

Improving palliative care for people who use alcohol and other drugs

There is a need to improve access to and experiences of palliative care for people who use alcohol and other drugs when faced with terminal medical conditions. Effective harm reduction interventions mean that people who use alcohol and other drugs are living longer, and continue to use substances as older individuals.¹⁻³ People who use drugs demonstrate high levels of resilience in the face of a lifetime of structural disadvantage and exclusion, but are still more likely to die at an earlier age than the general population.^{4,5} They also experience accelerated age-related declines in functioning compared with non-drug using persons of similar age, and often have complex care needs due to accumulated health effects from their substance use and a high prevalence of past trauma.⁶ The provision of palliative care to people who use drugs can be challenging for clinicians, specifically how to manage pain, anxiety and distress among these individuals.⁷ Person-centred care is often obstructed by policies that make generalisations about the risks associated with the use of alcohol and other drugs while receiving medical care. Clinicians and health services looking to improve access to palliative care should integrate the perspectives of people with lived and living experience of drug use into their person-centred care and explore opportunities for the harms of stigma to be minimised. Box 1 provides a list of elements of person-centred care.

There is good evidence that early access to palliative care can improve the wellbeing of people with serious illness; however, structurally marginalised people face significant barriers to accessing palliative care.^{8,9} Some people who use drugs experience severe debility in their day-to-day lives and present to health services acutely symptomatic of advanced or terminal medical conditions that might have been contained with active management earlier in the disease process.¹⁰ People who use alcohol and other drugs often receive palliative care following an emergency department presentation with symptoms of advanced disease, rather than being referred to palliative care services by primary care providers in the early phases of illness.¹¹ Delays in health care access and appropriate treatment are influenced by both anticipatory and experienced stigma.^{12,13} There is evidence that people who use drugs avoid presenting to health care services for fear of being judged, dismissed or disheartened by having their health concerns incorrectly assumed to be a consequence of their substance use.^{10,12} People who use drugs are further excluded from health care services by complex referral pathways and limited appreciation from clinicians of the multiple competing priorities of marginalised communities.¹³⁻¹⁵ The addition of peer support advocacy inside health settings is a promising intervention to redress some of the barriers faced by people who are using alcohol and other drugs and might enable increased access to important non-emergency services such as palliative care.¹⁶

An accurate and contemporary substance use history is likely to assist in managing pain, anxiety and distress for people who use drugs. Unrelieved suffering in people who use drugs exists in a complex web of individual-level factors such as tolerance, emotional distress and withdrawal from regularly used substances, and also systemic factors such as anti-drug stigma and racism.¹⁷⁻¹⁹ As illustrated by hypothetical case 1 (Box 2), experiences or anticipation of withdrawal from regularly used substances can complicate an individual's ability to remain in hospital and receive treatment. People who use alcohol and other drugs often require higher doses of opioid and benzodiazepine medications for management of end-of-life symptoms than people receiving palliative care who do not have substance use histories.¹¹ Clinicians need to be both analytical and non-judgemental in their exploration of pain and distress in individuals that use drugs — for example, considering the possible contributions of opioid tolerance and opioid hyperalgesia. Titration of benzodiazepines and opioids should be informed by histories indicative of tolerance to these substances and by anticipation of the impact of combined psychoactive substances, such as the continued use of alcohol or other drugs. It is also important to consider non-pharmacological and holistic strategies as interventions that could provide comfort.

A clinician's therapeutic relationship with an individual can be significantly improved by open and curious conversation about substance use. Individuals who have used substances as a coping mechanism across their life course might either reduce or increase their substance use as they approach the end of life, and these choices need to be factored into patient-centred care.²⁰ The explicit or implicit expectation of abstinence during in-hospital care is unrealistic, and efforts to enforce these expectations can have the ethically dubious consequence of making people who use alcohol and other drugs feel unwelcome or as though they are at risk of being discharged from inpatient care.²¹ People who use drugs often have a conflicted, complex relationship with their drug[s] of choice, which can affect decision making concerning accepting legitimate prescriptions, for example causing hesitation to use appropriate doses of prescribed opioids or benzodiazepines.²² Understanding the function of both prescribed and non-prescribed substances in the life of an individual might provide a useful foundation on which to formulate a management plan in the context of challenging end-of-life symptoms.

Health-system risk management practices complicate the environments in which people who use drugs can receive palliative care. Traditional end-of-life care settings, such as hospitals and palliative care units, can be experienced as "risk environments" where people who use drugs feel misunderstood and excluded by

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1 Elements of person-centred care

Supporting people who use alcohol and other drugs to die with dignity requires the formulation of person-centred management plans. Elements of person-centred care might include:

1. Improved pathways for people who use alcohol and other drugs to participate in shaping their palliative care journey, including through timely referrals and efforts to minimise structural barriers to health care access
2. Incorporation of accurate and contemporary substance use histories into assessment of the risk of withdrawal and the potential implications of tolerance on medication titration, and prioritisation of an individual's own perspective and feedback regarding medication effectiveness, risks and benefits
3. Having some understanding of and empathy for reasons why people use alcohol or other drugs — be they for pleasure, for management of psychological or physical symptom or distress, or to relieve or prevent withdrawal symptoms
4. Identification and management of the patient's goals with regards to their substance use as they approach the end of life, rather than assuming that abstinence should be their goal
5. Consideration of the best environment for a particular individual to receive palliative care and involvement of people with lived experience in co-design of environments for delivery of care
6. Assessment of any risks related to palliative care for people who use alcohol and other drugs with a very specific (case-by-case) focus on the circumstances of the individual involved, and considering these risks through the lens of harm reduction
7. Creation of an evidence base to guide best practice delivery of palliative care to people who use drugs and alcohol, prioritising the perspectives of people with lived and living experiences of substance use.

2 Hypothetical case 1

A woman is admitted to hospital with functional decline and complex pain in the setting of an invasive cancer. She has anxiety, chronic pain and an opioid use disorder, with long term methadone treatment and regular prescribed benzodiazepines. She talks of a recent return to injected heroin use precipitated in part by an escalation of her pain. In her first days as an inpatient, she experiences opioid withdrawal, and the woman expresses a concern that her pain is being undertreated because she "is a junkie". She considers leaving hospital as she felt her symptoms were better controlled at home with access to illicit substances. Her pain and frailty render her dependent on care that she cannot access in the home environment, and she remains as an inpatient. She complains of significant sleep disturbance and, on exploration, identifies cannabis withdrawal as a potential contributor to her restlessness. She expresses a wish to continue to use cannabis at night-time to aid sleep. Despite significant increases in prescribed opioid doses, she experiences minimal pain relief. In her last few weeks, she injects heroin on the ward, triggering reprimanding conversations with clinicians about their discomfort with her use of illicit substances while under their care.

policies incompatible with their own active illicit drug use.²³ However, people who use alcohol and other drugs also face challenges in accessing outpatient palliative care. As described in hypothetical case 2 (Box 3), people who use alcohol and other drugs can struggle to access community-based services because of organisation-wide policies that cite active substance use as grounds for exclusion from that service. There is a high burden of lifetime housing instability in this population, and service providers struggle to provide care to people who are unhoused or have unstable accommodation.^{9,24} Safety policies that prevent outpatient care from being delivered in settings deemed risky make stigmatising assumptions

3 Hypothetical case 2

An older man presents to a new opioid agonist treatment prescriber to seek assistance with the management of his lifelong opioid use disorder. The new prescriber is concerned about the man's frailty and dyspnoea and directs him to the local emergency department. The man is admitted for investigation of breathlessness and investigations culminate in a diagnosis of an advanced cancer. After surgery and radiotherapy with palliative intent, he is eventually discharged home to the care of his partner, who also has a long history of injecting heroin. The couple struggle with care needs, including management of his symptoms of dyspnoea, pain and anxiety. In light of his guarded prognosis, he is referred to the local community palliative care service for support in the community. The community palliative care service is able to support him by telephone but are unable to visit him at home after hours due to occupational safety related organisational policies that discourage home visits in the setting of active substance use. The couple are left isolated and vulnerable, and ambivalent about any change to heroin use.

of what a safe home is or should be, and exacerbate vulnerabilities of people living in overcrowded or unstable accommodation.⁹ People who use drugs need to be involved in the co-design of environments where they can feel comfortable receiving care, as modelled by collaborative innovations such as the United Kingdom's Improving Hospital Opioid Substitution Therapy project.²⁵

Clinicians and families perceive several risks in the provision of palliative care to people who use alcohol and other drugs. These include the unsanctioned use of palliative care drug delivery devices/equipment, oversedation, use of prescribed medication to experience intoxication and occupational insecurity for clinicians. These risks are often cited as universally applicable to people who use drugs rather than considered after case-by-case assessment or reflection on the specific circumstances of the person receiving palliative care. For example, the risks and concerns about overdose on prescribed medication need to be seen in the context of receiving palliative care. Clinicians must be careful to ensure that responses to perceived risks do not ultimately exclude people who use drugs from the opportunity to receive clinically and humanely indicated treatments.²⁶ People who use drugs should be afforded the dignity of risk, whereby clinicians respect the autonomy of people to make choices that may lead to possible harm. Discussions about the goals of medical care should include open and frank exploration of an individual's preference with regards to resuscitation in the context of overdose or oversedation on prescribed or non-prescribed substances. In Box 4, we present some often-cited risks and proposed mitigation strategies.

There is scant Australian peer-reviewed research that documents and synthesises the experiences of people who use alcohol and other drugs who are seeking palliative care. There is also a relative paucity of literature that speaks to management of non-malignant fatal conditions such as end-stage airways disease, end-stage liver disease, and end-stage dilated or valvular heart failure, which are conditions that could be expected to be more prevalent among people who use drugs and alcohol.²⁷ While there is academic discussion about the challenges of providing palliative

4 Examples of risks identified when providing palliative care to people who use alcohol and other drugs

Risk	Potential implications	Possible mitigation strategies
Unsanctioned use of palliative care drug delivery devices/ equipment	• Delivery of lethal doses of intravenous substances • Line-associated infections • Impaired ability to deliver prescribed medications in event of line malfunction	• Dignity of risk • Open and transparent discussion about the intended role of certain devices and equipment, and the risks of their malfunction
Oversedation and respiratory depression	• Morbidity or mortality relating to interactions between prescribed and non-prescribed drug use	• Dignity of risk • Clear discussions about the goals of care, outlining circumstances where an individual wants resuscitation • Provision of naloxone to interested patients
Experience of intoxication from use of prescribed medication	• Staff anxiety about potential medication misuse is often high, but an intoxicating experience is a low risk outcome	• Focus on key risks of sedation, oxygen saturation and respiratory rate and modify subsequent doses of medication based on these measures
Development of opioid use disorder or benzodiazepine use disorder	• Development of a new substance use disorder might be less significant at the end of life than at other life stages	
Insecure storage of large volumes of sedating medications or diversion to others	• Harm to non-tolerant individuals	• This is generally a poorly understood phenomenon without evidence-based responses • Provision of safes, staged supply where practicable
Occupational insecurity for clinicians	• Clinician exposure to environments where people are using drugs, where clinicians may worry about exposure to sharps, to people with altered conscious states and unpredictable behaviour	• Context-specific risk assessments rather than blanket organisational positions • Provision of sharps-disposal units

care to people experiencing homelessness, there is no evidence to guide provision of home-based care for people who use drugs. There is limited evidence that informs provision of palliative care to First Nations or culturally or linguistically diverse people who use alcohol and other drugs.²⁸

When symptomatic of advanced or life-limiting illness, people who use alcohol and other drugs require care that is sensitive to the resilience and vulnerabilities of a community who is often pushed to the margins of society. People who use alcohol and other drugs are often late to be referred to palliative care services. Their anxiety and pain can be difficult to manage. Health services must actively seek out the perspectives and reflections of the community of people who are actively using drugs to better understand what it means to offer person-centred care for individuals that experience significant barriers to engagement with mainstream health services because of substance use. Many people who use alcohol and other drugs have been excluded from access to services and adequate health care over their life course, but they should not be denied the dignity of a good death.

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