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## **Seeing the common ground: family and practitioner caregivers' perspectives of palliative care for people using substances**

Sam Wright, Sarah Galvani, Gemma Yarwood

### **Introduction**

This chapter examines caregiving similarities and tensions between families and friends<sup>i</sup> supporting someone who uses substances<sup>ii</sup> and has palliative care<sup>iii</sup> needs and health and social care practitioners. People who use substances and are approaching the end of life tend to present late to healthcare services (Ashby et al., 2018) resulting in family and friends providing the caregiving role. Typically, the person's health trajectory is unpredictable due to multiple health conditions. They may not recognise the full extent of their symptoms, partly because their substance use can mask how ill they are. They may also be reluctant to engage with services. This means that they, their family carers, and the health and social care practitioners working with them, have very little time to forge the working relationships that will help them to achieve a dignified death.

Palliative care research and practice recognise the importance of families and practitioners communicating effectively to bring about good end-of-life care, whilst also acknowledging the challenges of working together (Leadership Alliance for the Care of Dying People, 2014; National Palliative and End-of-life care Partnership, 2015; Standing et al., 2020). Substance use adds yet more complications, not least the long-term impact of the emotional strain that many family members experience when living with, or caring for, someone using substances, including the prospect that their loved one will die unexpectedly or prematurely

(Valentine et al., 2018; Yarwood et al., 2018). The strain family members face are mirrored in the heightened levels of practitioner concern over potential challenging behaviours from both the person using substances and/or substance using friends and family (Galvani et al., 2018). This already complex combination of factors can be further exacerbated by professional uncertainty about how to treat someone using substances at the end of life.

Reflecting silos in policy, practice and academic enquiry (Galvani, 2018; Galvani et al., 2019), research typically focuses on *either* substance use or palliative care. However, combining knowledge about substance use and palliative care is at the heart of our research and provided inspiration for this book. In developing this chapter, and in conversations between ourselves as authors, we realised that addressing family experiences singularly would articulate only one side of the story and risked alienating practitioners by ignoring their viewpoints. Our aim therefore is to uncover the ‘middle ground’ where the shared priorities of families and practitioners caring for someone with both substance use and palliative care support needs can be articulated. Hopefully this is one step towards promoting more compassionate understanding and, as a result, greater collaborative care.

In this chapter, we draw on qualitative data from three strands of our mixed methods end-of-life care and substance use study (Galvani, 2018) to discuss how differing perspectives can compromise care. We explore how poor (or absent) communication can lead to polarised perspectives between practitioners and family members and provide some insights into the common ground between them to offer a more helpful reconstruction of that ‘social reality’. By unpicking the separate standpoints between families and

practitioners in this way, we offer an alternative framing to show how differing priorities and needs can be better conjoined.

*It is important to note that whilst our research gathered experiences from practitioners working in hospices and substance use teams, most of the families' criticisms of care were based on their experiences of primary and acute care. This is an area for future research and practice improvement.*

### **The study and participants**

Like the rest of this section, this chapter draws on data from a programme of research designed to consolidate and extend the limited existing knowledge about end-of-life care for people using substances (Galvani, 2018). This chapter presents findings from three qualitative strands of the study:

- i) 18 family members currently or previously providing care for relatives who used substances and were approaching the end of their lives;
- ii) 53 health and social care practitioners working in hospices or substance use teams; and
- iii) 20 key informants (policy makers and practitioners working in this specialised field).

Interviews with family caregivers sought to explore both how they experienced their relative's end of life, and the extent to which services recognised or responded to the whole family's needs. The interviews with practitioners and key informants also sought to elicit

examples of good practice as well as the challenges faced when caring for people with both support needs.

### **The emotional strain of caring for people using substances at end of life**

For many families where a relative has a life-shortening condition, relationships may be under strain both before diagnosis and during their subsequent care, challenging simplistic notions of family as a mutually sustaining and supportive environment (Monroe and Oliviere, 2008). But where the person who is dying also uses substances, this stress is likely to add to years of prior emotional strain, including anticipatory grief (over loss of intimacy with their relative), as well anxiety over their possible premature death (Da Silve et al., 2007; Oreo and Ozgul, 2007). Many of the family interviewees described years of offering extensive care and support in response to their relative's substance use:

It's been horrific for everyone involved. For all of us...it's 14 years of daily care, which is a massive impact on everyone.... I haven't been on holiday for ten years, I don't think my mum's been for like 16 or something. So it's very hard. It affects everyone... Basically, me and my mum were his carers for the last 14 years and it's not financially viable. It makes you very depressed sometimes. It's very tiring. It's a big responsibility and I don't think you should have to deal with [it alone].

Sister, Brother died alone at home

Whilst each family had a unique history, they commonly described the enormous impact, stress and multiple disadvantages that they had experienced over a prolonged period of

time caring for a relative who used substances. This caused direct and indirect harm to their wellbeing as individuals and families. Some practitioners acknowledged this emotional toll, discussing the years of strain and care prior to the palliative care diagnosis:

The family that are around will have had ... a bad time with them [the dying relative] over the years and quite often - through guilt - will continue to look after them. But will have been treated quite badly.

Key Informant, Frontline HSCP

Understandably, family members could feel extremely frustrated and distressed that their relative was dying, particularly if there was a direct link between their substance use and their premature death. Many practitioners understood and empathised with the longstanding emotional difficulties families were undergoing:

When you speak to those families, families themselves can get angry, because they feel that this person has done it to themselves.

Hospice professional - focus group

Some health and social care practitioners we interviewed were aware of the support needs of family members - even though they were not in a position to provide it:

There is a massive need for them to get psychological support, to actually deal with it...there's limited availability in the area, we don't have ... psychological support. So it's us who supports them to look after [their relative] and it can be very difficult because there's two needy people there who are needing access to support.

Frontline health and social care practitioner

However, practitioners also felt the emotional strain even among those who knew the person was very ill or dying:

For all of us, somebody dying, we're at risk of feeling a bit of a failure really and I'm not sure that we've totally yet got to the way of looking at how we can think about a good death. ... When you're in a generic service and somebody dies, you think, "Oh my God." Either: "What could we have done better?" Or: "If only he'd stopped drinking." ... I don't think that there's a lot of preparation as staff that we have for these situations. Let alone supporting a client who's in this predicament.

Substance use professional - interviewee

The biggest thing ... I'm trying to learn [is that] things aren't always..., you can't always totally resolve [patients' problems] in the end.

Hospice professional - focus group

While different for each individual, this emotional impact when a person dies is one area of mutual experience between family and practitioner caregivers:

**Common ground 1:** While the sense of loss is often greater among family members, there is nevertheless a shared experience of sadness between family and practitioners when the person they care for dies. This is often accompanied by some self-questioning of whether more could have been done to delay death – meaning that both family and practitioners would benefit from emotional support and an opportunity to air their frustrations and anxieties.

#### **Poor communication of palliative care need**

For many family members, it had taken a number of years, multiple symptoms, and numerous GP or hospital appointments before the severity of their loved one's condition was recognised. Even then, medical professionals often had not explicitly communicated that their relative was approaching the end of their life:

We got to a point where he did start to deteriorate and we noticed he was [be]coming ill...nothing was diagnosed for sure...and then we noticed the yellowing of his skin and his eyes and this was where he kept saying, 'I feel so terrible'

Nephew, Uncle died in hospital

Lack of explicit identification of a life-shortening health condition meant that relatives were rarely able to access palliative care and the family members' own support needs were



usually unacknowledged. Among the people participating in our research, referral to palliative care was rare. One example was a young man (the brother of the interviewee), who had stage four kidney failure and was on the transplant list. Not only was his health deteriorating, but his situation was clearly complex: he had learning difficulties, was not managing his diabetes well, had chronic pain, was experiencing depression and also using substances:

We weren't signposted to anything decent. I'm going to say it's a very niche thing, but there must be so many people suffering from the same type of things in this area. Sister, Brother died alone at home

Aside from the historical frustration and strained relationships that can exist within families where a member uses substances, there can be distressing physical and mental health symptoms as the person's health deteriorates. Practitioners were conflicted over the extent to which they should explicitly warn families about potential symptoms or manifestations of their relative's illness, wanting to prepare them for distressing situations, whilst not exacerbating their anxiety over what their loved one might face. Getting the balance right will inevitably be a difficult task. However, it is important that practitioners at least start conversations with family members about the challenges that a substance-related death may entail, sensitively recognising the added complexity and that distress it can bring for family.

The need for family members to have a clear diagnosis – even if that includes uncertainty over the prognosis – is clear. Specialist palliative care practitioners could also help families

by supporting effective communication between them and their relative about their illness and their wishes for the end of their lives. They could also speak to the family about what palliative care can offer, and how the person's substance use may or may not influence the care provided.

Substance use practitioners faced similar challenges in understanding someone's diagnosis and prognosis. They spoke of the fluctuating condition of someone's health that mimicked, and was exacerbated by, their changing patterns of substance use. It made 'predicting' end of life and tailoring care accordingly, particularly difficult:

...the cancer things are quite predictable, you can almost see where things are. But with the organic deaths, it's this lumpy bumpy graph that you don't know where you are from one minute to the next...

Substance use practitioner focus group

Once client permission to share information is given, practitioners can find family members' insights to be helpful in determining the person's health status and planning for their care:

...because you're going to have clients that obviously sit down and go, "Yeah, yeah I'm fine. I'm fine. Yeah, nothing wrong with me, I'm fine." And then, when you talk to the family members they'll say, "Well, actually they had a really bad week last week and they was really down." And then you can talk to them again the next time you see them.

Substance use professional - interviewee

**Common ground 2:** The combination of substance use and complex health conditions can make prognosis unpredictable but both practitioners and families need clear communication to facilitate their role in caregiving. Practitioners have a delicate balancing act of trying to share helpful information whilst not overloading the family with distressing details. This necessitates building rapport from an early stage - to allow everyone to work towards a good and dignified death.

### **Overcoming stereotypes and challenging stigma**

Unfortunately, many people's previous attempts to access primary and acute health services – either as someone using substances or their family carer - were often poor, featuring experiences of being stigmatised and dismissed. This led to a quite natural wariness towards services. One female ex-partner described how her previous experiences of discrimination (when she had been a drug user) and negative interactions with a range of health and social care practitioners had left her mistrustful of services following her ex-partner's death. She reflects on whether, in hindsight, trying to explain more about their drug using histories might have brought about a more understanding response from the health practitioners:

Maybe I should have tried to get them [district nurses] to understand. But I think for me, my barriers were coming up more and more and because - I think it's like anything: if somebody starts to attack you, I don't so much usually attack back, now I just tend to go: "Oh fuck you." And put barriers up and just carry on as best as possible. But I do agree, maybe if I had

explained more of, “It’s really difficult because emotionally we haven’t grown up and we struggle with our emotions.” That probably would have made a big difference. But I do think as addicts, we get so pissed off having to explain ourselves ... .

Female ex-partner, Former partner died at home

This sense that she should perhaps have ‘explained more’ reveals how communication barriers between practitioners and families can cause substantial difficulties: solidifying resentments about stigmatised identities and past negative service experiences.

Negative stereotypes about people ‘addicted’ to substances can also influence perceptions of their families and close friends, with outsiders assuming that they are implicated in, or to blame for, their relative’s substance use (Guy 2004; Guy and Holloway 2007; Chapple et al., 2015). Many families had experienced social isolation and an associated lack of support because of their relative’s substance use. Sadly, several of them reported prejudiced attitudes from some health practitioners within primary and acute healthcare settings – resulting in both poor treatment for their relative and an absence of emotional support for them. For example, at one point when the family of a man dying from liver failure suggested to hospital staff that their loved one needed to be in a hospice, the response they received was: “There’s nothing we can do about that.” One of the family members was later told by a nurse to provide personal care to their loved one themselves, because staff were too busy. He told us:

I changed the bed and I bagged everything up, I got these wipes and [the nurse] said, 'If you're going to make [the bed], at least make it properly.'  
And I said: 'It's not my fucking job'

Nephew, Uncle died in hospital

This family's experience reveals how negative practitioner attitudes towards people who use substances can 'spill over' into deprioritising their care and actual neglect: revealing how crucial it is to provide staff with training and challenge any discriminatory beliefs (Galvani and Wright, 2019). The family also highlighted the importance of compassionate approaches to supporting carers:

Why did they always have a stern, cold exterior to everything that they said? Whenever you spoke to them, it was so abrupt and there was no feeling. There was nothing there ... they should at least empathise with the family.

Nephew, Uncle died in hospital

While any family could have experienced poor, uncompassionate professional care, interviewees believed that their experiences had been based in negative practitioner judgments about their relative's substance use. Another research participant described how carers coming into her ex-partner's house in the last months of his life were overly suspicious, expecting a high-risk environment:

It's not like they were walking to a house with needles all over the floor; or we were threatening them or smashed out of our faces. I wasn't using anymore. Even when I was using, I wasn't like that. I still had a really clean house, lived in a completely normal life.

Female Ex-partner, Partner died at home

Some family members had realised that they needed to instil boundaries to the care they provided – to prevent the emotional burden they were facing from damaging their own well-being. Unfortunately, this could lead to practitioners misinterpreting these emotional boundaries as suggesting an uncaring or neglectful attitude from them. One interviewee described her feeling of being stigmatised by a nurse who was judgmental of her limiting her contact with her father – a decision she felt she had to take to protect her own mental health. Similarly, this son felt judged initially by nursing staff when he was finally able to persuade his father to attend hospital:

We took him to hospital and because of the state that he was in....they took photographs of his legs...I also was a little bit, well, quite angry because there was some suggestion that I had completely neglected him. That I had just left him there to rot at home...I understand it on a very basic level. But obviously they didn't know the history... it's also very important to establish all the facts and the situation before laying blame as it were.

Son, Father died in hospital

There were, in counterbalance, numerous examples of good care – typically from hospices and substance use services. One family was particularly effusive in their praise of a peer volunteer from an alcohol service who had supported them:

[The alcohol service] are the only people that have been an absolute rock to this family since [relative's] passing. [Volunteer], I couldn't thank him enough. I will be eternally grateful to [volunteer] for what he's done...from the word go when they first come here, they put themselves out that much to do things for [relative and us]. They took us both in like family and helped us right the way through... they've provided aftercare to the family that have been bereaved and they need to be recognised for that.

Family, Relative died in hospital

**Common ground 3:** A greater mutual understanding of the stress and strain of the caregiving role on the family members might lessen judgemental attitudes. This can be achieved through empathetic and compassionate care, active listening skills and explicit acknowledgement of the anger, pain and need for psychological support that often accompanies caring for people who use substances.

### **Providing palliative care when family carers use substances**

It is important to be realistic in recognising that, in their role as informal carers, all families have the potential to either help professional care by supporting their relative effectively or, conversely, negatively impact both their relative and the practitioners working with them.

This is why practitioners need the knowledge and skills to be able to forge good, trusting relationships with families whenever possible.

Practitioners in our research spoke of the challenges that substance using family members presented to the care of their relative. Practitioners shared their concerns about how family carers who used substances might impede delivery of a patient's palliative care, particularly in the home. From a hospice perspective, there were concerns about the safety of take-home prescription medicines for people approaching end of life when other people who used substances lived, or had access to, their home. Concerns related not just to the diversion of drugs into the community, but also the safety of everyone in the home if substance use was not managed carefully. One hospice practitioner related the story of a young intravenous drug user living with an elderly person, where neither were coping with the situation:

So, the police come. Then an ambulance comes. And I've had to literally back out and do like an incident to Social Services for safeguarding. They came back, and actually he'd been putting dirty needles in his father's commode and one of the ambulance men that were moving him nearly got a needlestick [injury].

Hospice professional - focus group

Other challenges included family members bringing substances into the relative's home or hospice or being intoxicated themselves. Practitioners spoke of the medical risks posed for the person in their care, putting them in the position of needing to 'challenge' the family



members – arguably not the best basis upon which to build good relationships. Indeed, some hospice staff working in peoples’ homes were concerned about the aggression they could face from family members who were using substances. Hospice staff talked about the difficult ethical position they faced when working in homes where illicit substances were used: questioning what they could do and how far they could ‘step in’ to raise the issue with the family members concerned. A hospice community nurse visiting someone at home described how they had explained to a family about the need to stop people visiting who were providing illicit drugs to their dying relative, as it negated the care they provided:

It was also [about] speaking to the family and saying: “Look, if you know who these people are, you need to speak to them and stop them from coming because this is not helping him and it doesn't help us.”

Hospice professional - focus group

Practitioners wanted people to be open about the potential for medications to be stolen, so that appropriate measures could be put in place. Those safety measures might include the use of a lock box or arrangements between social and health care practitioners for only one prescriber rather than several from different services. There was also concern about the management of ‘stockpiled’ drugs that people no longer needed – a particular concern was that family members who used substances might be tempted to use the medications prescribed for their relative as a coping mechanism in their bereavement. There was, however, a reflection that many nurses’ fears about risks related to drug use may be disproportionate – potentially leading them to put a lock box in place even if a family member had not used drugs for many years and currently lived hundreds of miles away.

Relatives visiting hospices in an intoxicated state could also be challenging for staff. In one focus group, participants described having to put intoxicated relatives into a taxi to make their way home.

Other examples of challenges from family members included:

- causing disruption in hospital and being physically and verbally aggressive towards staff
- disagreement within families and with hospital staff about their loved one's care
- airing views that the person had brought their problems on themselves
- wanting the focus to be on them and their suffering
- blaming professionals for their loved one's condition and death.

**Common ground 4:** Family members who use substances are not all the same and are likely to need support in their own right. Some of them will facilitate good care, others may hinder it (unintentionally or otherwise). Accepting that both family and professional caregivers can help or hinder the care each other provides could help to build a stronger mutual sense of interdependence. Equally importantly, this will keep the best interests of the person at end of life at the heart of the care plan.

### **Post-death – the need for specialist support**

The provision of ongoing support for bereaved families is important. It can be particularly difficult for families if a death has to be referred for a post-mortem examination or to a coroner (Galvani et al., 2018; Valentine et al., 2018). At such times, the family may be

anxious that they have done something wrong or that someone has either overprescribed or administered too much medication. Police involvement only further escalates tensions and anxieties.

The frustration and anger families often feel about a relative's substance use during their lives is accompanied by shame and stigma for family members too. This can continue post-death, taking a particularly destructive toll on family members (Chapple et al. 2015), partly because of the premature and often avoidable nature of the death (Da Silve et al. 2007; Degenhardt et al. 2014; Nambiar et al. 2015). Feelings of shame, guilt and stigma heighten the pain of bereavement (Chapple et al. 2015; Feigelman et al. 2011). Therefore, it is not surprising that some practitioners had encountered families who were very reluctant for their loved one's alcohol or drug use to be named as the cause of death on their death certificate:

Families do not like alcoholic liver disease, so they do not want that putting on the death certificate. So there's pressure on doctors who've got a family that's recently bereaved.

KI interviewee - Other Professional

In summary, our data revealed both positive and negative relationships between social and health care practitioners and family members. Both groups have such an important role to play in supporting people to have the best death possible, but where substance use is part of the picture, suspicion and distrust looms large for both parties. Substance use within the family can undermine professional care and pose risks to staff safety. Yet practitioners need

to not operate on the mistrustful assumptions that focus solely on risk-avoidance and are communicated defensively.

**Common ground 5:** Practitioner assumptions about substance use can easily lead to families feeling stigmatised, leaving a legacy of negative feelings about asking for support in the future. A better approach that ensures good care for the person approaching end of life whilst also supporting both family members and practitioners into bereavement is needed. Effective communication that exudes compassion is the cornerstone to such good palliative practice.

## **Discussion**

Whilst families share many experiences and support needs with other groups of carers, they also face unique difficulties (Hudson and Payne, 2008) not least in having to continuously review health and social care needs and make adaptations as their relative's health declines (NCPC, 2012; Payne and EAPC Taskforce, 2010). As such, they may be involved in discussing care priorities with their relative, helping them to make choices, and supporting them to communicate their end of life wishes. Other families, perhaps estranged from their relative through choice or circumstance, may not have the capacity to provide palliative or end-of-life care.

In either case, our research suggests support for family members is limited at best. Poor communication between family members and health and social care practitioners was a key part of the problem, underpinned by perceived and actual negative attitudes from some practitioners. Improving care for both people who use substances and their family carers

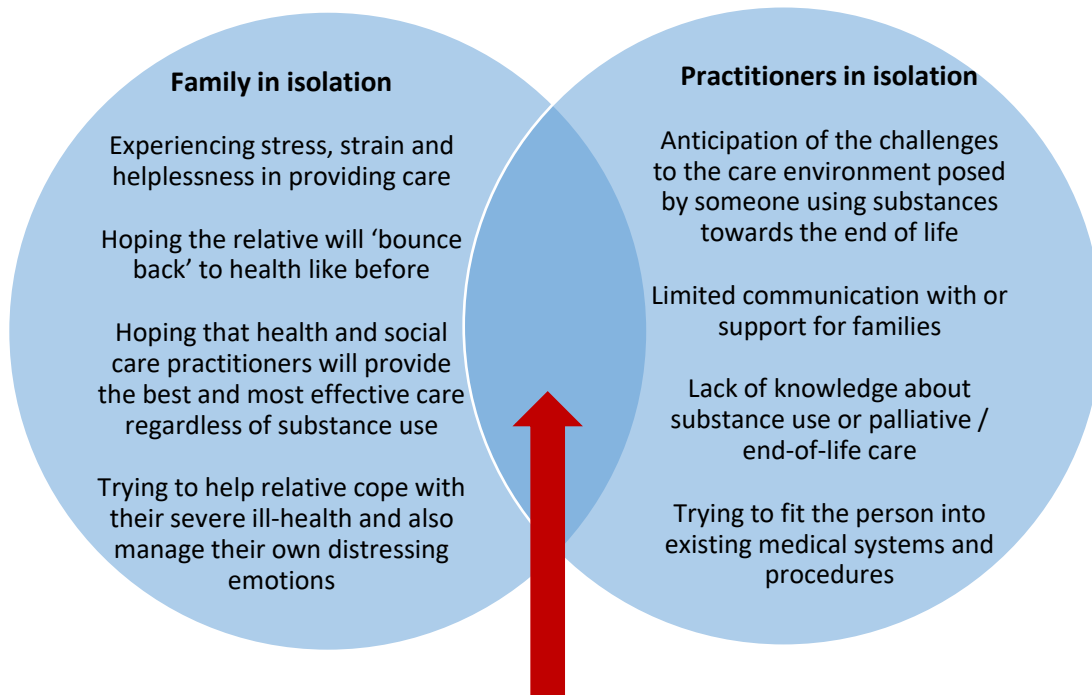
requires the development of trusting relationships between practitioners and the family. Even those family members who may hinder care may do so without malice. For example, substance use may be a significant part of their life and may be a shared experience and space with their relative. They may now suddenly feel dislocated and disrupted from their shared normality and routines at the end of life.

Without good formal support, the burden of palliative care places heavy demands on family caregivers, often to the detriment of their own wellbeing (Wittenberg et al., 2017). Family caregiver support needs can include psychological and emotional needs; their own physical ill health; insufficient symptom management skills; limited respite time; deteriorating family circumstances; financial difficulties and inadequate health or social care input (Hudson, 2004; Payne and European Association for Palliative Care Taskforce, 2010). There is considerable value, therefore, in health and social care practitioners providing timely, tailored support to family carers (Mathieson et al., 2020). An important component of this is provision of the information and skills training necessary to undertake physical nursing tasks (Bee et al., 2009; Connolly and Milligan, 2014). By increasing family carers' mastery of care tasks, as well as their confidence to do them, they are likely to find it easier to accept the practical support that enables them to provide care – although they still may not recognise the extent to which they need emotional help for themselves (Grande et al., 2009).

Yet one substantial constraint is that families and practitioners involved in end-of-life care are often brought together in crisis, with only a short period of time to facilitate a peaceful and dignified death for the person they both care for. For them to work closely together, practitioners and families need to be able to openly communicate their concerns, share

knowledge about the person's condition and resolve any challenges. This makes it all the more crucial that practitioners are able to reflect on, and counter, any personal bias they may hold against people who use substances and their social networks. This can be achieved through effective use of supervision, continuing professional development and honest conversation about feelings with peers. There may well be pre-existing, challenging, family dynamics (Young Bushfield & De Ford, 2010), and families may have different patterns of informal social support than those that palliative care practitioners are used to working with. Family relationships will have been constructed and negotiated over many years, whereas the practitioner relationship will be new - bringing external observations and judgements to what is often a sensitive situation. Any negative assumptions can lead families and practitioners separately to perceive themselves 'at odds' with the other party, and to position themselves in opposition to the other. Whereas, if we can encourage both to acknowledge the commonalities between them, they can hopefully recognise what needs to be communicated to each other and work together collaboratively. It is, therefore, imperative that families and practitioners cooperate to break down pre-existing assumptions and pave the way to more effective communication and compassionate care.

Diagram 1 (below) offers a simple summary of the positions that health and social care practitioners and families may take if operating alone - as well as clarifying the 'middle ground' where families and practitioners share common concerns and goals.



**Common ground: weaving perspectives together**

- Shared uncertainty over health prognosis, substance use and related behaviours
  - Shared concern about 'doing the wrong thing' and being judged
- Shared desire to provide person with a dignified death and best possible care for them and their families
  - Shared sense of loss and need for emotional support after death

*Diagram 1. Common ground between practitioners and family carers*

Palliative care at its most beneficial is compassionate, collaborative, coordinated and tailored to individual need. It facilitates the delivery of responsive, needs-led care that supports both the patient and the family in its own right. However, in the absence of open communication from the individual or their family members about the person's substance use, practitioners will struggle to meet their support needs. This can be catastrophic to

families: compounding existing family tensions surrounding their relative's substance use as they die, and potentially deepening the trauma of seeing their relative die with little or no formal support (Yarwood et al., 2018). The common ground identified here in the midst of these complex and constructed perspectives offers a basis on which to develop mutual understanding of, and better support for, family and professional caregivers.

## **Conclusion**

Effective and compassionate communication is the foundation for delivering mutual understanding of the needs of family members, their dying relative and the practitioners who provide palliative care. Building good, trusting relationships between informal and professional carers can support the identification and understanding of problems, decision-making and problem-solving. However, it must be done from a non-judgemental position about a person's substance use, and an understanding of the possible feeling of mistrust for services held by people who uses substances and their families. The family and practitioner experiences presented in this chapter provide powerful illustrations of how effective communication and shared values of care need to be at centre of relationships between family and formal caregivers. For practitioners, good communication needs to be shored up by education, training, ongoing support and genuine, mutual respect. For family members, clarity from practitioners about what will help and/or hinder their relative's care, can pave the way to recognising the shared goal of providing the best possible care and most peaceful and dignified death for their relative.



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<sup>i</sup> Hereafter 'family'.

<sup>ii</sup> Including both current and past use of alcohol and other drugs.

<sup>iii</sup> For the purpose of this chapter, we use palliative care as an umbrella term to include end-of-life care.