



End-of-life care for people using substances

Sam Wright, SUAB, Dept of Sociology, ManMet

Our body of work



6 strand exploratory project

- Funder: National Lottery Community Fund, 2016-2018

Good practice guidance

- Funder: NLCF, 2019

<https://endoflifecaresubstanceuse.com/wp-content/uploads/2022/02/Good-practice-guidance-EoLC-and-SU-April-2019-Web-version.pdf>

Policy Standards: a working document

- Funder: Metropolis, Manchester Met, 2019

<https://endoflifecaresubstanceuse.com/wp-content/uploads/2022/02/Policy-Standards-SU-and-EoLC-May-2019.pdf>

Development of new model of care

- Participatory action and mixed methods research
- Funder: NIHR, 2019-2022

What did we learn?

- Many barriers to accessing services - even when SU in the past
- Negative experiences of care and a fear of stigmatising HSCP attitudes
- Isolation, avoidance of services and late presentation to healthcare
- Many services and staff insufficiently equipped to respond
- People's health and social care needs often not met



What should EoLC look like for people using substances?



- Clarity of EoL diagnosis
- Timely practical assistance
- Regular emotional support
- Compassion
- Support for informal carers

More commonly it can be like...

- Not knowing how ill you actually are
- Little / no professional input
- Unsupported family carers
- Feeling lucky to meet practitioners who do not judge you harshly



Good practice and policy guides:



1. Philosophy of care / service
2. Joint working
3. Talking about it
4. Symptom & pain management
5. Support for staff
6. Family, friends and caregivers



Available at: endoflifecaresubstanceuse.com

5. Support for staff

1. Team/MDT approach to provide care and support decision-making
2. Emotionally responsive teams/managers
3. Regular (internal / external) supervision around loss and bereavement
4. Pairing practitioners for mutual support (or where risks are perceived)
5. Adapting existing guidance on managing multiple, long term conditions

6 Caregivers need support

Bereavement may be more devastating if family relationships were strained:

1. The person's life may have been unhappy or painful, leaving distressing memories.
2. Caregivers may feel powerless at not having been able to change their behaviour.
3. Caregiver guilt that they should have tried to make the person's life more bearable.
4. Family estrangement may leave regrets over not repairing relationships, or guilt at not providing more practical care.
5. Higher rates of substance use within these families? Intergenerational factors.

Key messages for practice

- Link practitioners across the substance use and P/EoLC fields
- Develop practitioners' knowledge and confidence to enable them to talk about both SU and health problems
- Assess family caregivers' support needs: how their relative's SU affects them and their decision-making responsibilities
- Sufficient support for practitioners undertaking this work.

NIHR research (2019-22)



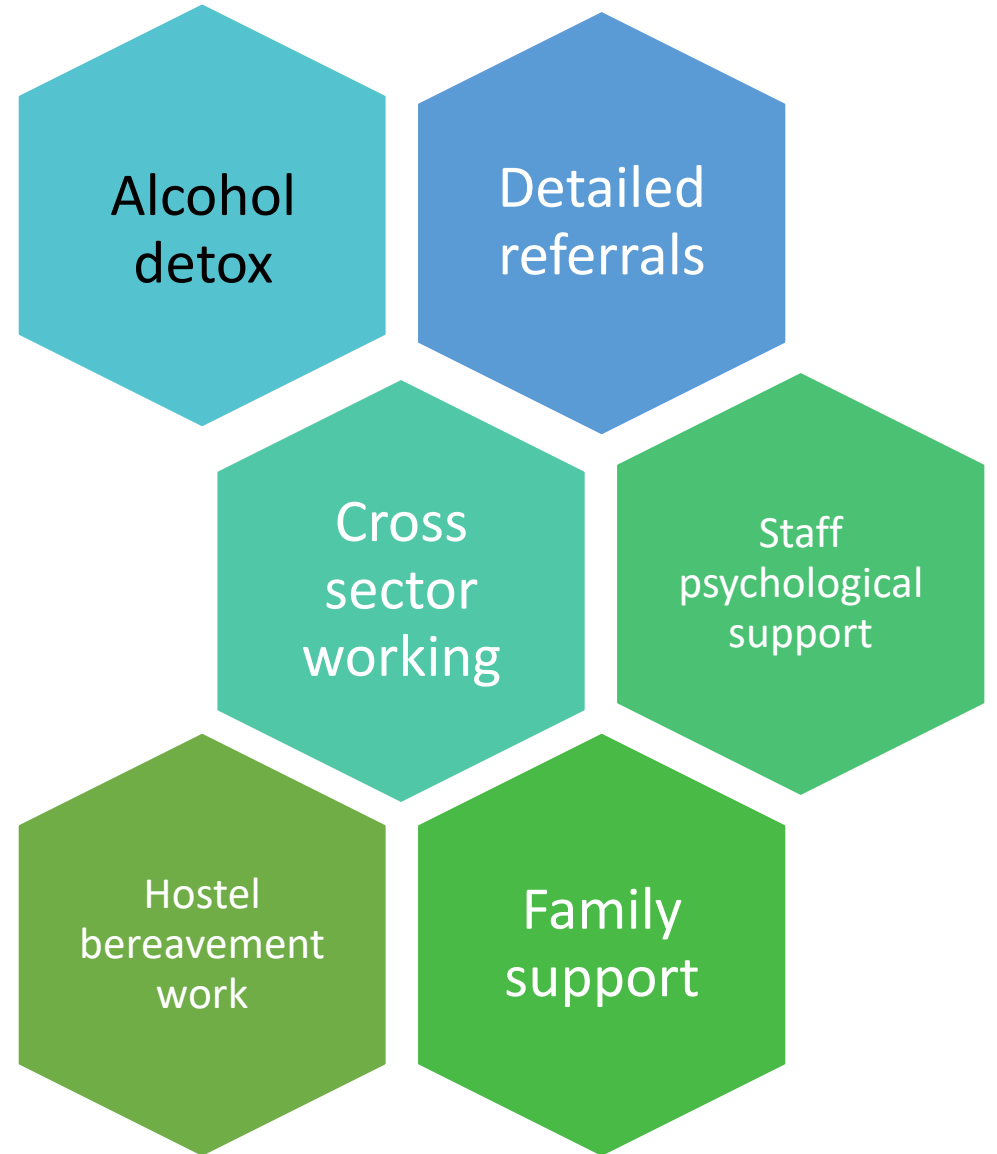
**A new model of care for
people who use
substances and have end
of life care needs**

1. What does good end of life care look like for people using substances?
2. Can a new model improve the quality of care?
3. Are people not currently receiving EoLC or substance use services better able to access care?
4. Do HSCPs feel better supported by the new model?

A new model of supportive care

Outcomes / Impact		
Short term	Medium term	Long term
Carers equipped to have sensitive SAIH, SU & ACP conversations	Routine identification and assessment of people using substances with SAIH	To provide compassion-focused palliative and end of life care for people using substances and their caregivers, that addresses current health inequalities.
Consistent advocacy for people using substances navigating health and social care pathways to access P/EoLC	Cross-agency service standards agreed to achieve equitable care	
Practitioners and peers feel better supported to work/live with SAIH and SU	Information sharing pathway between fora, local MDTs and commissioners	
Resources available for family/carers to access information & support	Families and carers confident that inclusive HSC is accessible	

Good practice examples



Case study 1: Craig

- Social worker supporting Craig (not his real name) – a man who was homeless and had cirrhosis and ascites. He had never settled anywhere and was moved to a small hostel providing consistent care. He decided he wanted to die there.
- Stress of waiting time in hospital had prevented him from attending appointments – GP arranged planned visits so that his wait was minimised and his health could be managed more proactively.
- Got a DNACPR in place.
- Worked with his family to rebuild relationships.
- MDTs set up between Adult Social Care, the Inclusion health GP practice, the hostel and district nurses to provide a wraparound service.
- Reduction in ambulance callouts for him.

Case study 2: Terry

- At the hostel for 3 years. Initially chaotic: sometimes had to have the police called. Hostel has helped him rebuild his relationship with his mum and sister who are very supportive. Has kids but does not see them. Stopped drinking (previously on 9l wine / day). Used to misuse meds (pregabalin), but wants to manage his health better. Now welcomes new residents into the hostel and helps them settle in.
- Health deteriorated and GP told him he was palliative. He didn't fully understand and didn't want to accept it. Started having panic attacks in the days after – scared to sleep because *'tomorrow's not promised for me.'* When sitting on his own, his mind plays over his fears and he gets upset. Using crack – knows that if he keeps using it his health will deteriorate fast. But it helps him to escape from his thoughts. A Marie Curie counsellor has taught him breathing techniques for anxiety, encourages him to do activities he enjoys, and to talk to staff about his fears - so they can reassure him that they will do everything in their power to avoid what he is fearful of. Difficulty maintaining hygiene: struggles to breathe in the shower and has collapsed. Now wears an alarm on his wrist.
- Been into hospital a few times – hates it. *'When they know you're a drug user they do treat you differently. Treat you like a piece of shit. You just feel paranoid.'* Hospitals keep you awake and respond poorly when you're agitated through stress. Has refused to go to hospital lots of times as a result. HSCPs involved : hostel staff, GP, homeless nurse, DNs for cellulitis. SW was involved when he was ill (care package dormant now). Has own carer who comes in twice daily: administers meds – from a safe in his room.
- Living at the hostel and having trusted people around him makes life easier. Feels he puts on a mask though so that people think he is more ok than he really is. Doesn't go into depth about how he feels. Likes painting and word searches. Would like to go for walks – but worried about repair costs to his mobility scooter.

Case study 3: Tony

- Using drugs since 14, stopped when he moved into the hostel: now using only alcohol and 10ml methadone.
- Came to hostel from other homeless provision (standard bed) when it was noticed that he wasn't getting washed or eating and was having multiple hospital visits.
- Began struggling to breath. Had reported pains: initial scans did not reveal anything and a camera scan was not possible due to his alcohol use. Blockage in his bowel led to an emergency operation and stoma bag. Sepsis.
- Diagnosed with COPD. Wanted to move into own flat (partly because several friends had moved out), but commissioners knocked that back – recognising he would not be able to cope on his own. The hostel has now received a hospital bed for him and a nebuliser.
- Now has nerve damage (no control in left leg or right arm). In a supportive care setting to minimise risk. City MDT. Social prescribing to tap into his interests: chess, Liverpool history. Also participating in a pain management course. Need to figure out how to increase his care package so that he can access these activities.
- Has own carer who administers meds – from a safe in his room.
- Has previously OD'd 6 times in six weeks. DNACPR in place – originally just for COPD – but after his recent overdoses, this was amended to include IV drug use and alcohol use.

How people need to be treated:

Information, Identification and Assessment

- Clear, honest, and open communication; 'No Bullshit'
- Supported to consider and express what they need
- Informed and supported re: the use of advanced directives

Non-judgemental practice

- Find points of connection to build relatability and trust
- Understand and accept who is important in the person's life
- The need for trust in managing pain medication
- Recognise areas of particular emotional sensitivity
- Recognise the roots of your/colleagues' defensive practice
- Avoid or question potential myths and stereotypes

Support for staff

- Look after staff!
- Build greater participation in the range of support services involved

Support for family and friends

- Enhance support for friends
- Work with individual needs and family dynamics

Opportunities for Greater Manchester

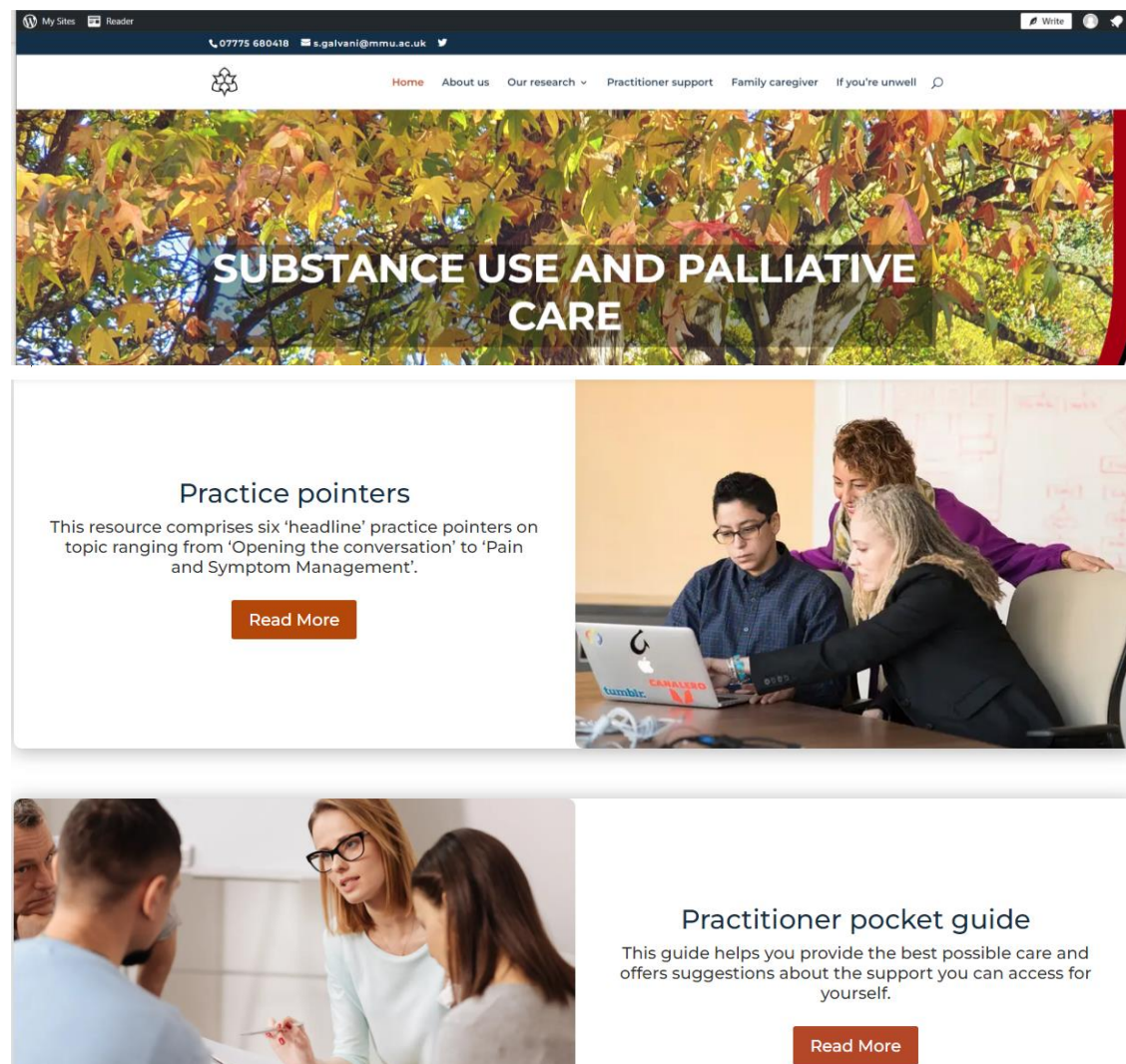
- Interest among practitioners
- GM NHS Integrated Care P/EoLC Improvement Network and education network
- Homeless/inclusion health work



Our next steps

- Having disseminated the model to all 10 partner agencies, we want to expand training nationally
- Deliver the practitioner and family support forums
- Continue developing and adding resources to the website

<https://endoflifecaresubstanceuse.com/>



The screenshot shows the website's interface. At the top, there is a dark navigation bar with contact information (07775 680418, s.galvani@mmu.ac.uk) and a 'My Sites' menu. Below this is a white navigation bar with a logo and links for Home, About us, Our research, Practitioner support, Family caregiver, and If you're unwell. The main content area features a large hero banner with a background image of autumn trees and the text 'SUBSTANCE USE AND PALLIATIVE CARE'. Below the banner are two resource cards. The first card, titled 'Practice pointers', includes a description of six 'headline' practice pointers and a 'Read More' button. The second card, titled 'Practitioner pocket guide', includes a description of the guide's purpose and a 'Read More' button. Both cards feature images of people in professional settings.

Home About us Our research Practitioner support Family caregiver If you're unwell

SUBSTANCE USE AND PALLIATIVE CARE

Practice pointers

This resource comprises six 'headline' practice pointers on topic ranging from 'Opening the conversation' to 'Pain and Symptom Management'.

[Read More](#)

Practitioner pocket guide

This guide helps you provide the best possible care and offers suggestions about the support you can access for yourself.

[Read More](#)

What families need to know

ALCOHOL CHANGE^{UK}

Caring for someone with an alcohol or drug problem who is seriously ill



Author: Dr Sam Wright, Manchester Metropolitan University



Caring for someone using alcohol or drugs whose health is poor

Essential Information for Family, Friends and Carers

December 2021



Home About us Our research Practitioner support Family caregiver If you're unwell

VIDEOS & PODCASTS



GOOD PRACTICE: IMPROVING CARE

Feb 15, 2022 | Videos & Podcasts

In these six podcasts, the practitioners discuss approaches and improvements to palliative and end of life care for...

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GOOD PRACTICE: PARTNERSHIP WORKING

Feb 15, 2022 | Videos & Podcasts

There are five podcasts below focussing on some aspect of partnership working: 1. Partnership working and developing...

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GOOD PRACTICE: COMPASSIONATE CARE AND SELF-CARE

Feb 15, 2022 | Videos & Podcasts

These podcasts discuss compassionate approaches to care of both the individual and the self-care of the practitioner....

[Read More](#)



Thank you
for listening

Sam Wright

Email: sam.wright@mmu.ac.uk,

Tel: +44 (0)7815 595609

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@SUABManMet

