

Supporting families affected by another's drug and alcohol problem, and those bereaved through substance use

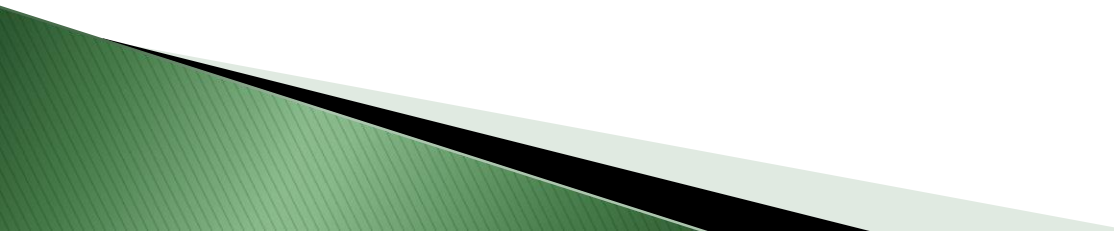
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Overview

1. Understanding how substance use can affect families and children.
 2. Supporting family members affected by a loved one's substance misuse: the 5-Step Method/Steps to Cope.
 3. Supporting family members who are bereaved following a loved one's alcohol- or drug-related death.
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Acknowledgements

1. Substance misuse and families, and the 5-Step Method/Steps to Cope.
 - Jim Orford, Richard Velleman, Alex Copello, Akan Ibanga, Ed Sipler.
2. Bereavement through substance use.
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Supporting family members affected by a loved one's substance misuse: why is it important?

1. Theoretical and practical failures to recognise and address gaps in knowledge and support.
2. A group which is poorly understood, marginalised, isolated and lacking support.
3. More research needed to understand experiences and needs, influence practice and policy, and improve support.
4. Scale of the problem worldwide.

1. 1,020 adults 18+ in NW England & 1,007 aged 16+ in Scotland. 79% experienced one of 20 harms and 51% experienced one of 16 harms in the last 12 months respectively.
2. 1,071 adults aged 18+ in Wales asked about 19 harms. 60% had experienced at least one in the last 12 months.
3. “The range and magnitude of harms from others’ drinking are substantial but not well-described” (Connor & Casswell, 2012).

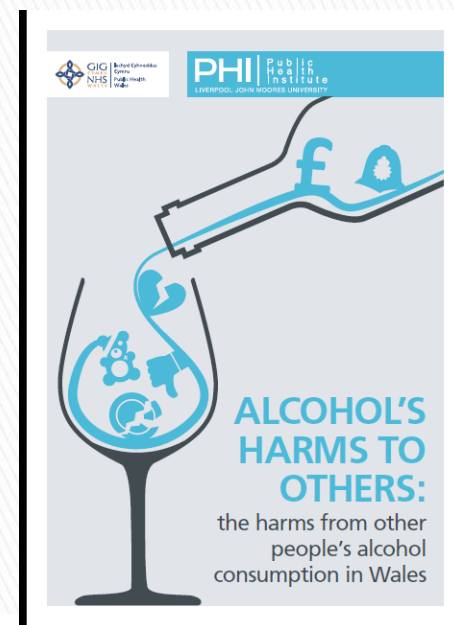
Harm to Others



An Institute of Alcohol Studies report

By Lucy Gell, Abdallah Ally, Penny Buykx, Ann Hope, Petra Meier

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Alcohol's harm to others: An international collaborative project

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Substance misuse and families: our programme of work

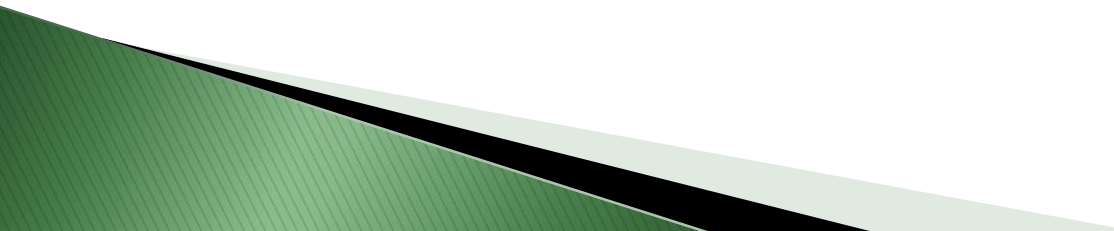
1. Understanding family members experiences: UK and international research.
2. Describing that experience: stress-strain-coping-support model.
3. Developing the 5-Step Method intervention.
4. Testing and rolling-out the intervention.
 - UK and internationally (translations etc. as appropriate).
 - Research, training, accreditation.
5. Applications of the model.
 - Steps to Cope for young people; gambling.

Understanding family members experiences

“...the experience of living with a relative with a drinking or drug problem is a very particular experience. It brings together in some combination elements of stress, threat, and even abuse, often simultaneously affecting different family functions and different members of the family. Worry about the loved relative is a core characteristic. It is bad for the health of family members and for the health of the family as a whole. There is no simple name for that kind of experience...” (Orford et al., 2005: 117)

“The particular qualities of the experience of having to cope with excessive drinking or drug taking in the family, in combination, can make it a unique and highly stressful and disempowering experience” (Orford, 2012: 60)

An International Picture

- Other problems are often also present; mental health problems and domestic abuse are common.
 - Living with substance misuse is very stressful.
 - Relationships and family life can suffer greatly.
 - Family members worry about their relative.
 - Strain manifests itself in a range of ways.
 - Range of negative emotions, including shame, guilt, anger, despair, confusion, and hopelessness.
 - Belief that the only solution is for their relative to reduce or stop misusing alcohol and/or drugs.
 - Struggle to know how best to cope or respond on.
 - Often isolated and struggle to access help.
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What about children?


"...children of parents with drug problems face numerous obstacles to achieving even the basics needed for their safety and well-being....." "What does the world look like to the child whose parents are unable to provide consistent care, security and reassurance and whose responsiveness is greatly limited by a preoccupation with problem drug use?" (Barnard, 2008)

"Chronic worry emerges as a corrosive presence in the lives of many children and young people living with harmful parental drinking. The emotional toll of constant stress, fear and anxiety appears to impact on their mental health and well-being"
(Wales et al., 2009: 9)

How children can be affected

- Chaos, unpredictability, isolation, fear.
- Families wanting to keep the problems a secret.
- Loss, through family break-up or bereavement, or because of absent, inconsistent or neglectful parenting.
- Accumulation of risk if other problems are present, particularly conflict & disruption.
- Risk of themselves developing substance misuse, mental health or behavioural problems.
- Attendance & performance at school can be affected.
- Often have to care for their parents or siblings and/or take on particular roles and responsibilities.
- May blame themselves and think that problems are their fault; often they will have been told this by others.

Are all children equally affected?

- Some children are not always as affected by parental substance use as we might expect.
 - Increased recognition of a set of protective factors and processes (individual, familial and environmental), constituting a dynamic process usually referred to as 'resilience', which can buffer children against the negative effects of parental substance misuse and reduce the risk of negative outcomes.
 - Increasingly part of interventions in this area.
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Protective factors and processes, and evidence of resilience

- Presence of a stable adult figure (esp. a non-using parent).
- Close positive bond with an adult in a caring role.
- Wider, positive, support network including with peers.
- Parenting style and positive family environment.
- Individual temperament.
- Engagement in a range of activities.
- Positive opportunities at times of transition.
- Problem short-term / parent seeking help.
- Deliberate planning by a child that they will be different.
- Self-efficacy, self-esteem, confidence.
- A good repertoire of coping responses.
- Ability to cope with change.
- Problem-solving skills.
- Feeling that there are choices and that the child can be in control.

Describing the experience of family members: the stress-strain-coping-support (SSCS) model

- Families experience **stress** as a result of someone else's problem drinking or drug use.
- The resulting **strain** leads to physical & psychological ill health
- Stress & Strain is influenced/mediated by:
 - Quality & amount of **information** available.
 - Method(s) of **coping**.
 - Level and quality of social **support**.

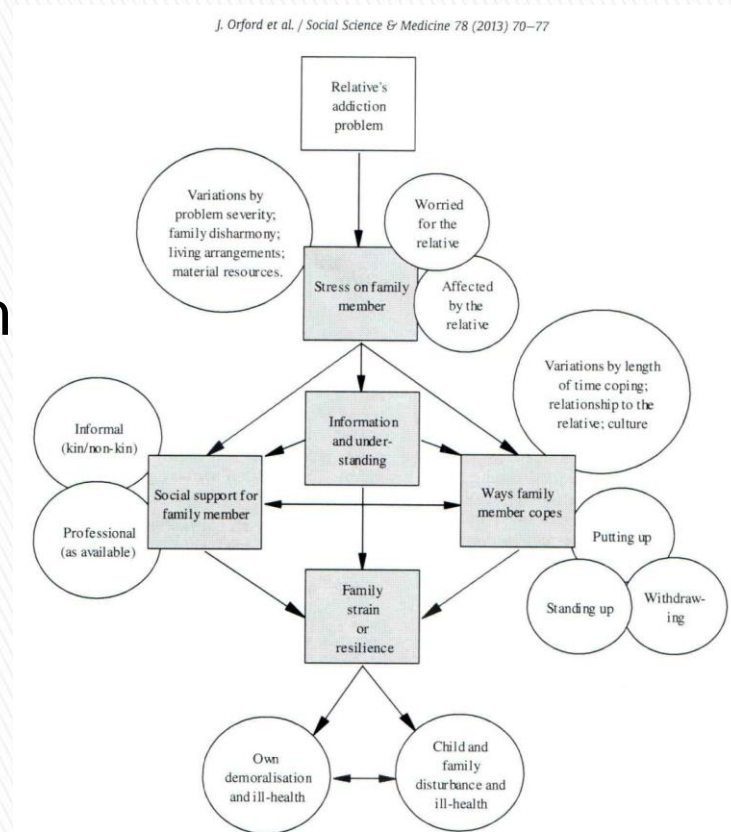


Fig. 1. The stress-strain-coping-support model.

The 5-Step Method: a brief intervention for family members *in their own right*

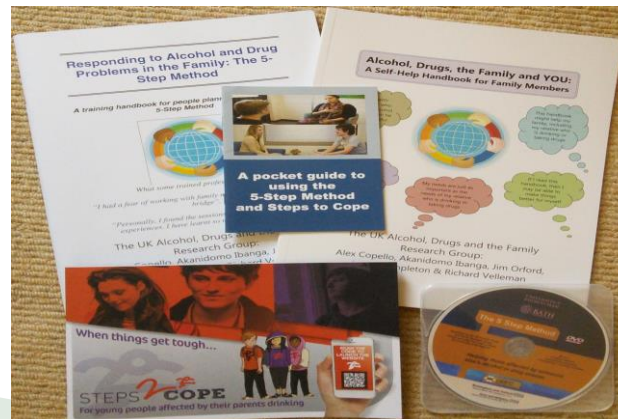
one Listen, reassure and explore concerns

two Provide relevant, specific and targeted information

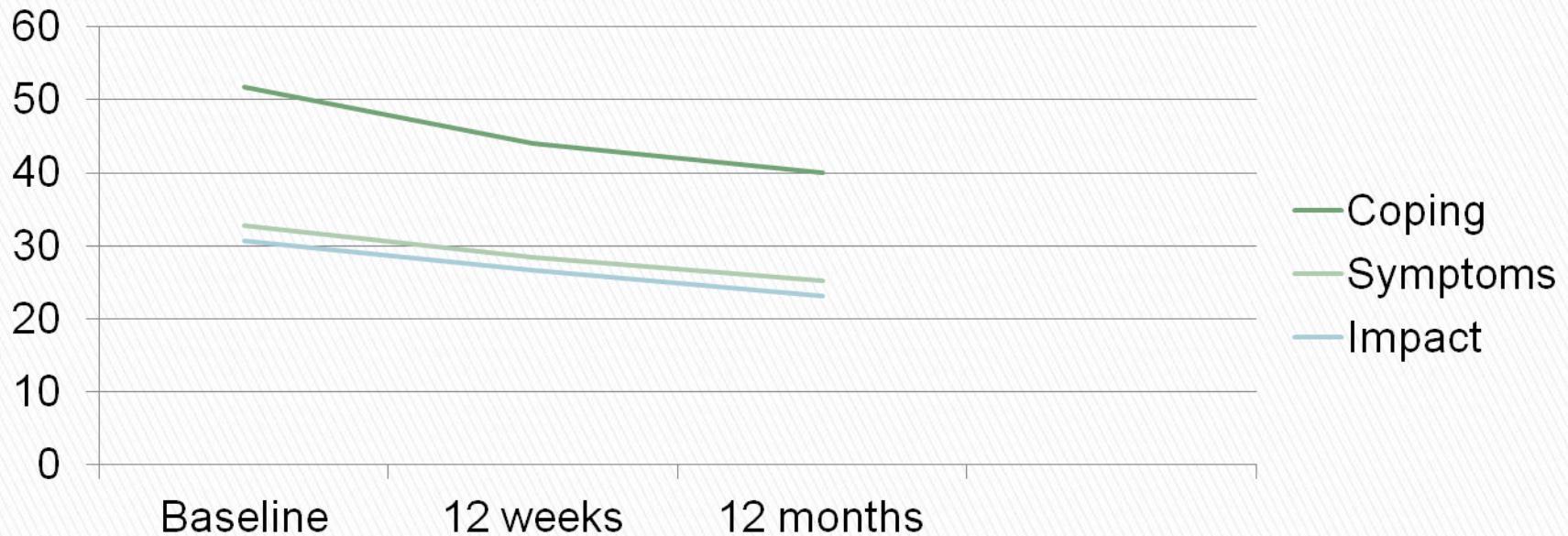
three Explore coping responses

four Explore and enhance social support

five Discuss and explore further needs

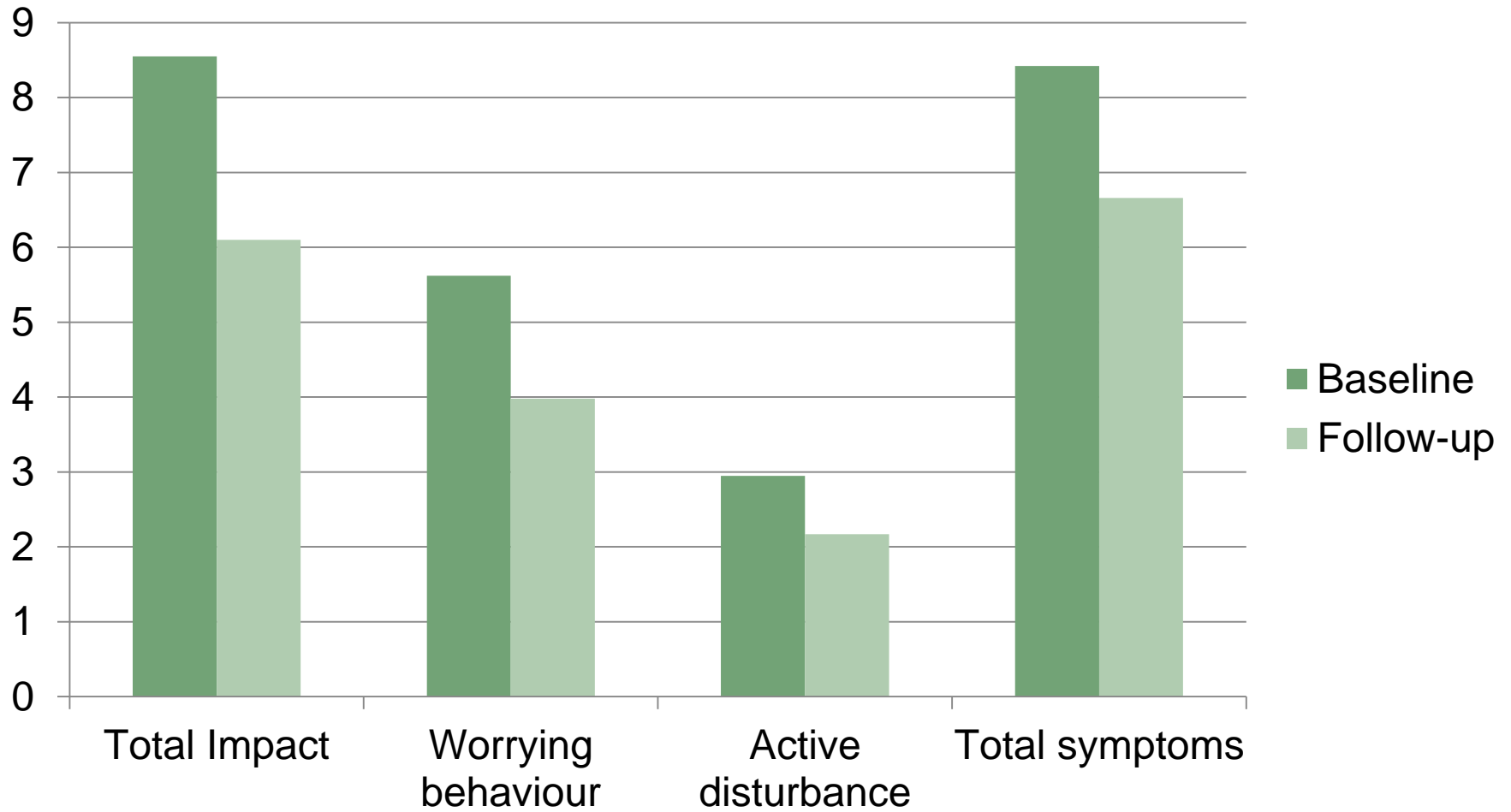


The 5-Step Method helps family members

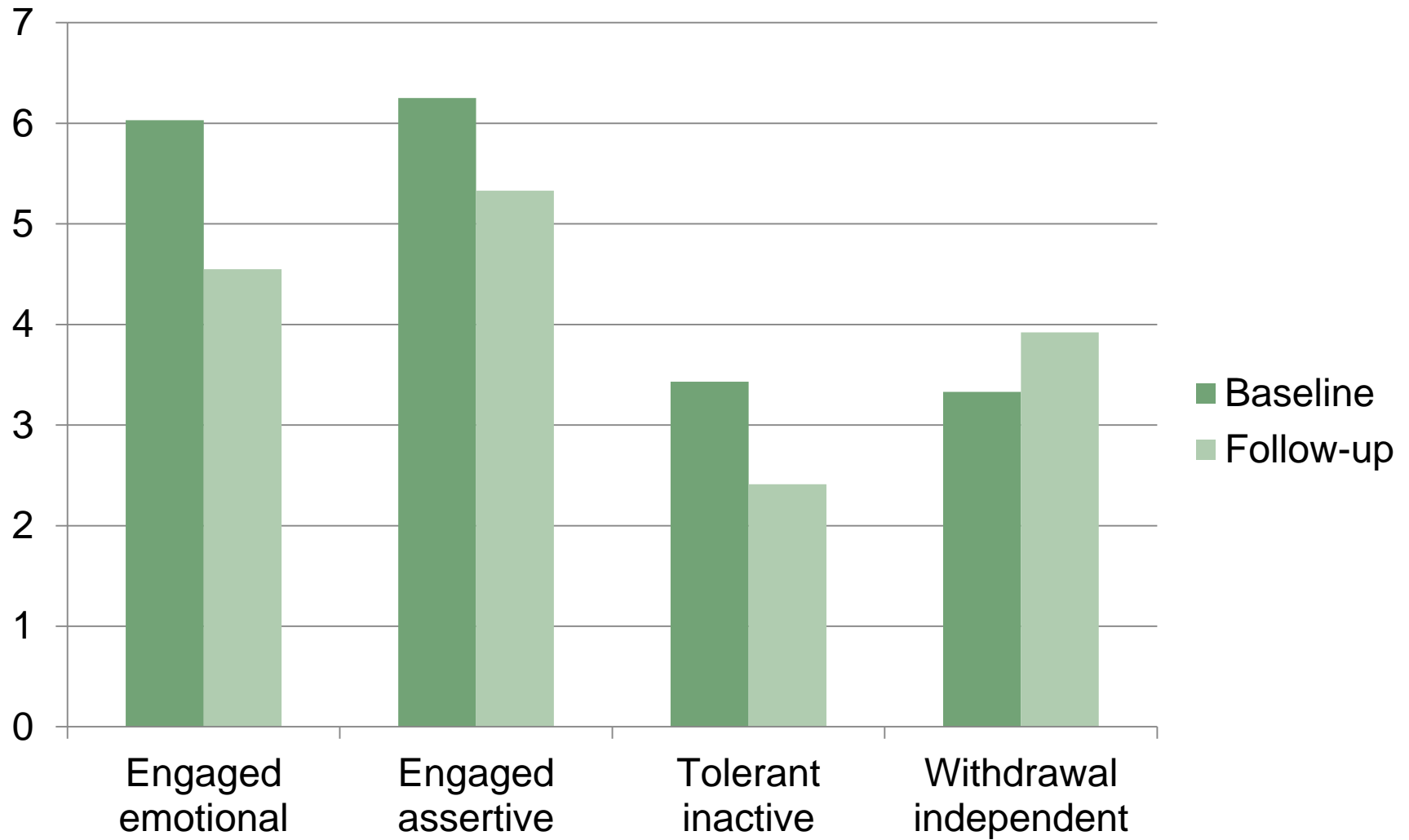


- RCT in primary care with 143 family members which compared 2 levels of the intervention.
- Nearly two thirds of FMs followed-up at 12 months.
- Reductions in 3 areas over time (some statistically significant)., supported by qualitative data.
- No differences with those not followed up; no differences according to intervention intensity; some differences between sub-groups of family members.

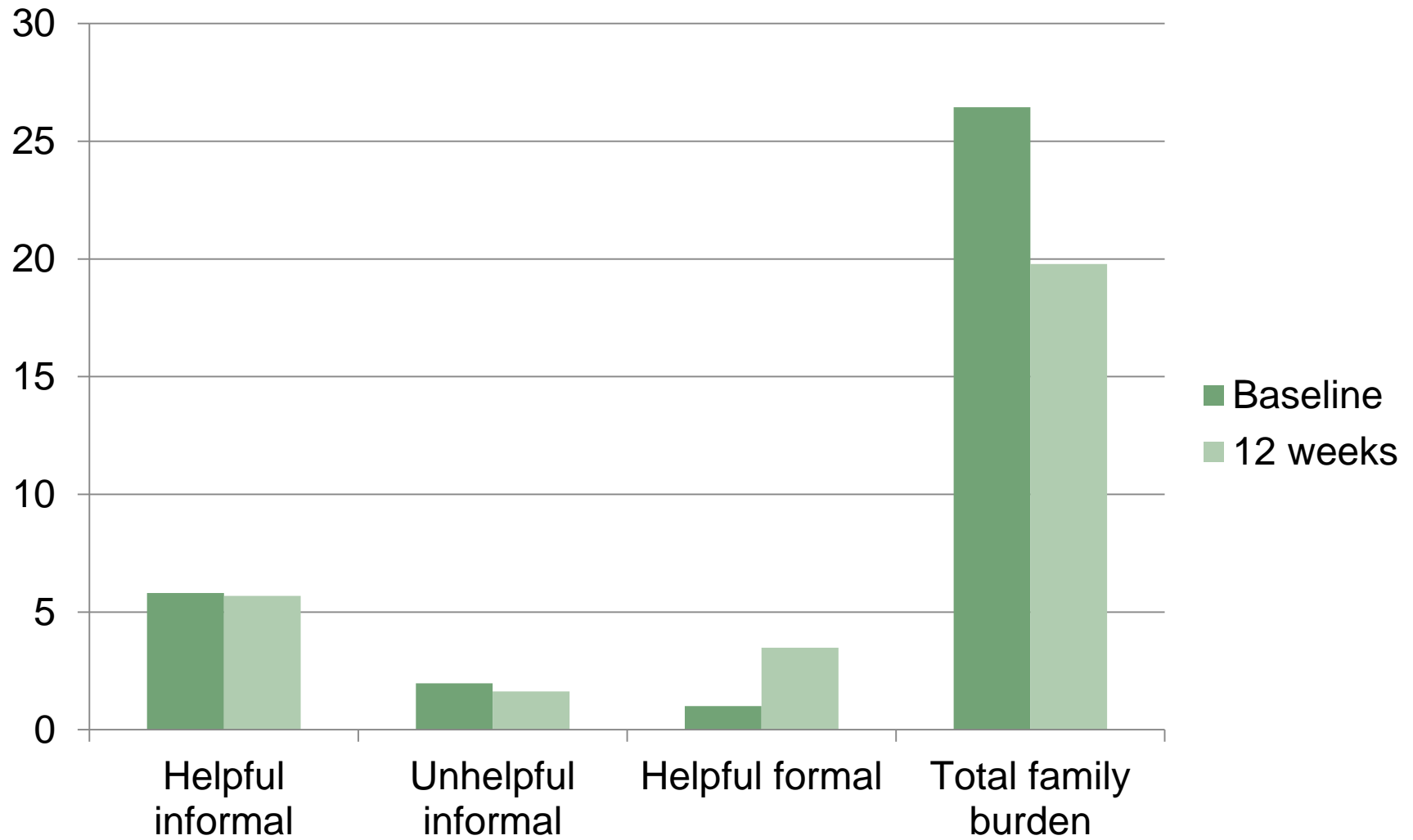
Impact and health



Coping



Support and total family burden



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

“She let me find my own way....she helped me to arrive at ways of dealing with things”

“It did me good, it was helping me....that was my time.....I felt like I was spoiling myself”

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

“As a Mum, I'm used to only thinking of others”



Steps to
Cope: girl
aged 14



Steps to Cope: girl aged 14

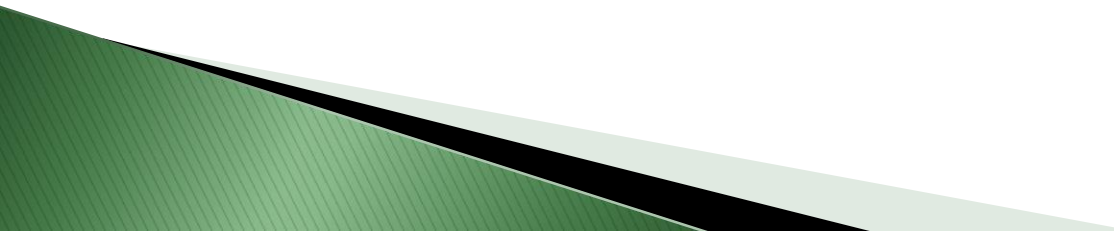
“Before I started meeting with [Jane], I didn’t like talking about any problems I had and often bottled my issues up, this always ended up in the same result. I would end up breaking down and often didn’t realise why I was so upset as I was used to blocking things out. I found it hard trusting people, including friends which had quite a negative impact but I [saw] this as a way of protecting myself, as I was always used to people letting me down”

BEFORE

“Since I’ve started working with [Jane] I’ve become more open. I know that I have to learn to trust people because not everyone is going to let me down. I can talk about my problems more easily and this has had a very positive impact on my life. I have also learnt to sort out my problems because avoiding them does not help the situation. I think the booklet is the main reason I have progressed so much, in my own state of mind”

NOW

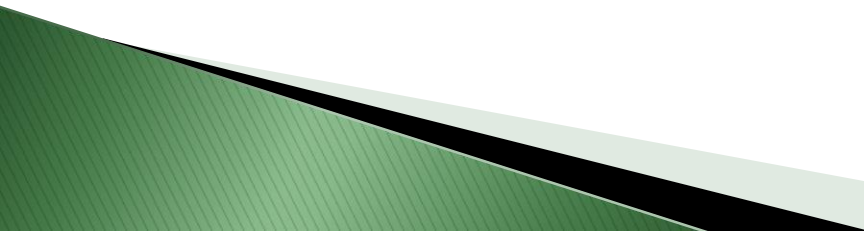
The 5-Step Method today

1. A rare, evidence-based, form of support for family members *in their own right*.
 2. Importance of following the steps in order.
 3. Value of flexibility, including potential use in different settings by a range of practitioner groups in different countries.
 4. Value of maintaining fidelity to the model; importance for professional development.
 5. Steps to Cope for young people and other versions e.g. gambling, other languages.
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Supporting adults bereaved by an alcohol- or drug-related death: why is it important?

1. Almost total lack of research in this area.
2. A 'special death': particular features such as circumstances of the death, stigma, disenfranchised grief.
3. A group which is poorly understood, marginalised, isolated and lacking support.
4. Research needed to understand experiences and needs, and influence practice and policy.
5. Size of the problem?

Study overview (2012-2015)

1. Scotland, and South West England.
 2. 100 interviews with 106 bereaved adults (71 England, 35 Scotland).
 3. 6 focus groups with 40 practitioners (including some bereaved in this way).
 4. Working group (12 professionals plus an Independent Chair) who developed our practice guidelines.
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Interviewees

- 79 women and 27 men.
- Average age at interview: 52 yrs (22 to 75 yrs).
- Relationships: 56 parents; 21 children; 13 spouses/partners (inc. former); 13 siblings; 6 friends and 3 nieces.
- 12 people in treatment; 9 in recovery.
- Time since death: 6 weeks to 30+ years (average 8 years).
- Close others who died: majority male; average age: 38 yrs (range 16 to 84 yrs).
- Majority of interviewees and those who died were White British.

Before the death

1. Nature of the substance misuse (mainly alcohol and opiates – usually heroin).
2. Living with the possibility of death.
3. Circumstances before death could continue to play out and have an impact after death.

Addicted families have been bereaved for a very long [time], they lost that person a long time ago (Mother)

Nature of the death

- Overdose, illness, accident (2 RTAs), suicide, murder.
- A small number of deaths occurred abroad which brought further stress and complexity.
- Mostly unexpected and sudden (more likely with drugs) though others expected due to long term health problems (more likely with alcohol).
- Dying alone or in a public place. Discovery within the home often came with accounts of attempts to resuscitate.
- Dying without privacy, dignity or peace.

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)

Involvement with official processes

- Many informed of death by police.
- Investigations by police, post mortems and inquests – often drawn out.
- Complicated, confusing, often lacking in consideration for the bereaved who felt poorly informed and supported.
- Limits to viewing or touching the individual's body; how the body was handled (especially where IV drug use involved).

We were just part of the process, we weren't a bereaved family (Father)

Direct, perceived and self-stigma

It was like heroin addict killed....stabbed to death....once people read that they just think oh well, it's only one more gone (Brother)

My biggest fear [was that] nobody will come. It will be a miserable, sad, little funeral...because of the circumstances of his death...I thought people would be judgemental and shocked, but as we drove up I thought there are an awful lot of cars....people milling about. And somebody said they're for [your son]....it's the old stigma again, isn't it? There's real stigma, but there's also perceived stigma (Mother)

Stigma

- Impact on receiving or asking for help.
- Acknowledging role of substances in the death.
- Responding to stigma.

*I only ever say to people he actually died as a result of a road accident, I never ever say it
(Mother)*

*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)*

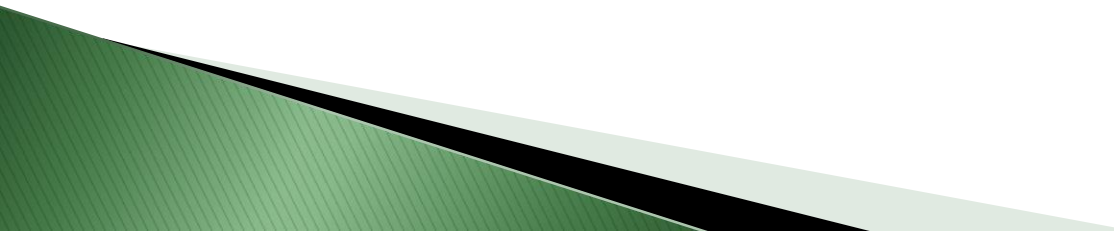
Grieving

- Complex emotional reactions.
- Creative responses.
- Remembering: not wanting the deceased to be 'defined by their addiction

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.....it took me a while to realise that I had the right to be upset (Daughter)

I didn't want anyone to think just because he was an alcoholic and just because he died young doesn't make him a bad dad, he was a fantastic father....and I wanted people [at the funeral] to know how special he was to us (Son)

Adult children (N=21)

- 16 female & 5 male (age at interview 27-58yrs).
 - Deceased parents: 10 female & 10 male.
 - Majority not living with parent when they died.
 - Some were under 18 when their parent died.
 - Majority of deaths involved alcohol, often following years of problems.
 - 4 interviewees were in treatment when interviewed; 2 were in recovery.
 - Before death: mixed impacts, mirrors literature.
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- Loss before death & when death came
- Loss of parent as a child, regret that unable to help parent, loss of hope, relief, guilt.

Iwas also grieving for the father that I'd never had...at least when he was alive, even when he was being absolutely awful there's always a tiny bit of me that thought well maybe one day I'll get the dad that everyone else gets (Daughter)

I lost my mum when this started. I always hoped I would have my mum back. So I grieved the loss of my mum [and then] I have a second grief for the person she became with her addiction (Daughter)

- Support mainly from family/friends. Examples of professional support rare (incl. schools).
- Dealing with grief e.g. continuing as normal (e.g. education/employment), own substance use.
- Impact on child's health, behaviour and education: difficulties obtaining professional help.

“I still think my youngest son might be a sort of time bomb in a way because he's never really grieved at all” (Ex-wife)

“(The head teacher's) answer to it was to suspend him for three days... His behaviour wasn't good... they just thought he was a bad wee boy” (Mother)

- Understanding & making sense of the death.
- Involvement with official processes.
- Excluded from key decisions.
- Remembering the parent could be difficult.

The kids wanted him to be buried in the clothes he went walking in and they (deceased's parents) wanted him buried in a suit (Partner)

I didn't want anyone to think just because he was an alcoholic and just because he died young doesn't make him a bad dad, he was a fantastic father....and I wanted people [at the funeral] to know how special he was to us (Son)

Interviewees in treatment or recovery (N=21)

- 12 in treatment, 9 in recovery (some for many years).
- Some (friends, siblings, partners) had a history of substance use with the person who later died.
 - One was directly involved in his friend's death & served a prison sentence as a result.
- For some their substance use history was different – e.g. adult children with a history of parental substance use.

- Close association between their own substance use and the impact of, sometimes unresolved, grief associated wholly or partly with, the death of their relative or friend.

I haven't dealt with his death, hence me being an alcoholic (Daughter)

I carried on [drinking] for 18 months....running, running, running, trying to avoid the pain....it was probably the worst two years of my life....and of course when I put the drink down....I still had to start grieving again (Son)

- Grief can impede recovery.
- Importance of bereavement support as part of treatment/recovery.

It's affected me a lot more than I am allowing myself to accept.....I think talking about it now is making me aware that I have not dealt with it (Friend)

It's only now, since I've been coming [here] that I've been offered grief counselling, and it's really helped in the last seven weeks I've [come] to terms with it more than I have in 18 years.....if I'd had that years ago I would be such a different person, I would not have completely screwed up my life (Daughter)

RTAs (N=2)

- Mother talked about death of son (26) in 2005. Son was the driver & crashed his car (he was alone), received a brain injury and died in hospital 1-2 days after accident.
- Inquest: son over the limit (alcohol/cannabis) which surprised mother. Continued uncertainty over how crash happened.
- Stigma: “[the police]....would actually regard it as a drink driving [accident] but....I only ever say to people he actually died as a result of a road accident” (because it would misrepresent him).
- Woman talked about death of sister (36) in 2007.
- Sister was extremely drunk, fell in road, was unconscious and was run over by a man who did not realise what was in the road was a person.
- Feeling of pity towards the driver & of anger towards pub.
- Relief at inquest that it was an accident & not suicide.
- Public nature of death - dealing with various professionals, media coverage of accident etc.

Support

- Interactions with a range of professionals and organisations.
- Support from families and networks, incl. of the deceased.
- Mixed experiences – isolation and poor experiences more common.

I noticed how lost the family were after this death. And we just didn't have any support (Niece)

If it's a murder there would be a family liaison officer, if it was an accident 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.....So you feel like you fall between everything and there is nothing that I can see particularly for families where it's been drugs (Mother)

How support is delivered is important

Her [the procurator fiscal] manner was terrible, there was no warmth in her. And I felt as if we were the wrong ones (Mother)

The inquest was incredibly professionally and sensitively done....it was conducted by a woman who was gentle, sensitive, unrushed (Mother)

The doctor in A&E who signed his death [certificate] said 'This gentleman had died' and that made such a difference to us. We were upset and I thought he wasn't referred to as 'This drug addict has died' (Parents)

Mapping the response

Responding to Bereavement through Substance Use [covers England & Scotland]

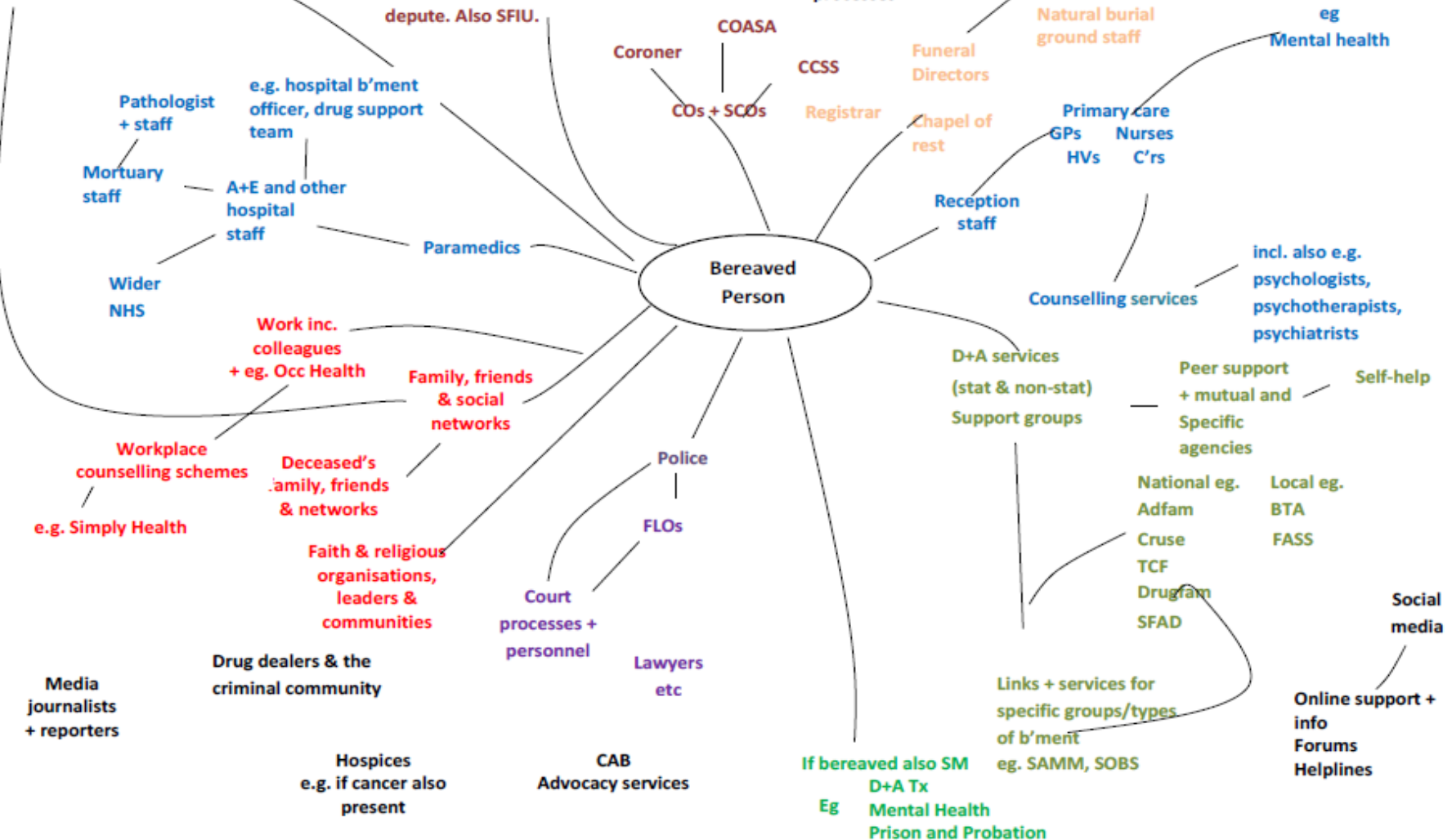
Support to children e.g. nannies/childcare
Schools + nurseries
Child b'ment services
CAMHS

In Scotland: COPFS and the PF system incl PF and PF depute. Also SFIU.

Commissioning structures & processes

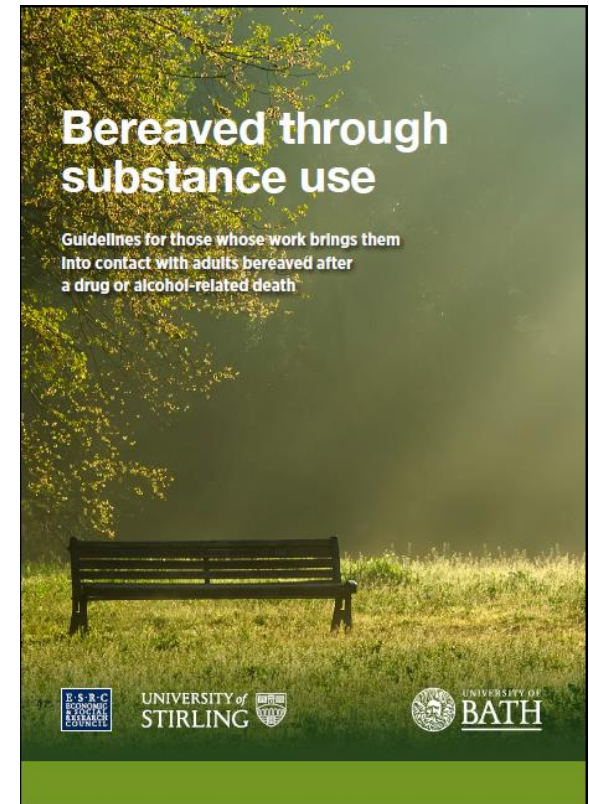
Funeral celebrants

Practicalities of dealing with a death e.g. solicitors, banks, assets, probate, benefits, utilities, wills




Practice Guidelines: 5 key messages

- Generic & developed by practitioners for practitioners; so **not** specifically for bereaved people.
 1. Show kindness and compassion.
 2. Language is important.
 3. Every bereaved person is an individual.
 4. Everyone can make a contribution.
 5. Working together.



Concluding thoughts

- This is a group who face several complex and distressing dilemmas – both before death and when death occurs – application of our theoretical model.
 - Study extends knowledge about how people can be affected by the alcohol- or drug-related death of a relative/friend.
 - Diversity of experience and need means that the response needs to be individualised.
 - This is a group lacking in support (before and after death) and we hope that our study will make a contribution to raise awareness, and change policy & practice.
 - Services (including drug and alcohol, and mental health) have a part to play in improving the response.
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To find out more....

○ www.afinetwork.info and www.bath.ac.uk/cdas

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