





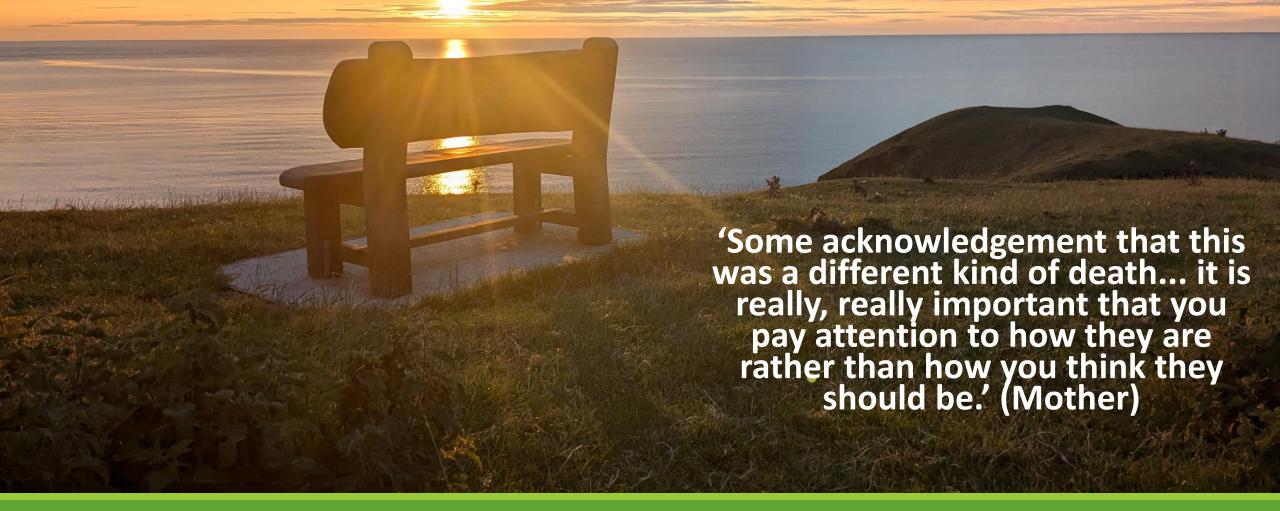
About Me

- Social sciences researcher ~30yrs.
- NHS, academic sector, freelance.
- •Primary focus on substance use (& related issues) & families.
- •UK & international research; work widely published.
- •Helped establish AFINet in 2013: now 900+ members from 55+ countries https://afinetwork.info/

Overview of webinar

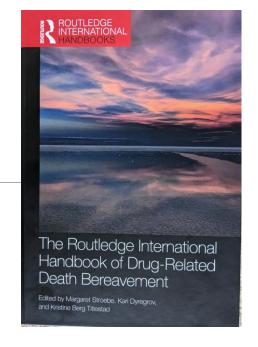
- 1. Understanding bereavement through substance use.
- 2. Voicing Loss: bereaved people's experiences of the coroner service (incl. alcohol, drugs, gambling).
- 3. Implications for support for those bereaved by substance use/gambling:
 - Good practice guidelines.
 - 5-Step Method adapted for bereavement.
 - Supporting Loss project.

Understanding & responding to bereavement through substance use



Substance-use related deaths

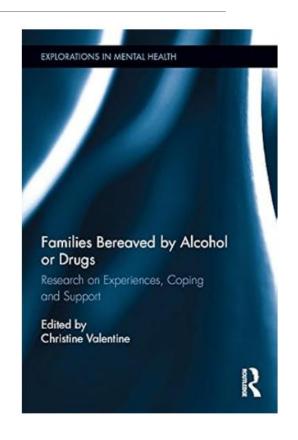
- •Global prevalence, social & public health impacts.
- •Annually (England & Wales), ~10,000 alcohol-related & 5,000+ drug-related deaths (ONS).
- •Increasing understanding of what is different, unique, nuanced about this bereavement.
- •Implications for help-seeking & support yet, remains a largely ignored & hidden issue, with little consideration of the experiences & needs of those bereaved.



'One of the most difficult, most neglected, most rapidly increasing causes of death & types of bereavement... the impact on those surviving... has emerged as particularly complex & impactful' (Stroebe, Dyregov & Titlestad, 2024)

Understanding bereavement through substance use project

- N=106 interviews across England & Scotland.
- Professional focus groups.
- Working group chaired by Peter Cartwright
 - good practice guidelines.
- Multiple publications.



Understanding adults bereaved through substance use

- Emotional roller coaster.
- Lack of understanding by the social world.
- Meaning making.

(Titlestad et al., 2019, systematic review)

- Living with the possibility of death.
- Official processes.
- Stigma (actual & perceived).
- •Grief challenges (including disenfranchised grief).
- Support often poor, unhelpful, unkind responses from numerous professional & other sources.

(Templeton et al., 2016, research)

- Nature of the drug (substance) use.
- Unfinished business associated with the person who died & their drug use.
- Circumstances of the death.
- Stigma, disenfranchised grief & lack of social support.
- Coping with specific difficulties.

(Cartwright, 2024, research & clinical experience)

Living with the possibility of death

'The day I found out he was on drugs was the day that part of me died. And the day I realised that he would probably not make it....the progressive illness of addiction had really taken hold. There was really no hope any more, he was definitely dying and it would just be a matter of time.' (Mother)

Official processes

'The police weren't brilliant, the way they told my mum. She has a post-office [and they told her] in the shop with customers there.' (Sister)

'They [detectives] were very nice. I didn't feel they were being judgemental or anything towards me or [him], they were very sorry about [his] death.'

(Mother)

Stigma

'I've always talked about [my son's] drug problem, I have never shoved it under the carpet....it's in our life, it's part of who we are now.' (Father)

'My aunt didn't want to tell anyone how my mum died, she wanted to say that she'd had a heart attack, she's so ashamed.' (Daughter)

Grief

'When she first died it was a relief that that was over...it is difficult because you feel guilty for feeling like that...you think it's wrong to have feelings like that and therefore you feel that perhaps you don't have the right to grieve and be so upset...it took me a while to realise that I had the right to be upset.'

(Daughter)

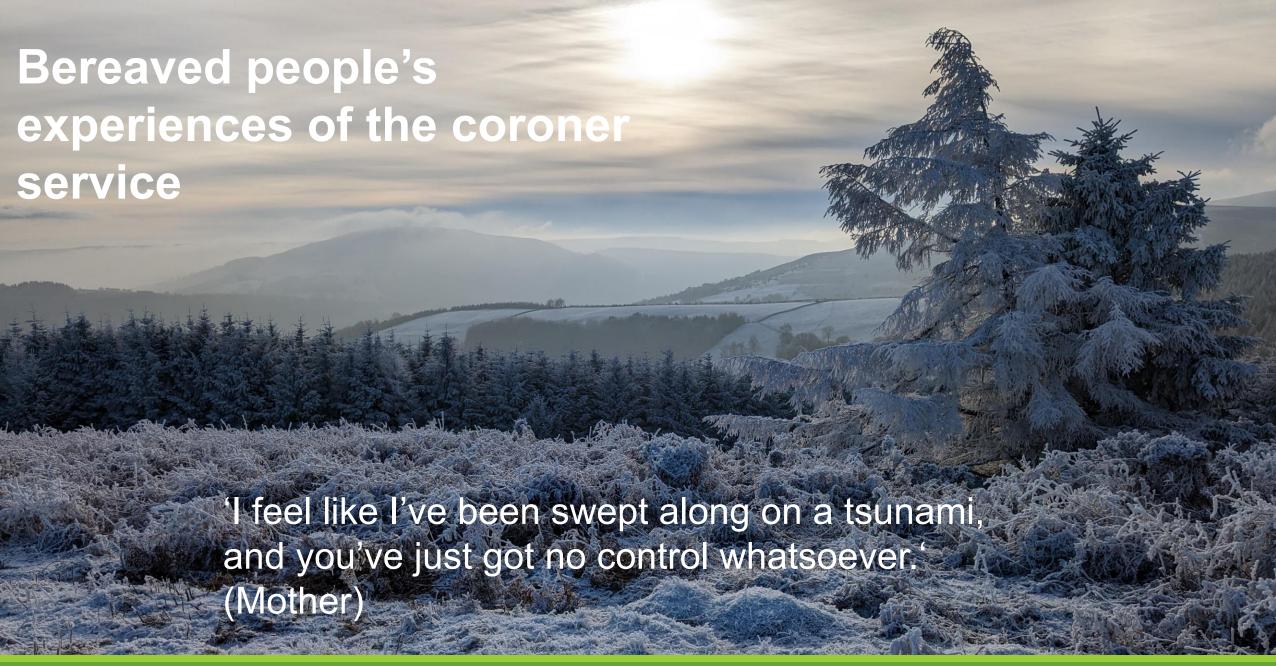
'There are so many bad memories that you actually forget any good memories....it's twice as bad when somebody is an addict of some kind.' (Mother)

Support

'I noticed how lost the family were after this death.

And we just didn't have any support.' (Niece)

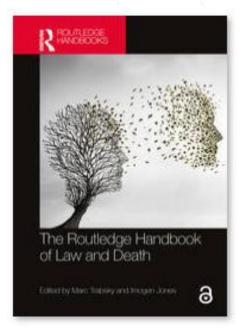
'If it's a murder then there would be a family liaison officer, if it was an accident then there might be victim support. But there was nothing at all. Nobody who made contact or that I was put in contact with. And somehow you don't fit anywhere either...you feel like you fall between everything.' (Mother)



Voicing Loss project

- General aspiration for bereaved to be 'at the heart' of coroner service (C&J Act 2009 in 2013) reiterated by govt & successive chief coroners. 'Interested persons', such as families, have certain rights in coroner's investigation & inquest.
- Explored bereaved people's expectations & experiences of the coroner process & their involvement in it; considered how inclusion & involvement could be improved.
- •Interviews with wide-ranging recruitment.





Who we talked to

89 bereaved people

- Almost half: mothers. Others: fathers, siblings, adult children, spouses/partners, friends, cousin, aunt.
- Deceased aged 6-83 at time of death.
- Range of deaths & circumstances incl. drug- & gambling-related.
- Diversity in time between death & inquest, & length of inquest.
- Approx 40%: conclusion of suicide;
 ~fifth narrative conclusion.
- About a quarter included PFD[s]; small number of Article 2/jury inquests.



We also interviewed:

- 17 coroners & 21 coroners' officers/staff.
- 20 lawyers representing families & state organisations.
- 12 staff & volunteers from the Coroners' Courts Support Service.
- 12 other 'key informants'.
- 19 individuals who have given evidence in a professional capacity.

Bereaved respondents' experiences

Some positive experiences: kind, compassionate treatment; sense of death being properly scrutinised; respect & inclusion of personhood of the deceased; resultant feelings of 'catharsis', 'peace', 'relief'.

'The whole thing was dignified, sensitive, inclusive – beautifully managed by the coroner... She was very clear, courteous, very unofficious. She made sure I was able to ask my question. She asked me if I had any other questions. It was just dignified. It wasn't frightening.' (Partner)

'For the whole [hearing, my daughter's photograph] was up front and centre, just in front of the coroner... I can't overestimate the positive impact that had for us, as a family, to really feel that she was part of the proceedings... Just to remind everybody that this name on the documents that they're talking about was a person, and a young person, who had funny-coloured hair.' (Mother)

Negative experiences more common

Lack of information & poor communication; insensitive, disrespectful, rude treatment; ignored & silenced; inconsiderate, disrespectful or absent representation of the deceased; did not get hoped for answers with missed opportunities for learning from deaths.

'The coroner never spoke directly to me... it just felt like a process was happening. I was present, but I wasn't really part of it.' (Daughter)

'My brother had no face, no name, no nothing. He was just called 'the deceased'. And it upsets me that all these parties involved – it suits some of them to keep calling him like that, a faceless, nameless human – not even a human.' (Sister) '[The coroner] kept on saying, 'Sorry for your loss,' and she had the biggest grin... I just kept on thinking, 'Why do you keep saying that and your face isn't saying it?' ... It's personal to you, but they're just totally detached from the whole thing.' (Mother)

Impacts of poor experiences

'Justice' for deceased not achieved & those with responsibility for the death not held to account; distress & re-traumatisation during hearings; deep mistrust in system; long-lasting emotional toll & delayed or complex grieving.

'It takes a while for you to realise it's not about justice. You get the feeling that this is mostly for the lawyers and the coroner ... It's not for the family. It's just for the system or whoever'. (Mother)

'Afterwards I cried for such a long time, because it was a soul-destroying experience... We lacked the knowledge and understanding... we were totally intimidated by the coroner, by the lawyers, by the whole process... Apart from [our son] dying, I think it's the most traumatic experience we've gone through.' (Mother)

Substance-use & gambling-related deaths

Actual or perceived stigma within & outside of the coroner's court; gambling not considered by coroners, scope is too narrow; issues not named so data & potential for learning are absent; media intrusion & nature of reporting.

'It was just another student to him, it was another death, it was another young person who took drugs... I felt there was no respect. I felt that [Name] did deserve respect, because he was a human being, but he had had his struggles... As soon as you say the word 'drugs' people judge.'

'I suppose I thought there might be some sort of closure, but it didn't close anything up... I suppose I wanted the gambling companies to be mentioned more. I suppose I wanted to know what his feelings were in the last day... and piece together what happened.' 'Other people will career down this path, will lose their lives, and still nothing will be done about it because the coroners are not looking to even tick a box that says causation... process takes over and nobody's interested in the human cost at the end of it... I didn't want other people to experience the same trauma.'

Reflections from Voicing Loss

- Expectations & hopes rarely match reality.
- Inclusion, kindness, respect can bring comfort, ease grief, & reduce the likelihood of (re)-traumatisation.
- Poor experiences can result in exclusion, anxiety, fear, intimidation, distress, despair, system mistrust. Stigmatising attitudes/behaviours.
- Potential for harm to individuals who are grieving & may already feel marginalised & disenfranchised – far-reaching consequences.
- Implications for a coroner service that faces multiple challenges
 whose role needs to be reimagined.
- OBereaved family said to be 'at the heart' of the process, but their role is in fact limited; service is not <u>for</u> the bereaved.



Voicing Loss: A research and policy project on the role of bereaved people in coroners' investigations and inquests



Visit https://voicing-loss.icpr.org.uk/ for a range of outputs.



Good practice guidelines



Supporting People Bereaved through a Drug- or Alcohol-**Related Death** Peter Cartwright

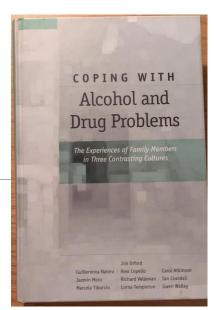
'Bereavement is a difficult thing for people to deal with, or death is a difficult thing for people to deal with anyway. But the fact that it is death through an addiction I think emphasises that.' (Daughter)

The 5-Step Method

•Evidence-based SSICS (stress-strain-information-coping-support model) to explain the experiences of affected family members.

•Remains a unique model – specific focus, language & terminology.

Information: •Foundation of the 5-Step Method intervention. Knowledge enables feelings of control Stress: Strain: Coping: AFMs are stressed due to the Physical and/or psychological How AFMs cope with (respond impact of the alcohol use, health problems other drug use, gambling to) the situation behaviour Support: Level and quality of support available to AFMs



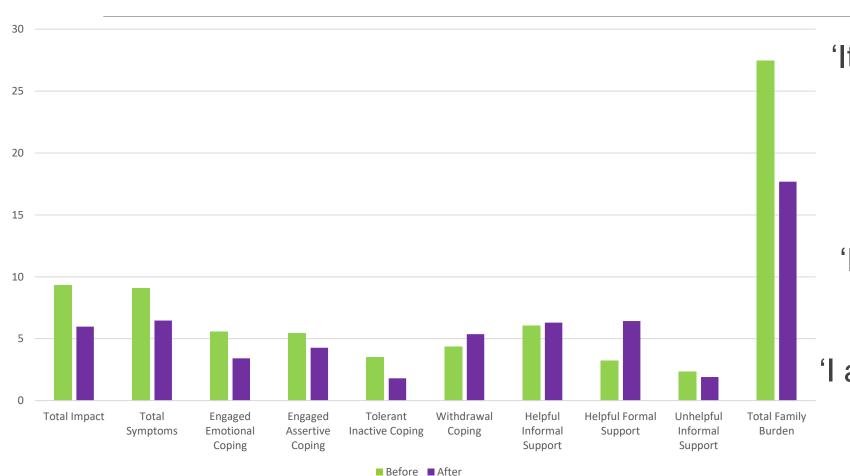
The 5-Step Method

Step 1: The AFM's story Step 2: Targeted & relevant information Step 3: Coping & responding Step 4: Support Step 5: Exploring further needs

- •Focus on AFMs in their own right.
- Alcohol, other drugs, gambling.
- Brief, structured approach.
- •Evidence-based development & ongoing research/evaluation.
- •Training, Competency Framework, Family Member Questionnaire.
- Globally widely used.
- •AFINet Resource Hub; membership.

How the 5-Step Method helps AFMs

(matched data N=853-871 AFMs globally, statistical significance)



'It was about the first time I felt somebody had listened to me... someone was interested in how I was feeling.'

'I can't solve the problem; I've got to stand back and that's helped me.'

'I am able to deal with things better and cope and understand it better.'

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Check for updates

apporting adults bereaved through substance use with the 5-Step method:

Lorna Templeton

Independent Research Consultant, Brist

ABSTRACT

While substance-related deaths across the United Kingdom are of continued concern, insufficient su port is given to those who are between diseptive existees that this is a particular berevinement regular existing intervention, the 5-days Method, within a substance misure treatment service. It was possible to adapt the 5-days Method and to the substance with a substance with a tasked to use the intervention. The Family Benevament Support Service (FRSS) was established with the substance of the substance with a substance with a substance with a substance was retored to use the intervention. The Family Benevament Support Service (FRSS) was established with too with its between the substance was the substance was retored to the substance was the substance was the substance was a finding are exceedingly but it was a smill study, to contain it needed when interpeting the finding much needed support for adults beneaved through substance use, an area which has received insul much needed support for adults beneaved through substance use, an area which has received insul content consideration inelative to the attention given to substance related other and their increa-

Revised 5 March 2020 Accepted 15 March 2020 KEYWORDS

Backgroun

Alcohol- and drug-related deaths are an ongoing put health concern across the UK in England and Wales in 20 Unlike most other models of addiction and the family, the SSCS model does not view families as pathological, dysfunctional or to blame for the addiction. Rather, influenced by

Φ About Me and
My Bereavement

O Understanding

My Bereavement

Responding to
My Bereavement

Getting Support from Others for My Bereavement

What Else Might be Helpful for Me

'She [another counsellor] didn't understand....people don't understand that somebody you've lost through drink is different to losing somebody through an illness....it needs somebody who actually understands.'

'It just makes me know I can do this, I can carry on with my life and I will...I can't give up....[worker] reiterates 'you're doing fantastic, you're stronger than you think', it gives you the oomph to think you will do this....gives me confidence, makes me feel positive, [worker] makes me feel that after this terrible tragedy that I'm strong enough and I can carry on.'

Further evaluation and development

- Working with Addiction Family Support. Service is already using the 5-Step Method.
- Small group of family/bereavement workers received additional training.
- Practitioner handbook; 2 outcome questionnaires.
- Clients engaging with the intervention & some have already completed their sessions. Additional support.
- Evaluation underway.
- Future plans?



Supporting Loss

- Builds on the 2 previous projects; May 2025-April 2026.
- Partnership: CDAS (University of Bath); Turning Point;
 ICPR Birkbeck (University of London).
- Develop an online Toolkit to support people bereaved by substance use when the death is subject to a coroner's investigation/inquest.
- Accessed directly by bereaved people; used by staff at a range of relevant services to support bereaved clients.
- Knowledge Exchange events; develop & launch Toolkit; monitoring & evaluation activities.

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