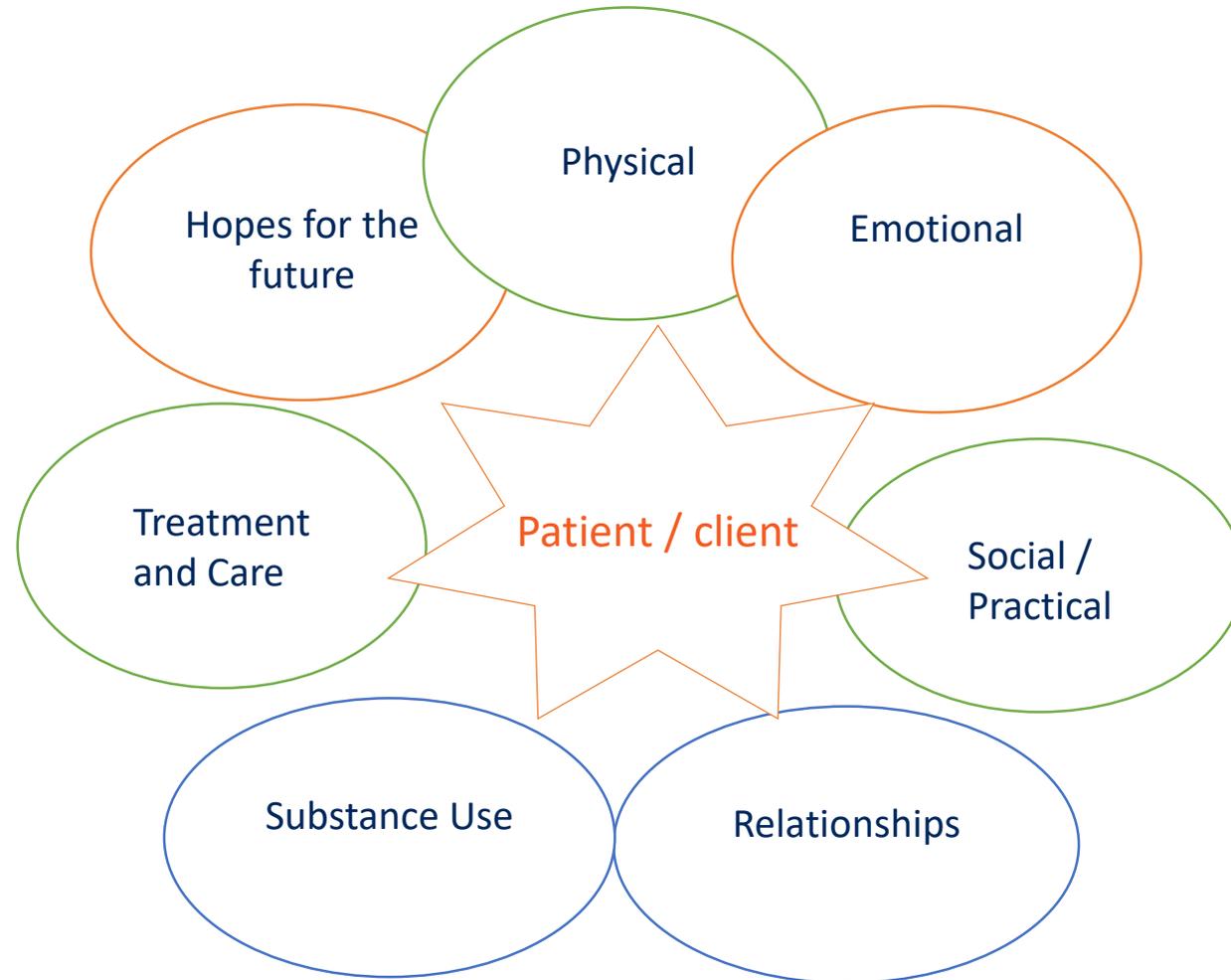
www.homelesspalliativecare.com



Person centred care - support and concerns mapping

start from where client is and work alongside them

- Place patient in centre
- Locate important issues to address
- Colour lines according to priority



Questions to consider

PHYSICAL

- Do you have thoughts about where things are going with your illness?
- What do you understand about your current health situation?
- What are your main concerns?
- What would you like to see happen next?

SUBSTANCE USE

- Do you wish to reduce your drinking/substance use?
- Say you struggled to stop drinking, what do you think might happen in the next 3/6/9 months?
- Would you like to go to detox/rehab?
- Can we make a plan to meet again in a few days/weeks/months, and see where you're at with everything then?

TREATMENT AND CARE

- Do you feel you need any extra support with your care (nursing or personal care)?
- Are you having any difficulties getting around?
- If you became very ill, where would you want to be cared for? Here at the hostel, in a hospital or a hospice?
- Would you like to talk to your GP/doctor about what treatments you want/do not want?

EMOTIONAL

- How are you feeling about your recent diagnosis/hospital admission/poor health?
- I've noticed you seem a bit withdrawn lately, can I help with anything?
- Would you like to tell me about your concerns/worries?
- What do you feel would help right now?

HOPES FOR FUTURE

- What is most important to you at the moment?
- Are there things you have always wanted to do?
- Would you like support to reconnect with family?

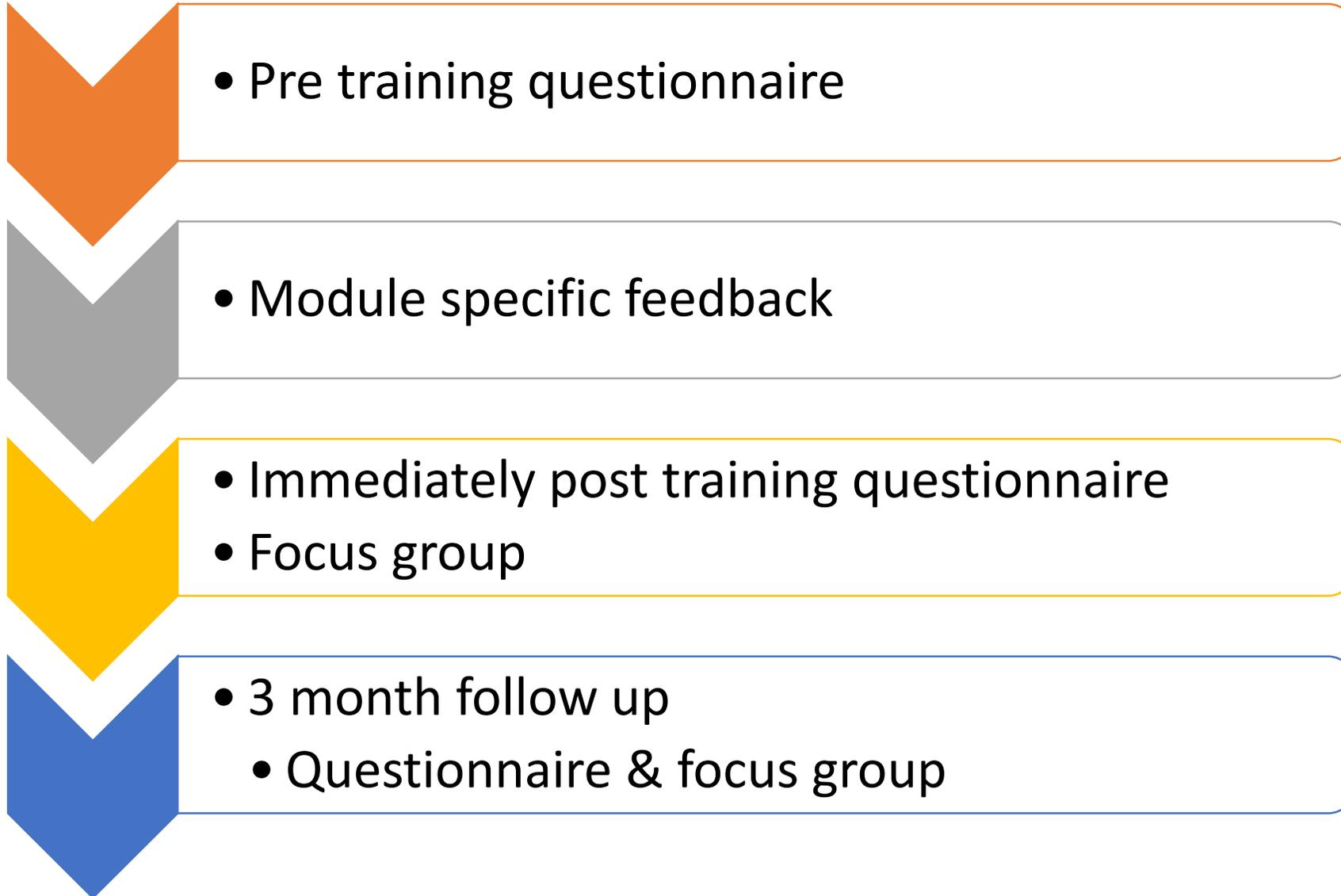
SOCIAL / PRACTICAL ISSUES

- Have you been having trouble attending appointments, could we help with this?
- Have you thought about making a will or letter of wishes?
- What do you want to see happen with your possessions/pets after you die?
- Have you ever thought about how you'd like to be remembered?

RELATIONSHIPS

- Who are the people you trust the most?
- Who would you like to be there if you got ill (again)?
- Who would you NOT want to be there if you got ill?
- Would you like to get in touch with family?

2 day Hostel Training - Mixed methods evaluation



Qualitative findings – post training

8 years of training... today was the first time any trainers have bothered about us. Its always been focused on client's needs. Never about us, and if we are less stressed ...the clients are going to get the best of us.

Keep everything in but spread it out more...

When just you do training, it can be very difficult to implement... because you're just one of many. Whereas if it's all of us... the voices of many that's going to push changes through.

3 month follow up – qualitative findings

Impact

- More discussion about end of life care within hostel – though some staff concerned their service would become a hospice
- Some conversation tools being used
- Deaths and memorials being used as a trigger for conversations
- A section has been added to the agenda of team meetings to discuss clients of concern

Yet to be established

- Regular MDTs discussing clients of concern
- Relationships with hospices for advice and support
- Development of hostel policy around end of life care

However

High staff turnover meant that many staff who were working 3 month later had not accessed the training

Training alone is not enough

For lasting change, training needs to be accompanied by
multi disciplinary, multi agency support

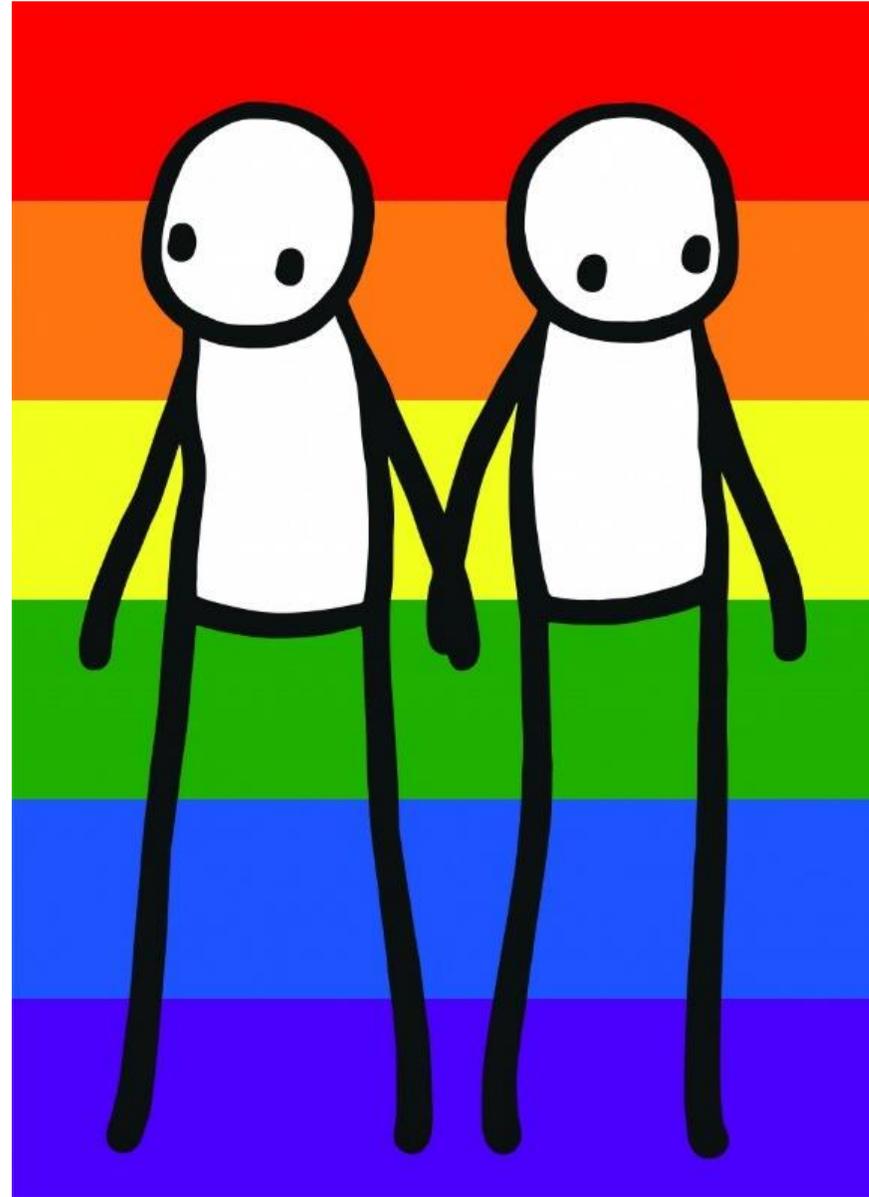
*“...very few people know what our lives are like in the hostel. We need someone who could support us... I think it could only come from a hospice. If we had somebody ..to come and give us the benefit of their experience. Or even on the end of the phone and we could call them and say ‘so and so passed away this morning and its just so upsetting’ or ‘I don’t know what to do about this’ that would be fantastic”. **Hostel Staff***

Current Project

Aim:

Improve access to high quality care and support for people with advanced ill health & reduce burden on frontline staff by embedding training and support into hostels

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Methods

1. Twin hostels with community palliative care teams
2. Train palliative care professionals to become 'homelessness champions' (2 day training)
3. Stakeholder event held within the Borough at start – co-design
4. Champions provide support for one day a month each to the hostel teams with:
 - *Bespoke training e.g., palliative care, health concerns, referrals, external services*
 - *Identifying residents of concern*
 - *Giving advice and facilitating multidisciplinary care planning*
 - *Linking and referring of residents into appropriate services*

Aiming for in-reach and multiagency working to discuss clients of concern



Project evaluation – mixed methods

Qualitative interviews at 6 months with champions and hostel staff

- Achievements & challenges of the project
- Impact on stress & staff morale
- Impact on quality of support for residents
- Perspectives on sustainability / going forward
- Illustrative case examples

Questionnaires for hostel staff at baseline & 6 months

- Confidence about:
 - Identifying and securing support
 - Supporting a resident with advanced health needs
- Attitudes regarding a planned hostel death
- Support received from managers
- Collaboration with external services

Monthly data collection from champions

- Number of clients discussed
- Referrals made to:
 - Social services
 - Palliative care
- Ambulance call outs
- Unplanned hospital attendances
- Advice & training given
- Progress & challenges

Baseline barriers

Different boroughs starting from different places (eg GP support)

Difficulty accessing adequate social services

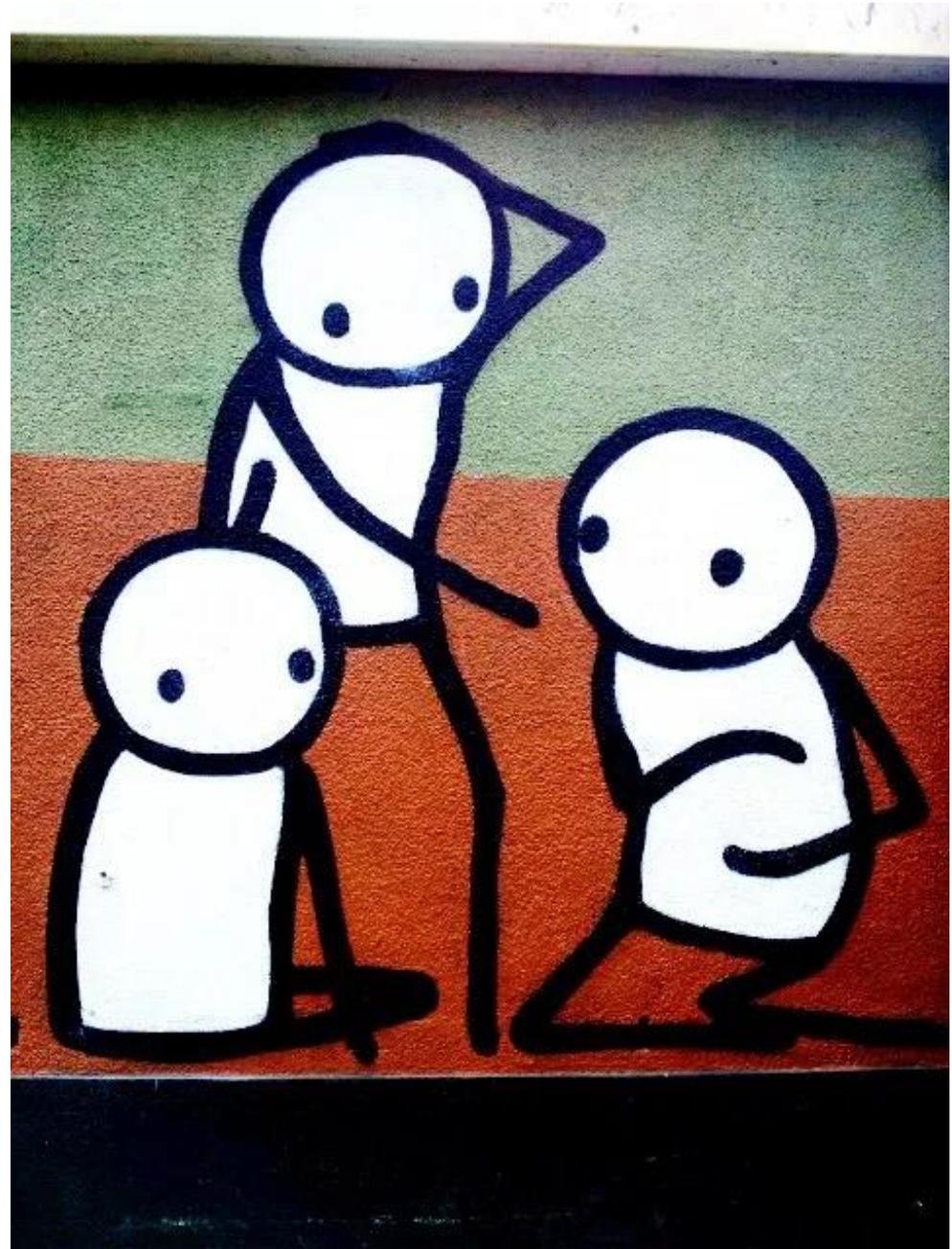
Many very sick people in the hostels

Recovery focus – planned death ‘not a palatable option’

Hostel staff unsupported and not listened to by external agencies

Focus on ‘move on’ targets

Preliminary Findings



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Six month follow up – Hostels

- Regular case review meetings in hostels to discuss sick residents
- Improved coordination with adult social care / OT
 - More people with social services support including move on to high support facility
 - Support with equipment (Hospital bed)
- Local homelessness commissioner more flexible regarding 'move on'
- More discussion about death and dying – death café
- Planned death within the hostel

Six month follow up - Hostel staff

Increased staff's knowledge, confidence and empowerment

"I have learnt a colossal amount, to the extent that I have been promoted here. I started updating my CV, and it was like wow everything was related to the palliative care project."

"I think everyone is just a little bit braver now, to step forward and [to outside agencies] be like, actually, this is how it is supposed to be. You're not supposed to be telling us that."

Six month follow up - Hostel staff

Support with grief and bereavement

“We still don’t know the cause of death....But that had a really detrimental effect, especially on E because she had been working so closely with him. And she found him, with his carer who had come in to clean the room. So she has been able to sit down with MK [champion] and ..have a debrief around it, just to talk to someone about it, about the death and how that made her feel on a personal level...”

Change in culture around planned death

“..initially when we think that someone is going to die, we would have said “no,no,no, we need to move them on quickly, we don’t want them dying within the hostel” ..but then we started to change our way of thinking because of this..we did start saying, well yes this is his home”.

Six month follow up - Hostel staff

Overview of the project

“Beneficial doesn’t really sum it up...invaluable. Because we have been working in isolation for such a long time and people don’t really know how hard it is to work here. It just a shame that this hasn’t always been in place.” Manager

“....I’ve worked in homelessness for such a long time and this is the first time that I have ever come across anybody doing anything like this... And I’ve seen so many people die ..so much of it over the last 19 years...And its invaluable having that second pair of eyes looking at it with you and going, have you thought about it this way? How can we change that? It should have been done years ago”. Palliative champion

Lots of other examples around the country including

Homelessness led

- Palliative care coordinator role, St Mungo's

Primary Healthcare led

- Bradford: specialist primary care & hospital Pathway team with intermediate care beds

Palliative care led

- Range of innovative projects providing training and additional support including: St Luke's Cheshire; St Luke's Basildon (with liver outpatients); St Ann's Manchester; Birmingham Hospice; Mary Stevens Hospice Birmingham; St Columbas Hospice Edinburgh (ECHO)....
- Much of this work has been done with little funding or by applying for funding from charitable sector

All have relied on someone championing for the need to support this excluded group.

PEOPLE WITH NO RECOURSE TO PUBLIC FUNDS



Outputs and Impact

Findings embraced by palliative care and homeless community

Invited presentation at 38 national conferences and 20 local conferences / events (approx 3000 people reached)

Paper of the year 2018 Palliative medicine

Briony Hudson received UCL Excellence in health research and public engagement awards

Toolkit > 5,300 unique users



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Homeless and standards for and service p

These standards are endorsed by the



A BILL

TO

Make provision about end of life care and support for homeless people with terminal illnesses, including through the provision of housing for such people; and for connected purposes.

BE IT ENACTED by the Queen's most Excellent Majesty, by and with the advice and consent of the Lords Spiritual and Temporal, and Commons, in this present Parliament assembled, and by the authority of the same, as follows:—

1 Duty to treat persons eligible for end of life care as not becoming homeless intentionally

- (1) The Housing Act 1996 is amended as follows.
- (2) After section 191 (becoming homeless intentionally) insert—

“191A Persons eligible for end of life care

- (1) Notwithstanding the provisions of section 191, a person shall not become homeless intentionally if they are eligible for end of life care.
- (2) For the purposes of subsection (1), a person is eligible for end of life care when in the opinion of a medical practitioner responsible for their care—
 - (a) they may reasonably be expected to die of a progressive illness within the next 12 months; or
 - (b) they are receiving or are in need of treatment which may reasonably be considered end of life care.
- (3) *A medical practitioner may not charge for an assessment conducted for the purpose of establishing whether a person is eligible for end of life care under subsection (2).*
- (4) In this section, “medical practitioner” means a person registered under the Medical Act 1983.”

5

10

15

CULTY
HOMELESS AND
VISION HEALTH



8.40 Any person who may reasonably be expected to die of a progressive illness within the next 6 months, or is in receipt of treatment that is reasonably considered to be palliative care, will almost certainly have a priority need. Effective arrangements for **liaison and co-ordination of support and palliative care between housing, social services and health services will be essential in such cases**. These services will want to take account of good practice guides and toolkits for providing effective co-ordinated care for such cases

17.10 Housing authorities should be alert to circumstance in which the suitability of accommodation will require more regular review because the applicant's needs are likely to change. This would include, for example, **regularly reviewing the suitability of accommodation provided to applicants who are terminally ill and in need of palliative care**.



Ministry of Housing,
Communities &
Local Government

Homelessness Code of Guidance for Local Authorities

Conclusions

- People experiencing homelessness are dying unsupported in unacceptable situations – with the burden of support lying with frontline hostel and outreach staff who have no training
- Identifying who would benefit from palliative care referral is complex
- For lasting change, training alone of hostel staff is not enough
- Preliminary findings of our project twinning hostels with palliative care teams confirms the needs and the value of holistic in-reach support
- There remains a need for alternative places of care for people with high support needs
- These findings have been widely disseminated to policy makers, commissioners and providers of care at national and local level



Implications – Listen to and involve people with lived experience

- **Practice**

- Palliative care in PEH is complex, but needs a shift in focus / parallel planning
- For high quality care we need collaboration between health, social care, housing and addiction services
- The palliative care community are well placed to provide holistic in-reach support and facilitate multidisciplinary approach in hostels
- GP support (ideally in-reach) is also vital in large hostels

- **Research**

- Explore other ways of disseminating / rolling out training and support
 - developing and evaluating videos for health care providers and frontline staff
- Explore other models of supporting a multidisciplinary approach for PEH in a range of settings
- Quantify problem: Develop tools to support identification of ‘people of concern’ & identify numbers of people dying with inadequate support

- **Advocacy and policy**

- Need for a cross departmental homelessness strategy – including addressing needs of people with NRPF
- Continue to advocate for *choice* in place of care and *care* in place of choice including high support need facility

Useful Resources

Homeless Link to find out about homeless hostels and day centers in your area

<http://www.homeless.org.uk>

London Housing Foundation Atlas to identify homeless services <https://lhf.org.uk/atlas/>

Advocating for homeless people around GP registration

<https://www.healthylondon.org/homeless/healthcare-cards>



Reporting a rough sleeper:

<http://www.streetlink.org.uk>

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Evaluation of training on palliative care for staff working within a homeless hostel



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Publications

- Faculty of Homeless and inclusion health: Join for free – Standards for providers and commissioners, publications, network, local meetings: <http://www.pathway.org.uk/faculty/>
- Training toolkit: www.homelesspalliativecare.com
- Hudson BF, Flemming K, Shulman C, Candy B. Challenges to access and provision of palliative care for people who are homeless: a systematic review of qualitative research. *BMC Palliative Care*. 2016;15(1):96.
- 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
- Shulman, C., Hudson, B.F, Brophy, N., Kennedy, N., & Stone, P (2018). Evaluation of training on palliative care for staff working within a homeless. *Nurse Education Today* Sep 29;71:135-144. doi: 10.1016/j.nedt.2018.09.022.
- NHS England podcast
<https://healthsector.webex.com/healthsector/ldr.php?RCID=437fdf890e93e01d09d09b45bec93975>
- NHS England End of life care Webinar:
- [Palliative care toolkit for people experiencing homelessness](#)
- *CQC & Faculty of Homeless and Inclusion Health* (2017). A Second Class Ending. Exploring the barriers and championing outstanding end of life care for people who are homeless