



END OF LIFE CARE FOR PEOPLE WITH PROBLEMATIC SUBSTANCE USE AND THEIR FAMILIES

People with alcohol and other drug (AOD) problems, and their families, deserve the same respect and dignity at the end of their lives as people without AOD problems.

They deserve care that is based on their needs, care that is delivered without judgement, and care that offers them the best possible choices in the final months, weeks and days of their lives. Our unique research project at Manchester Metropolitan University explored whether or not this was the case. It sought the views of a range of people including people with experience of AOD use and end of life care needs, their families, friends and carers, and the professionals and experts who supported them. It also

examined existing evidence to find out what we know and where the gaps are in our knowledge. Our partners included two substance use agencies, ADS (Oldham and Bury) and Aquarius (Midlands); three hospices (St John's in Lancaster, St Catherine's in Preston and Trinity in Blackpool), and a Manchester-based community enterprise partner, VoiceBox Inc.

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CASE STUDY – PEOPLE WITH EXPERIENCE

RICHARD, AGED 67

Richard used heroin for many years, but stopped eight years ago. He describes never being trusted by workers and being asked to wait outside the chemist's when trying to pick up his methadone prescription, while they served other

people before him. He has been living with cancer for three years and was recently told that there are no further treatment options. He and his wife are now thinking about his end of life care needs and planning for a funeral with little money. Having

experienced poor healthcare treatment in the past, which he largely attributes to being a drug user, Richard and his wife want to remain as independent as possible, but recognise that they may soon have to accept help from the community palliative care team.

CASE STUDY – FAMILY MEMBER

DEBBIE, AGED 61

Debbie's son had a longstanding alcohol problem and she felt he would die young. He was getting alcohol treatment but eventually died in hospital from alcohol-related liver disease after a period on life support. Debbie described her son's death as a

'good death'—surrounded by family and with compassionate care for both him and the family. However, there were no specific conversations about end of life care and Debbie felt that her grief was complicated by her son's death being associated with alcohol.

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ALCOHOL AND OTHER DRUG PROBLEMS: WHAT THE PROFESSIONALS TOLD US

‘Despite often coming from very different disciplinary backgrounds, there were a lot of shared common experiences and challenges.’

WE WANTED TO LEARN ABOUT the key challenges facing the professionals who worked with people with AOD problems at the end of their lives. We talked to two groups of people:

seventeen specialists from around the UK who work in professions such as social work, hepatology, general medical practice, nursing, and senior policy roles

more than 130 professionals who work, or volunteer, in our partner agencies (some via survey, others via individual interviews or focus groups)

Despite often coming from very different disciplinary backgrounds, there were a lot of shared common experiences and challenges. These fell into three broad categories: (i) challenges at an individual level; (ii) challenges at an organisational level; and (iii) challenges at a systems level.

INDIVIDUAL LEVEL CHALLENGES

1. Hospice professionals did not find it easy to ask, or talk, about a person’s substance use, and substance use staff did not find it easy to talk to someone about their end of life needs and wishes.

2. Not knowing how to raise the topic of substance use or end of life care was a barrier for some professionals. There was a clear lack of confidence about how to have that discussion.
3. Recognising end of life care needs was complicated at times by not knowing whether the symptoms people were experiencing related to the person’s failing health or to their substance use (or withdrawal), as both might change daily.
4. The professionals we spoke to had often advocated for someone where they felt the person was being stigmatised, treated unfairly, or their needs were being overlooked because of their substance use.
5. Professionals also found it emotionally difficult working with these overlapping issues: hospice professionals felt frustrated when working with someone whose substance use prevented them from having a better quality of death; substance use professionals felt loss and sadness when someone they worked with died, and this was not often recognised.

ORGANISATIONAL LEVEL CHALLENGES

6. Symptom and pain management was a major challenge for many of the medical professionals we spoke to. They had concerns about under- and over-prescribing pain relief medication as well as concerns about medication being used by family members or friends. Some used safes and locked boxes to try to address this concern.
7. Family members were not always seen as supportive, particularly when they had their own substance

problems. Examples were given about family members bringing illicit substances into the hospice or attending the hospice in an intoxicated state.

SYSTEM LEVEL CHALLENGES

8. The recovery focus of national policy and most treatment services was seen as unhelpful for this group of people. A harm reduction approach would be more beneficial given this group of people were never going to be able to ‘recover’.
9. There were calls for collaborative national policy to fill the policy gap underpinning work with people with substance problems at the end of their lives.

WHAT WE KNOW ABOUT THE SCALE OF THE PROBLEM

To try to determine how widespread the overlap is between substance use and end of life care, we looked at a large number of existing datasets. However, the headline finding is that currently, people with problematic substance use and end of life care needs cannot be directly identified in any single health or population data monitoring programme. This means that this group of people are poorly represented in estimates of their end of life care needs, and service providers lack evidence about how to meet their specific needs.

There is no ‘typical’ end of life disease profile for substance users, so estimates cannot be calculated accurately based on morbidity. While liver diseases do give some indication of the cause of end of life among some problematic alcohol users, this group is still more likely to die from heart disease, making it impossible to separate problematic alcohol users from the general population.

Practitioners’ help is needed to produce clear evidence of the nature and extent of the end of life care needs of this group. Accurate recording by substance use practitioners of people’s health conditions and lifestyle history on a routine basis would start to build a database and enable the collection of evidence to identify and meet the specific care needs for this population.

GOOD PRACTICE EXAMPLE

DANIEL, AGED 41

Daniel has been a heroin user since he was 15. He has been in drug treatment several times, but never managed to abstain from drugs. Daniel found out that he had hepatitis B and C almost a decade ago and is under the care of his local hospital’s liver unit. Over the past ten years he started drinking alcohol as well, but his

mother’s terminal illness has motivated him to become abstinent before she dies. Daniel has been attending the substance use service for two years, receiving methadone treatment, key worker support and attending an art group. He has stopped drinking. At home, he is assisted by a carer for ten hours a week who makes sure he attends all his appointments

and supports him with some social activities. Daniel understands that he is not going to recover; fortunately, his carer has received end of life training and they have both recently attended a Death Café (where people can gather to drink tea, eat cake and talk about death) as a first step in beginning to plan for a good death. (Ashby et al, 2018: 25/26)

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PEOPLE WITH EXPERIENCE AND THEIR FAMILIES, FRIENDS AND CARERS

‘Many people reported positive experiences of care from substance use and specialist end of life services... These resulted from holistic and compassionate approaches.’

WE WANTED TO FIND OUT how well the support needs of two groups of people were being identified and met: firstly, 11 people with problematic alcohol and other drug (AOD) use who were approaching the end of life; and secondly, 18 families/friends who were caring for them.

PEOPLE WITH AOD AT THE END OF LIFE

Many people reported positive experiences of care from substance use and specialist end of life services. These resulted from holistic and compassionate approaches to care, in contrast to less helpful short-term, single-issue treatment. Examples of good care included staff being available to answer questions, offer reassurance and adopt a non-judgemental attitude to their care. These approaches allowed for trusting relationships to be built and enabled people to begin to overcome the marginalisation and stigmatisation they had typically experienced as a person with a substance problem. Services that were not effectively ‘joined up’ did not help people to have a positive experience of end of life care.

From the experiences of people we interviewed, we identified several care needs at the end of life. These include the need for:

1. Better consideration of palliative and end of life care needs within specialist substance use services to avoid people leaving treatment when they are chronically ill (or are discharged for non-attendance).
2. Greater practitioner understanding of how people ‘carry’ a substance use identity, and how guilt and self-blame can substantially impair people’s confidence in engaging with services. Some research participants described feeling that they did not ‘deserve’ treatment, declining to seek help at a time of real need.

3. More empathic approaches from health and social care practitioners to facilitate trusting relationships. Previous experiences of stigmatisation and discrimination from service providers tended to result in people anticipating future mistreatment from health and social care professionals. This led to: (i) late presentation to services (often only when a health crisis occurred); (ii) communication barriers with health and social care practitioners; and (iii) severely limited opportunities for end of life care planning.

4. Greater clarity in communicating end of life issues, with all services providing opportunities for people to discuss fears of dying and make informed decisions so that personal wishes could be acknowledged.

FAMILY, FRIENDS AND CARERS (‘FAMILIES’ FOR SHORT)

Families were often unaware of the extent of their relative’s illness until their health had substantially deteriorated. This was often due to their relative denying or minimising their substance-related health problem, avoiding healthcare services, or only seeking medical help at a late stage. For some families, their relative’s end of life condition was a shock and they needed clear communication from health and social care practitioners to understand how unwell their relative was. However, many families described multiple ‘missed opportunities’ for professionals to identify palliative and end of life care needs in the days, weeks, months and years before their relative’s death. Many also gave examples of poor care, more commonly from primary and acute care staff. Where professionals communicated clearly with families, and delivered compassionate care including recognition of their needs, the difficulty of their situation could be minimised.

Other families anticipated their relative’s ill health or death. They faced demanding caring responsibilities, which impacted negatively upon their own health and wellbeing. Families wanted support to help them deal with both the stigma they felt from having a relative die from a substance-related condition, and the longer-term effects of substance-related bereavement. Yet health and social care practitioners often had little recognition of families’ support needs as carers – whether before, at the time of, or after their relative’s death.

Practitioner training or new delivery approaches are needed to meet the many needs of this group of families.

RAPID EVIDENCE ASSESSMENT (REA)

We conducted an REA between 1 January 2004 and 1 August 2016 to explore the peer-reviewed evidence base in relation to end of life care and problematic substance use. There were 60 papers meeting the inclusion criteria. We found there was only a small and diverse literature that lacked depth and quality. Using recurring themes to categorise findings, the papers fell into three broad groups focusing on:

1. pain and symptom management (25 papers)
2. homeless and marginalised groups (24 papers)
3. alcohol-related papers (7 papers)

There were four ‘other’ papers that did not fall into the above categories. The headline findings of the REA included:

- Some clinicians might under-prescribe pain medication to people with problematic substance use because of an inappropriate fear of opioid misuse or a fear of overdose.
- Harm reduction appears to be a more appropriate treatment approach for this group of people than abstinence-focused treatment, and there is a need to involve local substance specialists to help people reach more realistic harm reduction goals.
- More creative support is needed for homeless and marginalised groups. This could include delivering services in settings familiar to service users (eg shelter/hostel-based care, end of life services in needle exchanges).
- Piloting supervised consumption of substitute medication with homeless people at the end of life by health and social care staff could be trialled in order to ensure safety and to avoid medication diversion and stockpiling of opioids.
- Health and social care staff need to assess and treat alcohol withdrawal at the end of life.

Most authors recommended universal screening for substance misuse in palliative and end of life care settings using a validated assessment tool. The screening and subsequent monitoring would then give clinicians the opportunity to communicate with patients effectively about their medication and treatment and generate effective supportive strategies alongside them. Assessing mental health needs and regular symptom reviews was also highlighted.

DIGITAL RESOURCES: 'INSIDER INSIGHTS' – THE COLLECTION

IN ADDITION TO OUR FORMAL REPORTS AND RESEARCH BRIEFINGS, our community partner, VoiceBox Inc, led by Amanda Clayson, produced the audio resources listed below.

They provide emotional and raw snippets of our research with people with experience, as well as with family members, friends and carers. They explain, powerfully, the difficulties people with substance problems, and their families, can face when seeking support at the end of life. All participants gave their permission for their voices to be used in these audio clips.

Please note: some people may find these upsetting, so be mindful of that. We suggest you listen to the short introduction first before dipping into the rest.

INVOLVING PEOPLE WITH EXPERIENCE IN THE RESEARCH PROCESS

Under the guidance and leadership of our community partner, a separate group – the People with Experience Advisory Group (PWEAG) – was set up to offer people flexible and creative participation in the research process. The PWEAG's report describes the important process of PWEAG involvement:

<https://endoflifecaresubstanceuse.com/2-people-with-experience-perspectives/>

As a community partner, VoiceBox Inc's main contribution was to extend the reach and access beyond the scope of the other practice partners – in particular, people with direct experience who may sit outside the parameters of substance use services and palliative care services.

The process was a blend of initiation and opportunity, facilitation and exploration, responsiveness and reactivity to circumstances and diverse contexts. Working closely with the MMU researchers was key to the approach.

COMMUNITY OF PRACTICE

At the request of practitioners, we have set up a Community of Practice for people wanting to share information on policy and practice around end of life care for people with AOD problems.

Please send us your email address if you would like to be added to this group.

FURTHER INFORMATION

The project website gives an overview of the project as well as providing links to our project reports and digital resources. These can be found at:

<https://endoflifecaresubstanceuse.com/reports-and-resources-2/>

MEET THE TEAM

From Manchester Metropolitan University:

Professor Sarah Galvani, Dr Gemma Yarwood, Dr Cheryl Dance, Dr Sam Wright, Dr Lucy Webb, Dr Jo Ashby, Dr Gary Witham, Professor Josie Tetley, Professor Carol Haigh, Dr Marian Peacock.

External consultants: Lorna Templeton – independent research consultant, Bristol, Amanda Clayson – founder, VoiceBox Inc, Dr Fiona Duncan – independent research consultant, Manchester.

Contact details:

For further details on this project, or to be added to the Community of Practice, please contact Sarah Galvani, s.galvani@mmu.ac.uk or Sam Wright, sam.wright@mmu.ac.uk

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FOCUS	OVERVIEW OF CONTENT	LENGTH	LINK
INTRODUCTION	01. A brief overview of the background and content of the collection	2m 20s	https://youtu.be/BuJgReRolwk
PEOPLE WITH EXPERIENCE Individual stories and personal impacts of care.	02. Common barriers to accessing information and support Lack of information / Difficulty asking for help / Impact of needing support	4 m 19s	https://youtu.be/zlTwcSuy7Ug
	03. Some specific issues to consider Struggles around medication / Feeling stigmatised and judged / Seeing beyond substance use 'behaviour'	3 m 41s	https://youtu.be/hoYPXfUsnjw
FAMILY MEMBERS, FRIENDS AND CARERS Personal experiences of caring and support, before, during and after death.	04. Some of the challenges families/carers experience in getting help Impact of denial / Not thinking about themselves / Asking and receiving	3m 12s	https://youtu.be/lyH3kOP9a8s
	05. The emotional impact of caring Responsibility and recrimination / Powerlessness and anger / Guilt and self-blame	2m 57s	https://youtu.be/wPTEf45cpGU
	06. Grief and bereavement support How grief is experienced / Does support help or hinder? / Moving beyond despair	2m 49s	https://youtu.be/VtLtxgfl48s
PRACTICE Messages for practitioners in specialist and non-specialist services across hospital, community and home.	07. Communication around 'end of life' – what helps and what doesn't? Timely and direct / Interpretation and sensitivity / Involving and proactive	3m 52s	https://youtu.be/YZqaM1Tamf8
	08. Compassionate care is crucial! At home and in hospital / The 'look and feel' / When it's lacking	2m 50s	https://youtu.be/-XLRbX6zgBE
	09. What influences the experience of compassionate care? Perceptions of stigma / Trust and relationship building / Vulnerability and humanity	4m 45s	https://youtu.be/kmW_upr0pFI
SYSTEM Policy and resource implications around substance use and end of life care across a range of settings.	10. Availability and access to appropriate care What's needed? / When and where? / Who can provide it?	4m 15s	https://youtu.be/BiDB21dUPNY
	11. What's needed to give real choice? Understanding the issues people face / Challenging stigma and shame / Confidence in and coherence of support	3m 41s	https://youtu.be/mLGyqk3ydWE
	12. Training and development themes Understanding impact of substance use / Connecting with the 'lived experience' / 'Humanising' practice	3m 56s	https://youtu.be/NVxnIoO-cjs