Good practice examples in palliative and end of life care for people using substances: Palliative care services

Good communication and support

Having undergone a month of medical investigation, a man in his 50s was admitted to the hospital palliative care team with chronic lung problems and a complex bacterial infection. Although he had not used drugs for over 10 years, he felt very distraught that his premature death was linked to his substance use. He felt guilty over how he had lived his life and that he did not deserve care or the medical interventions he was being offered. He had been in recovery for many years - participating in NA groups and supporting many other people who had used substances. He was very reluctant to take prescribed opioid painkillers as he feared becoming dependent on them. He was very open about his emotions towards his disease and imminent death, and the palliative care team undertook frequent reviews with him to assess the amount of psychological support he needed due to his high levels of distress and guilt. He received support from both his partner (also an ex-substance user) and his NA sponsor. As his breathlessness became more severe, the palliative care team introduced opioid medication very carefully. Although he wanted to go home to die, he was fearful that, having started opioid medication, he would be tempted to access street heroin. He did go home, however, and both the palliative care team and district nurses supported him, his partner, his mother and his brother.

Support for hospice staff

One young hospice patient had a PEG (a feeding tube into his stomach). He was a very heavy drinker and had such complex needs that the hospice nurses were finding it challenging to manage (he was also administering alcohol to himself via his PEG). The local substance use team put in psychological support for the nursing team to help them care for his end-of-life needs.

Alcohol detox at end of life

A hospice inpatient was in the last couple of weeks of life and, as someone who was physically dependent on alcohol, was being monitored for withdrawal symptoms. The hospice palliative consultant asked if they would like to undergo an alcohol detox and he said yes - wanting to be able to have some meaningful conversations with his family before he died. Medically, this also made his symptom control more straightforward.

Safe and effective pain management

A patient with respiratory disease was experiencing severe breathlessness, but as he was a smoker, oxygen therapy at home posed risks. Prescribing opioids were another option, but he was already on a substitute prescription. The prescribing physician needed to be mindful of that and so contacted his substance use service to ensure that his opioid treatment was jointly overseen by both services. He has been maintained well on methadone, although his prescribers are now considering trying to switch him to slow-release morphine. This joined up working between the respiratory specialist and the substance use team allowed treatment to be tailored to this individual's needs, taking account of his ongoing smoking and opioid use. Clear policies can ensure that this collaborative problem-solving approach is available for all patients and that no one is denied treatment simply because of assessed risks.

Support for family members

A woman with decompensated liver and encephalopathy had been refused a liver transplant because of other health problems. However, the alcohol service was able to provide her with ongoing support and liaised with her six sisters, estranged daughter and grandchild to rebuild family ties and support the wider family as they cared for her. She received home care from the alcohol service and the district nurses provided appropriate treatment for hepatic encephalopathy.

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Good practice examples in palliative and end of life care for people using substances: Substance use services

Joint prescribing practice

A community MacMillan nurse has started working with a medical consultant from a substance use service to give clear opioid prescribing advice to hospices - to ease referrals of people using substances into palliative care and hospice services.

In-reach working

A medical director of a substance use service was asked to visit a hospice where a woman with rectal cancer was a patient. The woman smoked heroin and was insistent on continuing to do so. The nurses did not know how to manage this but knew that she could not use illegal drugs on their premises. The Medical Director was able to alleviate the nurses' concerns and encouraged them to allow the woman to remain as an inpatient, whilst leaving the hospice for short periods to smoke.

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Dedicated health assessments

Example 1: One community drug service has among its team a practitioner who trained as a Registered General Nurse. This person has taken on the role of assessing service users across the whole service whose physical health is deteriorating. Colleagues who have concerns about the people they are working with can ask this person to do a joint visit with them where he can then provide a more thorough assessment of their client's physical health support needs.

Example 2: A substance use service in Liverpool has introduced on-site systematic hepatitis C screening for their service users - with automatic referral into treatment for anyone diagnosed positive. 36% of patients were identified and referred, but treatment completion was only 12%. Although this rate was a successful increase from the previous 5%, it highlighted the difficulties that many service users face in accessing healthcare - often because of a lack of social support and fear of stigma.

Specialist bereavement support for family members

National charity Adfam ran a joint project with Cruse Bereavement Care working with and supporting families, friends and carers bereaved through substance use. The project website (beadproject.org.uk) provides information, advice and guidance. Adfam is currently developing both a bereavement resource for people bereaved through substance use and practitioner bereavement training. Their consultation and mapping research produced a drug and alcohol-related bereavement scoping review.
Findings - https://adfam.org.uk/files/docs/report_02_BEAD_ReseachFindings.pdf
Scoping review - https://adfam.org.uk/files/docs/Adfam-Cruse_Drug_and_alcohol_related_bereavement_Scoping_review_-_October_2014.pdf

Joint working between substance use and palliative care

Example 1: A hospice outreach worker started working more closely with the local drugs team. Normally their referrals come through homelessness providers, but due to closer working relationships more referrals are coming through from the community drug team.
Example 2: Closer working relationships between the statutory drugs service and the community palliative care team resulted in joint visits and excellent working relationships which resulted in the patient's journey being dignified and well managed.

Good practice examples in palliative and end of life care for people using substances: Social and health care

Cross sector working: dying at 'home'

A strong working partnership was developed between the alcohol service and a hostel for homeless people, one of whose residents was approaching the end of her life and wanted to die there. Working closely together, the hostel, a specialist GP, the local alcohol nurse, homeless nurse, palliative care team and district nurses all collaborated to ensure that the woman died where she wanted. The provision of specialist end of life support to hostel staff meant that they felt sufficiently knowledgeable and supported to care for her in the hostel - which was where she wanted to die.

Social work support

One family had received excellent support from their social worker who coordinated their relative's care package over the phone with them for their ease and convenience. The family felt reassured and grateful for this flexibility.

Bereavement support for key workers and hostel residents

A hostel for homeless people has been actively developing bereavement support for staff and residents. They have recently opened a memorial garden on the premises for people to sit and remember their friends and relatives. For some people the hostel is their home and the staff and other residents their support and friends. This initiative acknowledges and respects those relationships.

Good communication with families

Families reported how good communication from health and social care professionals was exemplified by staff who listened to them and who recognised and supported the specific and often complex needs of them and their relatives. They recognised and acknowledged the family's needs in their own right - either face to face or via telephone support. They also facilitated conversations between family members and relatives about death to allow them to talk openly and confront any resistance to the fact the relative was dying.

Updating referral forms to include substance use

An outreach worker in end-of-life care developed a referral form for their local homelessness service that included a section looking at what non-prescribed drugs people were using, and also how many units of alcohol they were drinking. In this way they are supporting their medical staff to prescribe pain relief in a much safer and more informed way.

Initiating collaborative solutions

Liverpool Joint Working Group arose from work of the Drug Related Death panel which examines sudden deaths among people engaged in substance use treatment. This work identified that there were a substantial number of people aged in their 40s and 50s who had died with multiple chronic health problems and complex prescriptions. Furthermore, they seemed not to have been accessing many of the specialist services that could have supported them. The Liverpool Joint Working Forum was initiated as a result, inviting local commissioners, healthcare providers, hostels and mental health services to collaborate. The group has identified a lack of clear care pathways and lack of awareness about each other's services and have run joint training days to promote awareness and better working relationships. They plan on developing and assessing patient benefit from new care pathways.

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