‘Nowhere else will take him’ – Palliative care and homelessness

I have got a man who’s 40ish in a hostel with end-stage liver failure. The hostel seem … sort of … powerless and bewildered. There doesn’t seem anywhere he can go … the fact he’s a drug and alcohol user makes his chances of getting that much less, I think it’s discrimination.

Healthcare professional

Alarming new figures released this month report a continuing trend of increasing rough sleeping in England; 16% in the last year and a total increase of 133% since 2010.1 But homelessness is not limited to rough sleeping – it includes people who are vulnerably housed, including living in hostels, squatting or sofa surfing.

Unsurprisingly, the health of people who are homeless is often poor. Chronic ill health can be the result of a combination of mental, physical and substance misuse problems (tri-morbidity). Shockingly, the average age of death for homeless people is between 43 (women) and 47 (men).2 These deaths are often crisis led, with little or no advanced planning.

A striking finding from our research exploring palliative care for homeless people3 is the complexity and uncertainty involved in delineating who may benefit from palliative care support, what this support might look like and where it might be delivered.

For illnesses such as advanced liver disease, common among people who are homeless, prognosis is uncertain and is influenced by behavioural factors. Chronic poor health may be punctuated by several severe acute health crises over the course of weeks, months or years. Given that people with these illnesses can appear gravely ill but then improve, knowing when and how to introduce palliative care is challenging.

The delivery of high-quality care in mainstream settings for homeless people is complex for many reasons, including mistrust of health services, isolation, the impact and chaos associated with substance or alcohol misuse and, for some, alcohol-related early cognitive impairment. These factors, alongside the relatively young age at which homeless people may benefit from palliative care, means access to hospices and care homes is currently rare. As a result, homeless people often receive inadequate care and support.

As there are no alternative places of care available, people with chronic ill health and high support needs remain in homeless hostels as their health worsens. Hostels were designed to help people move towards less-supported accommodation and operate, and are funded through, ‘recovery’-focused systems. They are not equipped to provide palliative support and have very limited resources. Their recovery-focused ethos means that talking about death and dying doesn’t usually sit well with hostel staff, who fear that such conversations may leave people feeling rejected and hopeless. These challenges mean that the wishes and preferences of homeless people are rarely explored by those supporting them.

As securing assistance from social services can be extremely difficult, many hostel staff go above and beyond the remit of their role by providing personal care for residents. This places huge practical and emotional burdens on staff, who feel inadequately trained and supported, yet responsible.

Recognition of the inadequacies of current systems calls for a different approach to palliative care for people who are homeless. We know that prognostication is difficult in any population, but for people who are homeless, challenges are amplified by uncertainty, complexity, vulnerability and often substance misuse, which at present appear to close doors to traditional services. Parallel planning could be explored as a way of working with these complexities.

For the delivery of compassionate care at the end of life, there is a need for the promotion of multidisciplinary in-reach into hostels and the provision of a specialised facility, supported by health, social and housing services, that understands the needs of homeless people. This could offer short-term respite care and also be a place where someone could potentially die. An example of this is already in place in Canada.4

By addressing this inequity we have the opportunity to promote dignity and choice at the end of life for a population that have rarely had either.

References