

Good practice examples in palliative and end of life care for people using substances: Supporting families and friends

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_ResearchFindings.pdf

Scoping review - https://adfam.org.uk/files/docs/Adfam-Cruse_Drug_and_alcohol_related_bereavement_Scoping_review_-_October_2014.pdf

Referrals for support

- i) One mother found it helpful to access support for carers from a substance use service.
- ii) Other family members talked about support coming from a funeral director, counselling and therapy (including through IAPT and the workplace) and hospital social workers.
- iii) A mother appreciated an invitation to meet with hospital staff after her son's death to ask questions about his care and death.

Spiritual support

Family members found the presence of a chaplain to be a comforting, gentle and reassuring presence during their relative's final hours.

Liaising with family members in their caring roles

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

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 relative. 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.

Showing care for family members

Family members reported a range of examples of social and health care staff who had demonstrated their care for them:

- i) A mother attending hospital with her dying son described a doctor in the hospital at his bedside rubbing the mother's arm. This simple touch was hugely important to the mother who felt it was both empathetic and very helpful. She felt that someone understood and acknowledged her emotional stress and strain.
- ii) A son sleeping at his dying father's bedside was impressed by the staff providing extra blankets for him and treating his father as just someone in hospital who needed care.
- iii) A friend spoke about knowing when hospital staff genuinely cared rather than just routinely making a 'professional statement'. He spoke of being able to 'sense and feel' when it was genuine love and care from staff.
- iv) One mother said that being confident that her provision of care was as good as it could have been had made a real difference at an incredibly difficult time.

Authors:

Sarah Galvani s.galvani@mmu.ac.uk Sam Wright Sam.Wright@mmu.ac.uk

Gary Witham g.witham@mmu.ac.uk (October 2021)

Website: endoflifecaresubstanceuse.com