Please take a minute to write the answer to the following question on the handout you have been given.

What do you see as the biggest challenges to supporting homeless people with advanced ill health?

@carolineshulman

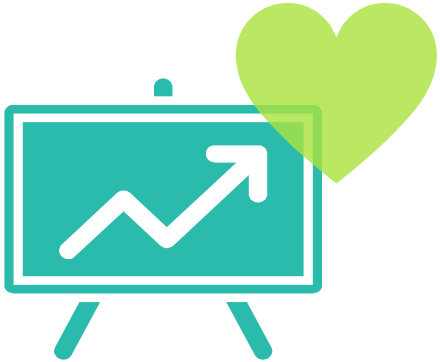
@brionyhudson

How do we improve palliative care for homeless people?

Dr Caroline Shulman, Dr Briony Hudson, Niamh Brophy & Julian Daley

How do we improve palliative care for homeless people?

- Rationale and introduction to research
- Main findings
    - Complexities in identification
    - Challenges in provision
    - What did people say helps and what's needed
- Parallel planning
- Case studies from the palliative care coordinator



Rationale

Recognition of concern from hostel staff & professionals about how to support homeless people as their health deteriorates

Deaths often not planned for & occur at a young age

Palliative care & homelessness

“I think that people are just resistant to the concept of them [homeless people] being palliative patients. You are dealing with people who are still relatively young, even if they are in their 50s, that’s still young…it's difficult”.

Specialist GP

Our research

What are the challenges to palliative care for people who are homeless in London, and what could be done to improve care for this group?

Interviews and focus groups with:

Julian's role

Why I got involved in the research

My contribution

- Planning
- Steering group
- Recruitment – posters and hostel visits
- Focus groups with EBEs and homeless people
- Feedback – making sure we got it right
- Sharing results

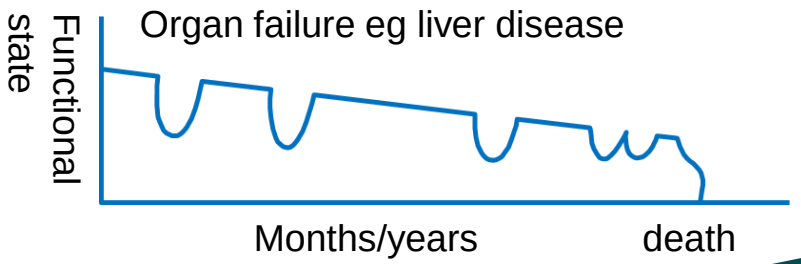
Findings:
Complexity

Who needs palliative care, when & how?

Uncertainty & Complexity

on account of:
disease trajectory
substance misuse
complex behaviour
access to health care

Many deaths are sudden, but not unexpected



“….the liver goes on and on…. and then it just decides that it has had enough. And it depends on whether the person gets septic or not…”

- Outreach worker

“Some of these patients, I’d fast track them every time they come in. But the reality is that they go on and pick up again. And obviously you can only do that so many times…”

Hospital palliative care nurse specialist

“The last time I tried to get a cirrhotic patient a bed at a hospice, they interrogated me. They wanted a very clear prognosis and it was because the woman I had sent there before, who we thought was dying…was there for months because she had no where else to go.”

Hospital palliative care nurse specialist

Lack of options

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

“We end up trying to make a sort of, best fit with what we’ve got locally. There was a useful resource, a step down from hospital… but it ended up becoming silted up with people with life limiting illnesses who couldn’t be housed anywhere else and weren’t doing very well. And then interestingly, the local authority closed that. That was like our last chance saloon, and now we are struggling”

– Drug and alcohol worker

Challenges for hostels

- Limited resources; low staff: client ratios, little night cover
- Difficulty accessing carers/social service support
- Recovery focused approach, impact on staff & other residents
- Planning for death within a hostel is difficult
- Difficulties around medication management & storage (eg daily supervised methadone & pain management)
- Many people discharged from hospital inappropriately to hostels

“I think this is the confusion. Hostels are not care homes, we are not nursing homes and we are not care providers… we are supported accommodation, you know, we are an accommodation provider, that provides a bit of support”

– Hostel staff

“…so he's young & he’s got HIV. He lives in a hostel….he hates it…it's got 28 beds & 2 staff. He's incontinent in there… lives in complete squalor…And then there was this report that said ’’this is a safe guarding issue; how could you possibly leave him in such squalor?’’ and the hostel are saying “but this is the best we can do!”. But there is no more suitable place, there is no alternative. So the big question is 'where should he go?’’

- GP

Challenges for hostels

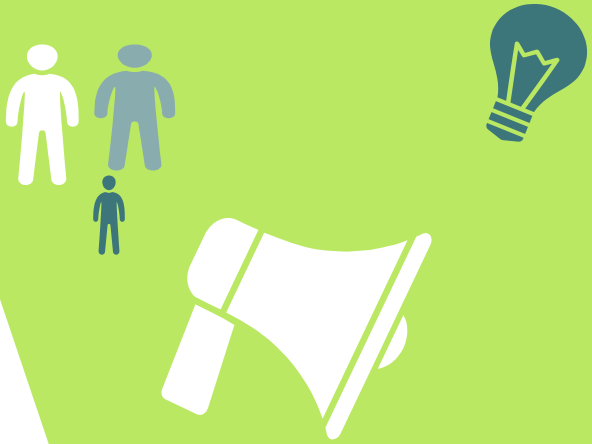
Mainstream services & lack of joined up care

- What it means to be homeless & ill (isolation, vulnerability, fragility, complexity)
- Why someone may not engage with treatment or self-discharge from hospital (understanding complex behaviors)
- The environments that someone is living in or may be discharged to from hospital – a safe discharge?
- Consider that assessments conducted in hospital may not reflect real life

What did people say helps & what's needed?

In an ideal world.....

A hostel based hospice



A facility that

Understands the needs of people who are homeless

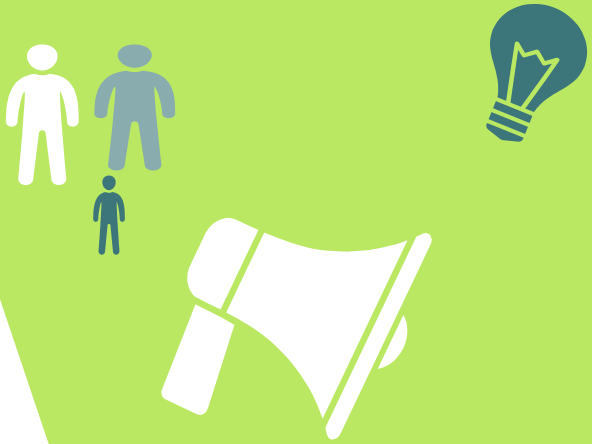
Acts as a step up from hostel or the street

Acts as a step down from hospital

Could provide adequate 24 hour support

Offers respite AND/OR an acceptable, comfortable place to live until the end of their life

Extending what works



Palliative care coordinator

Multidisciplinary working

- Case reviews
- Medical in-reach
- Individualized care plans

Hospital Discharge / Pathway Teams

Difficulties in discussing future preferences

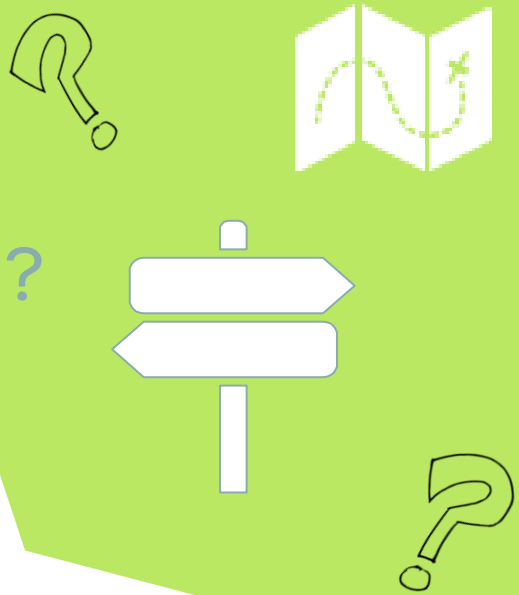
“A lot of people are frightened to think about it. Most people won’t talk about it, they won’t entertain talking about it. They see it as so far away, you know? Why bother now, let’s wait until it's a bit nearer the time”

– Hostel resident

If you cant predict, how do you plan?

Parallel planning

Supporting decisions, but keeping options open



A useful approach for working with uncertainty

Parallel planning - working with uncertainty & complexity

Early & repeated conversations to explore insights into current situation and aspirations.

Not just issues for the very end of life, but about living well.

Person centered & non judgmental - respecting peoples choices even if we feel they are unwise while revisiting opportunities for change.

Respecting variability between and within people.

What in-reach could help with

- Identifying people whose health is a concern
- Supporting & developing care plans
- Having conversations – not just issues for the very end of life, but about living well
- Training
- Bereavement support
- Accessing social services and NHS CHC

With thanks to:

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Niamh Brophy – Palliative care coordinator, St Mungos
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Patrick Stone - Marie Curie Chair in Palliative and End of Life Care, UCL

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MY EXPERIENCE AS PALLIATIVE CARE COORDINATOR – WHAT WORKS WELL

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OVERVIEW

- Case study - Darren
- Multidisciplinary working in practice
- Outcome and lessons learned

CASE STUDY - DARREN

DARREN

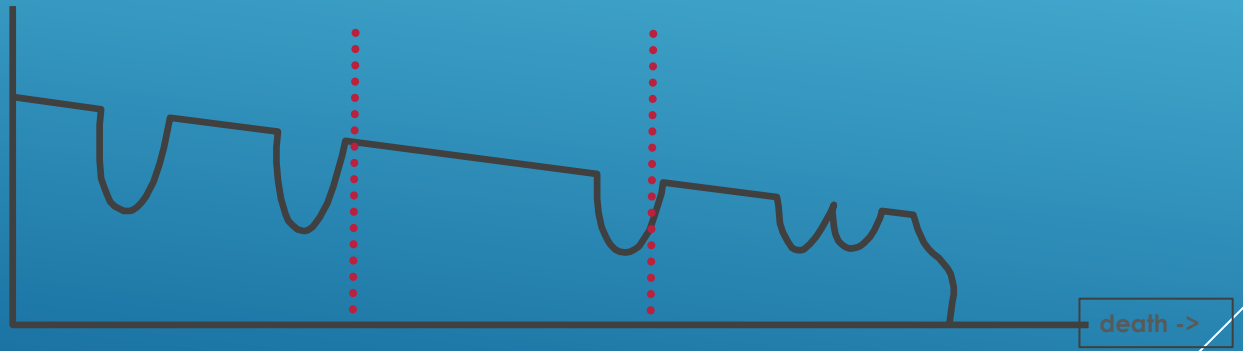
- Aged 35, intermittently homeless since he left care at 18
- Heavy drinker and IV drug user
- Presented with chronic hepatitis C infection, cirrhosis of the liver with recurrent gastro-intestinal bleeding and ascites.
- Poor compliance with prescribed medications, self medicated with OTC painkillers and other illegal drugs

DARREN

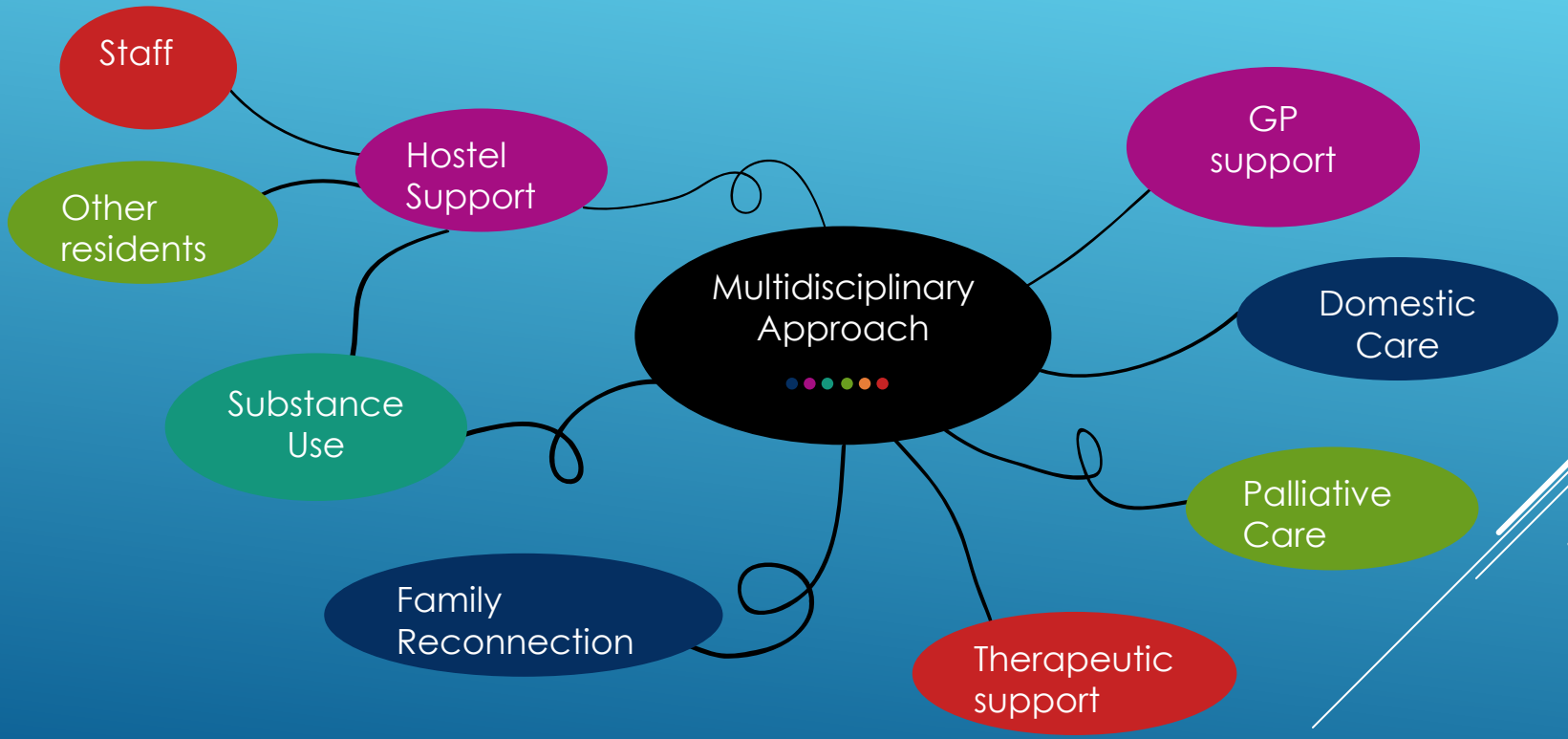
- Regular crisis led admissions for alcohol related issues, compounded by anxiety and marked ADHD
- Prone to disruptive behaviors and angry outbursts, making it difficult at times for others to engage openly with him
- Following each discharge resumes drinking, missing appointments with hospital and community alcohol team
- Rejected detox and rehab
- Hostel concerned that he might die

DARREN

ADVANCED LIVER DISEASE



WHAT WAS NEEDED?



Case review

Objective

- Bring medical, social and community services together to plan Darren's care
  - GP, hostel staff, drug and alcohol services, community palliative care and mental health advocate
- Identify and implement care plan
- Anticipate future care needs
- Darren to remain at the centre of all discussion and decision making

Parallel planning

'Hoping for the best, planning for the worst'

End of life Care involved

Treatment options reviewed

Shared care across team

Committed to person centred approach

Meet every 2 months

Open dialogue between MDT

OUTCOME

Informed decisions respected & wishes identified

Crisis admissions reduced

Open and honest dialogue about risks of continued drinking

Flexible and responsive care delivered

Reconnected to family

Cared for and remained in hostel until last days of life

What did we learn from this case?

The value of multi disciplinary working

- **Shared Care and early intervention**
- **CPCT and Staff support**
- **Support to engage with services**
- **Practical challenges remain**
- **+Planned admissions -Crisis led**
- **Staff felt they had done everything they could**

Thanks for listening

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Any questions?

Parallel planning – could you see this working?

“Deteriorating health” vs “end of life” – Would a shift in attitudes be helpful?