

Good practice pointers #1: Making palliative care accessible for people using substances

Substance use can divert professionals' attention from the person's underlying health and social care needs resulting in poor quality care.

"...it seems completely alien to us why somebody would drink themselves to death but when you understand the context of somebody's life and the things they've been through, it makes sense..."

Substance use professional

Basic principles of increasing access to palliative care:



Read our Good Practice Guide:

- How can my organisation build an accessible philosophy of care?
- How can we maximise joint working?
- How can practitioners feel confident in holding conversations about highly sensitive topics?
- How can symptom and pain management best be achieved?
- What support do staff need in undertaking this work?
- What support do family care givers need to sustain them?

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Good practice pointers #2: Opening conversations with people using substances whose health is concerning

You may be worried about what to ask and how to ask it – particularly if substance use or serious ill health are not topics you've talked about before.

"[people using substances can be] quite suspicious and find it very difficult to trust that the healthcare providers have their best interests at heart"
[Hospice professional]

'Opening' questions you may want to ask about someone's health:

- I feel concerned about your health and would like to support you as best I can. Could we talk about it a little?
- I worry that you are becoming unwell and I'm not supporting you enough with that. What can I do to help?
- How do you feel things have been with your health recently? Have you had any concerns about it?

Opening questions you may want to ask about someone's alcohol or other drug use:

- Can you tell me about your alcohol and other drug use at the moment and how it's helping you at this time?
- We will not judge you for your use of alcohol/other drugs, we just need to make sure we can give you the right care and medication – we don't want to make things worse for you.
- To what extent would you like to change anything about your drinking/drug use at this time?

Even if someone (e.g. a referrer), has already given you information on the person's health conditions, social care needs or use of substances, it can be worth asking the person if anything has changed or whether there's anything they'd like to add. You may be less threatening than the person who originally asked and may get more or different information.

Where there is shared knowledge and acceptance that someone is approaching the end of their life, questions could include:

- What do you want your end of life to look like? Is there anything you'd like to change?
- Would you like to be supported to continue drinking or using when you are at the end of life?
- How can we make your end of life experience what you'd like it to be?

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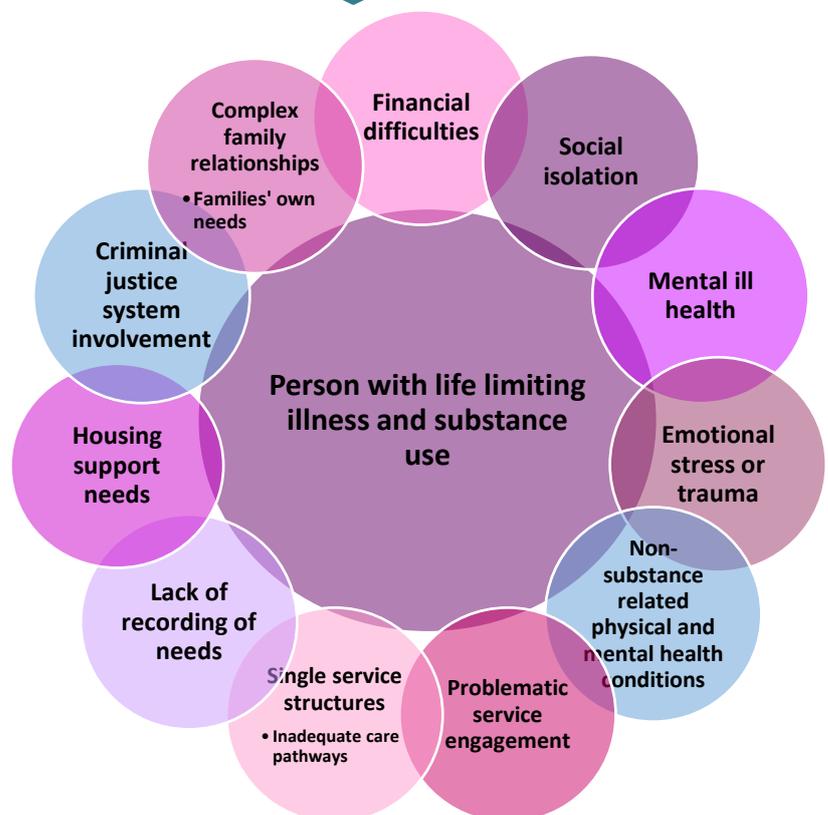
Good practice pointers #3: Understanding the complex needs of people using substances who have serious and advancing ill-health

Evidence suggests that people who use substances have multiple and complex needs. Identifying, and responding to people using substances at the end of life, is limited due to these overlapping and multiple needs.

"The thing that strikes me most about people is the loneliness and the isolation. ... they've been diagnosed with predominantly liver complaints, physical health complaints and have deteriorated and deteriorated until they've passed away - usually on their own. ... the thing that strikes me is I suppose is the feeling of hopelessness that clients have."

Responding to complexity:

- Understand that your best intervention will be about supporting the person across all of their needs, not just the one you're professionally trained to focus on.
- Start with the person's priorities – this builds trust and evidences you're listening.
- Determine who else is involved in their care and seek permission to make contact.
- Establish if there are any family and friends that the person who like support to contact.
- Be prepared to advocate for the person with other services that might have been negative or dismissive of the person previously.
- Refer people to social care where declining self-care risks their safety and wellbeing.
- Do not 'discharge' someone until you know there is a care plan in place.
- Remember – these multiple needs are set in the context of many experiences of hurtful stigma and stereotyping. Be different.



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Good practice pointers #4: Overcoming stigma for people using substances who have severe ill-health

The stigma attached to substance use, and the negative stereotypes relating to people who use substances deter them from getting health and/or social care and negatively impact their families and carers too.

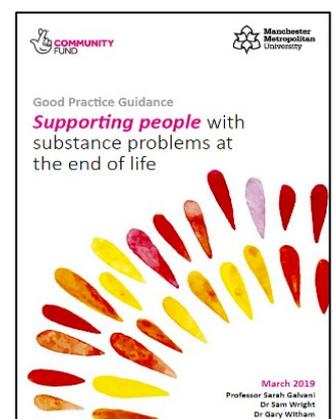
“They often ... are victims of something that’s happened to them. But towards the end of their life, they’re almost demonised for their behaviour. But they did originally start off as people that society would have real sympathy with, through sexual abuse, stuff that’s happened to them as a young adult or child, ... society doesn’t look at what originally started that off.” [Substance use professional]

Problem	Solution
<ul style="list-style-type: none"> • People using substances are reluctant to engage with health and social care services because of previous negative attitudes towards them. 	<ul style="list-style-type: none"> • Acknowledge this and the need for you to win their trust. Be explicit that you are not there to judge them, you’re there to care for them.
<ul style="list-style-type: none"> • Health problems are attributed to substance use by some clinicians with no further investigations until they have ‘stopped drinking’ or using substances. 	<ul style="list-style-type: none"> • Help them to self-advocate by suggesting things they can say, e.g. ‘I’d be grateful if you could listen to me – it’s not just the drinking/drug use that’s a problem for me.’
<ul style="list-style-type: none"> • Poor or absent care, or lack of timely health care, can lead to increased suffering for the person and their family members. 	<ul style="list-style-type: none"> • Maximise the care you can offer. Advocate for them with other health professionals flagging up the risks of not intervening.
<ul style="list-style-type: none"> • Practitioners make assumptions that people know about their health condition. 	<ul style="list-style-type: none"> • Often they do not, even at high levels of substance use. Check out their understanding of their health condition and talk with them about its symptoms and treatment.
<ul style="list-style-type: none"> • Assumptions are made by prescribers about people wanting prescription medication to misuse it, when in fact they are unwell. 	<ul style="list-style-type: none"> • Don’t make the same assumption. Talk to people about it, be open about your concerns. Be non-judgemental in tone.
<ul style="list-style-type: none"> • People do not discuss and/or hide their substance use within end of life/hospice settings due to anticipation of negative attitudes and reduced care. 	<ul style="list-style-type: none"> • Ensure you ask everyone about their alcohol or other drug use sensitively and confidentially (ie. not in an open ward). Be explicit that you’re not there to judge but it helps to know about it.
<ul style="list-style-type: none"> • Families, friends and carers feel unable to discuss their relative’s ill health because of the shame and stigma about their substance use. 	<ul style="list-style-type: none"> • Offer whatever support you can to family and friends. Sometimes a sympathetic ear or gesture is all that’s needed. Provide information on family support where it’s available.



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Good practice pointers #5: Supporting the families and friends of people using substances who have severe and advancing ill health

Family members and close friends are the main carers for people whose health is deteriorating. The stress and pressure upon them are intense, both emotionally and physically, particularly where relationships have become estranged or strained.

Services often work with family members in relation to their relative's needs. Families are often the person's primary carers and need support in their own right to ensure their own good mental and physical recovery before, during and after their caring role.

"One night I woke up in the night ... I just heard this scream. And it was me and I screamed on the landing. ... I just couldn't stop screaming - and [the neighbours] called the police ... that's how ill we all were." (Mother)

"I remember when I actually got him into hospital and it was just me and [my son] there at first and the doctor, just she rubbed my arm...It was very empathetic I think and very helpful at that point." (Mother)

Families report feeling unable to talk to people about their relative's illness and death because of the shame and stigma that surrounds substance use. Supporting family and friends may only require the simplest gesture or the briefest of sympathetic conversations to make a world of difference to the person. However, more formal structures for professional-led and peer-led family support within services need to be developed. The **practice recommendations** below are based on our research with families of people using substances at, or near, the end of their lives (Yarwood et al. 2018):

- Acknowledge the need for family support, in their own right, as they care for a relative using substances at the end of life. They may need practical advice as well as emotional support or empathetic responses.
- Consider your own/ agency's response to family members. How it can be improved?
- Strengthen your communication with family members around end of life, unpredictable health trajectories and associated uncertainties – you may be the first person to talk to them about it.
- Ensure you have a list of family support services handy for people with relatives that use substances and for family members bereaved through a relative's substance use. Keep it nearby so you can provide information quickly.



The **policy recommendations** below are drawn from our research learning:

- Ensure professionals are clear how to support family members/ friends
- Ensure policies about family support includes guidance on working with family members where there are concerns about their substance use, behaviour or safeguarding concerns.
- Consider introducing dedicated bereavement support for families of people who used substances – this could be 1-1 or a peer-led group in person or online.
- Consider the provision or expansion of proactive community outreach and hospital in-reach service delivery models to encourage family (and their relative's) engagement with services.



Good practice pointers #6: Pain and symptom management for people using substances who are seriously unwell

Prescribing pain medication for people with problematic substance use who are increasingly unwell is complex but good practice is achievable. Many prescribers and health professionals fear inadvertently overdosing someone by giving them too much and end up underdosing the person by giving them too little. Underdosing can lead to 'chemical coping' whereby the person 'tops up' their medication with substances because the pain medication is not effective enough. Conversely, people in recovery from substance use may refuse to take opioid painkillers – either through fear of becoming dependent or undergoing withdrawal if not managed well.

"another lady on my caseload ... she really will not take it. She won't take the liquid morphine, she's terrified of taking it. She'll try and put up with the pain, because of that fear of addiction. ... It's like they feel they're going to lose total control of their lives." [Hospice professional]

"... my clinical experience is that some people, particularly with heroin abuse or related drugs, have a very high tolerance for the drug and therefore they need really big doses...people are really afraid of really big doses and so I think that there is a tendency to underserve this population." [Policy & Commissioning Professional]

Practice headlines: Assessment

- Explain to the person the importance of knowing what they're taking so you can manage their pain – reinforce that you're not judging them – just wanting to care for them in the best way possible.
- Is the person an active user of substances currently or past? Are they happy or reluctant to take opioid-based medication?
- Have they taken/are they taking prescribed methadone and if so, for how long and how much?
- Use tools such as the Pain Assessment and Documentation Tool (PADT) regularly and frequently.
- Assess for withdrawal symptoms, particularly if the person becomes physically unable to access substances towards the end of their lives – medicate the discomfort properly.

Practice headlines: Prescribing

- Levels of prescribing may need to be higher because of increased tolerance from historic drug use – assess each person on an individual basis.
- Prescribers need expertise and confidence to manage pain requiring higher titration that may exceed standard prescribing protocols. Collaborate with drug and alcohol services.
- Where someone is using substances, offer more frequent outpatient appointments and use slow release medication with a small supply of breakthrough opioids.
- Ensure you communicate well with the pharmacy and any other health and social care professionals to minimise the risk of poly-prescribing and poly-pharmacy

Practice headlines: Managing

- Discuss with the person how and whether they can keep medication safe in the home and if not, provide lock boxes, safes or daily deliveries for example.
- Don't assume people have ulterior motives for "wanting" pain medication – discuss and plan with them and any family/friends or key workers you have permission to speak to.
- If you suspect people do have ulterior motives for wanting more medication, be curious rather than judgemental. Why is that? What's the context? Can you offer additional support?

