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When long-term recovery isn't an option: people at the end of life

Sam Wright and Gemma Yarwood

Introduction and caveat

Long-term recovery is not something that people who use substances¹ can aim for as they approach the end of their life². But we can learn much from the palliative care³ field about how to develop ideas about recovery that are more inclusive of all people using substances, as well as the people who care for them. This chapter uses brief descriptions of people's lives to question how useful the concept of long-term recovery is for people with chronic health problems (especially those approaching the end of their lives). We argue that substance use policy, commissioning and practice could become more inclusive by prioritising quality of life and physical / mental wellbeing of people using substances, regardless of how close to death they are. Drawing on lessons from palliative care, we end this chapter by making some suggestions about rethinking the concept of long-term recovery.

Palliative care is defined as 'provision of psychological, social, spiritual and practical support' (NCPC, 2006). It is both a medical speciality and a social movement that aims to improve the care of people who are dying by constantly evolving to each individual's changing support needs and maximising their quality of life (Graham and Clark 2008). Ideally, palliative care commences early on, as a life-shortening condition is diagnosed. It runs alongside active treatment, becoming the more prominent aspect of care as the individual becomes progressively more ill. The core ideas used to develop palliative care - focusing on immediate, day-by-day quality of life and attending to both the individual and social/familial aspects of a person's life in a holistic manner – complement current thinking about substance use recovery. In this chapter, we describe how the lives of people approaching the end of their life could be improved by integrating palliative care approaches within ideas about recovery, thereby achieving a more finely-tuned balance between health and social care.

At this stage we want to clarify that we are not experts in recovery. We are UK-based researchers interested in the end of life care needs of people using substances and the support needs of their

¹ Throughout this chapter we use the term 'substance use' to refer to the use of alcohol and other drugs, including prescribed medication. Nicotine use is not included however. The phrase 'problematic substance use' is used to describe when someone's use of alcohol or other drugs causes problems to an aspect of their lives, for example: their physical or mental health, relationships, education or employment, criminal justice involvement, finances and/or housing.

² People are 'approaching the end of life' when they are likely to die within the next 12 months. General Medical Council (2010) *Treatment and care towards the end of life: good practice in decision making*.

http://www.gmc-uk.org/static/documents/content/Treatment_and_care_towards_the_end_of_life_-_English_1015.pdf

³ *Palliative care* (sometimes called 'supportive care') is treatment, care and support for people with an incurable, life-shortening illness, and their family and friends. Its aim is to maximise each person's quality of life through: managing physical symptoms (such as pain); providing social care and emotional, spiritual and psychological support, and supporting family and friends of people approaching the end of their life. Palliative care can be appropriate at any stage in life-shortening illness, with some people receiving palliative care for years. It can be provided alongside treatments, therapies and medicines (such as chemotherapy or radiotherapy).

End of life care involves treatment, care and support for people nearing the end of their life. It is typically for people thought to be in the last year of life (although this timeframe can be difficult to predict and some people only receive end of life care in their last weeks or days). End of life care aims to help people live as comfortably as possible by managing their physical symptoms, identifying their care needs and end of life wishes, and providing emotional support. It also involves talking to family and friends about what to expect as their loved one approaches the end of their life.

Adapted from: <https://www.mariecurie.org.uk/help/support/diagnosed/recent-diagnosis/palliative-care-end-of-life-care#what>

caregivers – whether family and friends, drug/alcohol workers or hospice staff. In our end of life research upon which this chapter is based, we did not ask participants to talk about their personal perceptions or experiences of recovery. Instead, we describe our reflections on how their life histories - as told at the end of their lives – inform debates about long-term recovery.

However, it is important that we specify our understanding of key recovery terms and how we intend to use them in this chapter. The term ‘recovery’ is used in numerous contexts and in relation to a range of physical and mental health conditions (for example: cancer, depression, eating disorders and other mental health problems). When thinking specifically about substance use, recovery is generally agreed to refer to voluntarily sustained control over alcohol and other drug consumption (Best, 2019). The concept of ‘long term recovery’ is typically recognised as referring to being beyond five years in recovery. At that point the risk of relapse has fallen from 50-70% (reported for people in the first year of recovery from substance use) to about 15% (Betty Ford Clinic Institute Consensus Panel, 2007). So the five year point is an important marker in that for most people, recovery may then be considered to be stable or ‘self-sustaining’ and no longer requiring external support (Dennis et al., 2014). However, for people using substances who have a life-shortening condition, such long-term recovery goals are not feasible. In this chapter we therefore focus simply on the concept of ‘recovery’ as a more appropriate idea for people approaching the end of their life: exploring how its definition could be adapted or reinterpreted to better reflect the experiences of people using substances whose health is deteriorating.

We approach our argument in two ways. Firstly, we review people’s substance use over the life course (as told at the end of their lives); and second, we introduce ideas from palliative care to try to enhance current UK ‘recovery-oriented’ substance use policy. The chapter is structured with three main sections, through which we want to:

1. *Present five brief vignettes of people approaching end of life;*
2. *Draw on these vignettes to explore the range of social care needs among this group and unpick some of the ideas within a prominent UK definition of recovery, and*
3. *Propose an alternative way of thinking about recovery, informed by the field of palliative care, to encourage substance use policy and practice that adopts a more inclusive, person-centred approach.*

Introducing the End of Life Care study

Between 2016 and 2018, Professor Sarah Galvani led a multi-disciplinary team of researchers from Manchester Metropolitan University to explore end of life care for people using substances⁴. This programme of work was divided into six strands, two of which involved in-depth, semi-structured interviews with people who were approaching the end of their life and their families. We spoke to people who were accessing substance use treatment and/or hospice services, as well as those not using services. The aims of this research were to:

1. Document how substance use and end of life services supported people with substance problems and terminal illness;
2. Report the good practice and challenges that people faced in accessing support services; and
3. Provide an opportunity for people reaching the end of their lives and family caregivers to comment on the support received and how that could be improved.

⁴ Full reports and briefings from this work can be found on the study website: <https://endoflifecaresubstanceuse.com/reports-and-resources-2/>

Interviewees were recruited from a range of sources, including hospices, substance use treatment services and community networks. We completed interviews with 11 people approaching the end of their life who had current or past substance use difficulties, and 18 family caregivers. All interviews were audio recorded and fully transcribed and we analysed the data using thematic analysis (King, 2012, Braun and Clarke, 2006).

For this chapter we present vignettes of five people, sharing their experiences of using substances over their whole life-course. These five people were selected as their stories highlight particular limitations in current ways of thinking about recovery in its broadest sense. Most of them would not be considered to have achieved long-term recovery from substance use, because they had not attempted it, had not sustained it, or their abstention from substance use was not entirely voluntary.

The long-term social care needs of people using substances

Vignette 1: Anti-abstinence – people who do not wish to stop using

Bev (57 years old) Bev described herself as having been psychologically dependent on alcohol for decades. She had received alcohol counselling via her GP many years prior to interview, but she only ever wanted to reduce, not stop her alcohol use. She had one daughter (Lizzie), who developed a serious problem with heroin as an adult, ending up in prison where she received several drug interventions, which led to her own successful recovery. When we met Bev, she was still drinking throughout the day and was dying from lung cancer. We also interviewed Lizzie separately. Lizzie described how her Mum's emotional unavailability whilst she was growing up was linked to her own heroin use.

Vignette 2: Socially controlled use – Personal responsibilities drive control over substance use

Barbara (55 years old) Barbara's social drinking became increasingly problematic as she endured a painful separation from her husband. For several years she was in and out of alcohol treatment, achieving abstinence multiple times until another huge life stress would prove too much to cope with, and she returned to drinking. Barbara stopped drinking at one point to provide care for her father whom she was very close to. But she started drinking again when he died. By the time we met her, she had developed liver failure, with a range of related health symptoms.

Vignette 3: Health triggered recovery: Decision to manage substance use only as health fails

Rob (42 years old) Rob was a long-term heroin user who had been in and out of treatment for many years. He developed endocarditis (a bacterial infection of his heart valves), which permanently impeded his heart's functioning and reduced his lifespan to a few years. It was only when he realised that his life was limited that he stopped using street drugs and focused on strengthening his relationships with his mum, son and close friends. He started participating in his local hospice's day programme, designed to enhance emotional resilience and psychological wellbeing. However, he was very careful not to disclose his history of substance use to other patients or any staff who did not need to know – for fear of the stigma he might face.

Vignette 4: Fragile abstinence (with ongoing difficulties with relationships)

Trevor (61 years old) Trevor had abstained from alcohol since nearly dying from alcohol-related liver damage many years prior to our interview. But a period of illness, followed by his inability to repair his broken marriage, led him to return to drinking heavily. Although he had been involved with mutual support previously, he had found it unsatisfactory and so did not return. Nor did he not want to access treatment services again. Some of his close family also had difficulties with alcohol, and so opinions were divided on how serious a problem his return to drinking was. His adult children, hurt from his heavy drinking as they were growing up, struggled to talk to him about their concerns for his health – not least because he denied that he was drinking problematically. Despite the best attempts from his close friends to support him, he continued to use alcohol until he was hospitalised. He ultimately died from liver failure.

Vignette 5: Voluntary, long-term abstinence from substances, but suffering long-term stigma

Paul (67 years old) Paul and his wife had not used heroin for over eight years. Four years prior to our interview, he had been diagnosed with cancer and had since undergone a range of treatments. Days before our interview Paul had been informed that his latest treatment had not been successful and that his cancer was terminal. Although it was many years since using drugs, his former identity as drug user with his *'arse hanging out of my jeans'*, had left him and his wife cautious about opening up their lives to MacMillan nurses and other health and social care professionals. Although Paul and his wife had previously volunteered for a substance use service to challenge health professionals' negative attitudes, they still felt vulnerable to negative judgements from others. Paul's previous experiences of discrimination still coloured his expectations about how he would be treated as he approached his death. He was also very reluctant to use opioid painkillers – although his wife had been able to persuade him to take them when the pain became too much. Sadly, their poverty made the painful process of funeral planning even more distressing.

These vignettes provide insight into people's substance use over their whole life-course, as recounted from the viewpoint of the end of their lives. At various times all of them had sought to control, if not cease, their substance use. Most of them became abstinent at various points in their lives, although many subsequently returned to using substances. Indeed, with the benefit of the hindsight possible by being at end of life, it is clear to see the chronic relapsing pattern of substance use and how interwoven it is with longer-term social care needs.

The concept of recovery

The concept of recovery has been subject to much debate (Neale et al., 2015; Neale et al., 2014; Paylor, Measham, & Asher, 2012). In 2008, the UK Drug Policy Commission (UKDPC)⁵ convened an expert group to reach consensus on what recovery entailed. The resulting report stated:

⁵ The UKDPC was an independent body formed to provide objective analysis of UK drug policy and practice evidence. It existed between 2007 and 2012. Its work can be found at: <https://www.ukdpc.org.uk/>

“The process of recovery from problematic substance use is characterised by voluntarily-sustained control over substance use which maximises health and wellbeing and participation in the rights, roles and responsibilities of society.”

UKDPC, 2008

The Commission refuted the idea that total abstinence was a necessary condition of recovery, clarifying that the term “control over substance use” included opioid substitute maintenance therapies. Unfortunately, this broad and nuanced understanding of recovery as a long-term process of self-development has in its translation into UK substance use policy and practice, been narrowed into performance indicators focusing on programme completion and service exit (Drug and Alcohol Findings, 2016). As UK policymakers prioritised ‘recovery’ within the 2017 drug strategy (HM Government, 2017), the term became increasingly synonymous with not only abstinence from illicit drugs, but also cessation of long-term use of substitute prescriptions.

With insight from our vignettes, we now seek to revisit and build upon those original, nuanced UKDPC ideas about what recovery entails. For us, these stories pose the following specific questions:

- **What opportunities are there to generate ‘voluntariness’?** In the first vignette we see that although Bev never wished to become abstinent, her relationship with her daughter was impaired by her ongoing alcohol use. Although not aiming for recovery in the traditional sense, both Bev and her daughter had unmet support needs. Family-focused support that sought to maximise quality of life for both of them, was finally available from the hospice. This is just one example of how palliative care provided nuanced family focused response. Whilst palliative care is not a paragon of virtue in all cases, the good practice it does provide could inform a new model of care for substance use services. Sadly, in this case, opportunities to harness concerns for Lizzie’s wellbeing were not seized earlier as a means of building Bev’s motivation for controlling her alcohol use. Relying solely on self-referral into substance treatment (that the general public perceives to be abstinence-based) means that those who are not self-motivated to stop using are unlikely to access support. They never get a chance to *build* their motivation to use substances in a less harmful way, and their families may be left with the stark choice of accepting their substance use or separating from them.
- **What do we mean by ‘sustained control’?** Whenever people seeking to control their substance use have a relapse, it is crucial that they can: (1) determine whether they have experienced a minor, temporary setback or are at risk of sliding back to previous levels of problematic use, and (2) access timely support to *prevent* the re-emergence of dependence. In Barbara’s case, we see she was able to stop drinking alcohol for the sake of caring for her father. But she needed ongoing support to maintain her stability over the longer term, particularly through her bereavement. Barbara would have benefited from more help to develop her own understanding of the emotional triggers to her alcohol use, how to minimise risk of relapse and alternative coping strategies that she could employ. This insight would have helped her to exert greater control over her substance use and identify in a more timely way when she needed to seek external support. Without social care to help her address challenging life situations as they arose, Barbara was left struggling in isolation, relapsing into problematic alcohol use before accessing support. She spent much more time using alcohol to alleviate distress than would have been the case if long-term social care was

more readily available. Left isolated without any form of social care, Barbara ended up irreparably damaging her health.

- **Is the ability to maximise ‘health and wellbeing’ a necessary condition for long-term recovery?** Lots of people who use substances regularly have long-term health difficulties and multiple, complex support needs. Many of them will in part be using substances to suppress painful feelings. As such, if they try to reduce their reliance on substances, their mental wellbeing may actually deteriorate over the short-term. Whilst harm reduction, motivational interviewing and self-determined goals are at the core of many treatment interventions, we see in Rob’s story that until a life-shortening health condition triggered his move towards recovery from substance use, he was highly reluctant to approach health services for fear of being judged and discriminated against. Like many people who feel ashamed, guilty and want to avoid stigmatisation, he only accessed emergency healthcare when very close to death (Wright et al., 2017). An approach to recovery is needed that explicitly includes people whose physical and/or mental health is deteriorating. This is particularly crucial for the growing subgroup of older opioid users who are accessing substance treatment services (Beynon et al., 2010). Recovery-based policies need to include provision for people adapting to disability, chronic illness, mental ill health and possible premature mortality - whether that is caused by or unrelated to their substance use. Given that ageing and dying are inevitable experiences for us all, recognition that recovery should not be the sole preserve of people who are fit and healthy would be a much more inclusive and realistic approach.
- **Are there limits to the extent that people recovering from substance use can enjoy ‘participation in the rights, roles and responsibilities of society’?** Substance use policy is often couched in terms of responding to individual behaviour, invariably divorced from the relationships and social contexts within which people who use substances live their lives. The principles of palliative care on the other hand, place relationships and social contexts centrally within needs-led assessments. Palliative care recognises that people at end of life do not live in a vacuum but instead have rights, roles and responsibilities to others which need incorporating in assessments, planning and care provision. Notwithstanding the recognition of family relationships and social contexts within substance use treatment and mutual-aid, we argue that they need to be placed centrally through every stage of recovery work. With this in mind, we can critically consider how the vignettes highlight the following two aspects to the ‘rights, roles and responsibilities’ angle within long-term recovery:

Firstly, people whose personal relationships have been damaged by their substance use may need support to rebuild those roles and responsibilities, and to minimise the risk of wider family members developing or (continuing) unhealthy relationships with substances. Debates around recovery – particularly those emphasising the long-term view - need to put greater emphasis on work to repair personal relationships, undo harm and minimise substance problems among whole family networks. As Trevor’s vignettes reveals, the recovery process is navigated within an emotional and familial context. Despite many years of recovery, a combination of difficulties proved too much for Trevor and unresolved emotional difficulties (including his siblings’ own alcohol problems), made it difficult for his relatives to respond to his return to drinking. Recovery goals often include an emphasis on (re)building personal relationships and providing opportunities for meaningful connections with others.

The second point is that current conceptualisations of recovery do not sufficiently recognise the long-term negative impact of stigmatised identities upon people using substances, nor the extent to which these may impede their access to health and social care. Drawing on our research, despite deteriorating health and dire need for support, people at end of life often discussed feeling reluctant to access health and social care services. Like all of us, people in recovery have limited power to change other people's attitudes and behaviour towards them. Unfortunately, the people with negative attitudes can include some health and social care practitioners whose actions create huge barriers to accessing support for both people in active substance use and those in recovery (Ashby et al., 2018; Yarwood et al., 2018). Paul's story illuminates how his identity as an ex-drug user – even though that was eight years in the past - made it very difficult for him and his wife to ask for support as he became terminally ill. Indeed, in our research, hospice professionals disclosed reports of people with a history of substance use being denied medical treatment – particularly opioid painkillers - despite being in long-term recovery (Galvani et al., 2018). This gives just one example of how shared learning between palliative care and substance use services can enhance both fields of practice. Paul's vignette reveals that there is much more to 'recovering' than abstaining from substance use. It needs to include the idea of recovering an identity free from stigma and fear of discrimination by others. We argue therefore that regardless of how long a person has to live, recovery needs to include a focus on rebuilding a positive identity, free from fear of judgement and discrimination from health and social care practitioners. Can ideas about recovery include both the need for each person to adopt self-compassion for their own substance use history, as well as the confidence to challenge stigma and discrimination from others? It is difficult to envisage how these two goals could be achieved practically. But, it is nevertheless crucial that people can overcome feelings of shame arising from having had a substance problem, so that they feel confident to talk openly about their past and access health and social care without fear of being treated as second class citizens. Our research highlighted that in the last days of life many people with substance using histories are only too aware of the stigma they experienced over their lifetime and how their dying wishes are to not carry the 'spoiled identity' of the 'user' anymore regardless of where they sit within recovery definitions and interpretations (Ashby et al., 2018).

Our five vignettes highlight not only the precariousness of abstinence, but also its complex interplay with other aspects of life considered crucial to 'full recovery': such that physical or mental health may deteriorate, or that full participation in life may be compromised for the sake of control over substances. This brings us to consider whether it is possible to reconceptualise 'recovery' so that it can include all people using substances - however ill they are and however long they have left to live.

An alternative conceptualisation of recovery

Long-term recovery - particularly its suggested five year timeframe - is not a useful concept for people using substances who are approaching the end of their life. However, the experiences of those people, as well as insight from the palliative care sector, can offer ideas about how recovery could become a much more nuanced and ecologically-based concept. As described in the introduction, palliative care refers to the person-centred provision of psychological, social, spiritual and practical support that seeks to identify and meet the care needs of both the person who is dying and their family (NCPC, 2006). Ideally, palliative care is not something that starts when active treatment has ceased, but is introduced gradually alongside it, growing in prominence if other

treatment becomes unsuccessful. Thus it works well in supporting people experiencing a great deal of uncertainty in their lives; supporting them and their families to make the psychological and emotional adjustments needed as people become aware that they may be approaching the end of their life.

With this palliative care lens, we can be clear that the first recovery priority for people using substances who have chronic health problems needs to be maximising immediate wellbeing and quality of life. This must take precedence over and above cessation of substance use, particularly where someone's ability to manage their mental/emotional wellbeing may require maintenance or very slow reduction of substance use. The uncertain trajectory of trying to manage substance use – which often feature periods of controlled use followed by periods of relapse - mirrors the unpredictable health trajectory for many people with a terminal illness who will experience periods of feeling well against an overall background of deteriorating health.

The second (linked) priority is to recognise the centrality of relationships in everybody's wellbeing, and both the positive and negative effects that they play in substance use and long-term recovery. Again, the field of palliative care gives us clarity over the crucial importance of personal relationships to everyone's wellbeing. Recognition of the support needs of family members – both in terms of their role as carers, but also as individuals deserving assistance in their own right – is a way of bringing a more ecological perspective to ideas about recovery (Best, 2019). Although substance use services do provide social care alongside medical treatment, the balance between those two approaches may be enhanced by adopting a palliative care model whereby levels of social care and family support are constantly changed in response to evolving needs. Access to long-term social care that continues beyond cessation of any medical treatment and is provided to both the person using substances and their wider family, could help many people to achieve more sustainable control over their substance use.

Palliative care approaches can help people with chronic health problems and their families to cope better with these experiences of unpredictability, vulnerability and fluctuations in personal control.

What can substance use policy and practice learn from palliative/end of life care?

In underplaying the relational and emotional aspects of long-term wellbeing, UK drug and alcohol policy buttresses the idea of 'recovery' as an individual goal, overlooking the crucial social and emotional context for supporting that process (Best, 2019). Where substance use policy uses abstinence as the basis for judging 'successful completion' of treatment, this can lead to premature withdrawal of much-needed long-term support. A more holistic view of what it takes to achieve long-term wellbeing would allow the design and resourcing of treatment services to engage with a much broader group of people using substances and the social and relational contexts within which they live. Greater understanding of substance use over the whole life-course could enhance UK substance use policy and key concepts from the palliative care field (such as family-focused support) can help us to develop a more inclusive concept of recovery.

As long as substance use policies prioritise abstinence, they construct recovery as a binary notion of 'success' or 'failure'. For people using substances, this stark duality of recovery/failure can be counterproductive, because minor relapses after leaving treatment services are interpreted as 'failure'. Difficulties in maintaining abstinence can exacerbate feelings of self-blame and discouragement, strengthening personal justifications for continued use. By recognising the 'two-steps forward, one step back' pattern of developing control over substance use that is commonly

experienced, people are provided with more realistic and compassionate expectations of a recovery journey. This also means that family members and significant others have a more realistic understanding of the ebbs and flows of the recovery process. Using this insight as the basis from which to commission treatment services would result in much more tailored support for people seeking to achieve their own individual recovery over the long-term, enhanced by the support of those around them.

We need to develop substance use policies that prioritise provision of compassionate care to all people using alcohol/other drugs, and that recognise the relational context within which we all live and hope to thrive. We know from our research on end of life care about how much stigma people with drugs and alcohol problems face – even from health and social care practitioners (Witham et al., 2019). Even many years after ceasing to use substances, people can still be reluctant to approach health services for fear of being judged and discriminated against (Wright et al., 2017; Yarwood et al., 2018). Drug and alcohol services have a crucial health and social care role: not only to provide substance use treatment, but also to advocate with generic health and social care practitioners on behalf of their client group. This advocacy can foster recognition of the limited access to appropriate services facing most people with substance use problems.

In essence, we are arguing for a strong social justice basis to future substance use policy and practice, so that many more people with long-term support needs can access the care that they need. Our position can be summarised in the following recommendations for policy:

1. **Resource treatment services so that each person can receive long-term support to achieve a good quality of life** (irrespective of whether/how quickly they achieve abstinence). Palliative care seeks to provide holistic care and treatment for as long as the individual and their family or friends need it. For the substance use sector, this suggests that all statutory, voluntary sector and mutual aid support need the resources to allow them to respond to each individual's changing needs and the complexities of real life - especially the interplay between substance use, mental and physical health and the common, chronic relapsing nature of alcohol/other drug use.
2. **Provide long-term, whole-family social care and support** (with a definition of 'family' that allows each individual to identify the people who are most important to them). Like palliative care, substance use services need to be able to support family members in their own right (irrespective of whether their relative engages with treatment) and ensure that services are funded to provide practitioners with ongoing support for this responsibility and its emotional impact upon them.
3. **Identify and resource a systematic advocacy role for substance use services** (moving away from reliance on individual practitioners problem-solving with specific service users, towards a system-level change that seeks to eliminate the stigma and discrimination levelled at people who use substances and their families). In the palliative care field, Hospice UK and the Dying Matters programme both exist to raise national awareness of the needs of people approaching the end of their lives and lessen stigma and fear. Similarly, we argue that substance use services should be resourced and encouraged to challenge their own and other organisations' professional orthodoxies which do not work in the best interests of people using substances and their families. One key element of this is to ensure that practitioners are able to support each others'

emotional well-being through identifying, sharing and responding to both good and poor practice – to keep services constantly evolving to meet new challenges.

Conclusions

In this chapter we have reviewed ideas of recovery from the retrospective lived experiences of people approaching the end of their lives. The vignettes highlight how complexities in people's lives such as personal relationships, caring responsibilities, poor physical or mental health, changing social roles and long-term stigma all impacted upon their substance use. Moreover, it is clear that having had a problem with alcohol/other drug use casts a long shadow – such that even many years after recovery, people feel stigmatised and fearful about how others will treat them. This can include health and social care practitioners, whose negative attitudes and behaviour have serious ramifications for people who need support. Only by giving greater priority to developing positive interpersonal relationships, removing stigma and providing compassionate care, can policy and practice truly support people into recovery.

By contemplating the life-course of five people as shared at the end of their lives, we have been able to map their experiences onto key concepts within recovery debates. Our knowledge of palliative care has reinforced our ideas about the need for long-term social care for people with substance problems and their families. We raise a call to action for future substance use policies and practice to be designed in consideration of the winding trajectories of long-term recovery. One crucial element of this is listening to the voices of people with experience, placing them more centrally at the heart of policy and practice development. We hope this chapter has made a start on this. Policy and practice also need to explicitly address the breadth of emotional, relationship-based and anti-discriminatory support that people who use substances need in order to ensure equitable access to health and social care. Current UK substance use policies need revisiting to explicitly include people whose health is deteriorating (and who may be approaching the end of their life), for whom the current concept of 'recovery' seems quite irrelevant.

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Yarwood G., Wright S., Templeton L. and Galvani S. 2018 *End of life care for people with alcohol and other drug problems: Qualitative analysis of primary interviews with family members, friends and carers*. Manchester Metropolitan University. <https://endoflifecaresubstanceuse.com/4-families-perspectives/>

Resources and further reading

The End of Life Care research project has produced a range of policy and practice-related resources, including: good practice guidance, policy standards, a website with all the research reports and a Facebook group for practitioners working across the fields of palliative care and substance use support:

Galvani S., Wright S. and Witham G. 2019 *Supporting people with substance problems at end of life (Good Practice Guidance)* Manchester Metropolitan University. <https://endoflifecaresubstanceuse.com/practice/>

Galvani S. and Wright S. 2019 *Palliative and End of Life Care for People with Alcohol and Drug Problems (Policy Standards)*. Manchester Metropolitan University. <https://endoflifecaresubstanceuse.files.wordpress.com/2019/05/policy-standards-su-and-eolc-may-2019.pdf>

Website: <https://endoflifecaresubstanceuse.com/>

Facebook group: End of Life Care and Substance Use
<https://www.facebook.com/groups/457796088496347/>