

Bereaved through substance use

Guidelines for those whose work brings them
into contact with adults bereaved after
a drug or alcohol-related death



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Dedication

These Guidelines are dedicated to Joan Hollywood (1941-2015)

Joan Hollywood's son died in 2008 as a result of his drug and alcohol use. Unable to find support for grieving a death related to substance use, Joan and her husband, Paul, founded Bereavement Through Addiction (BTA), in Bristol. BTA provides a helpline, support groups and an annual memorial service for those bereaved in this way, as well as training to organisations in the field. A tireless campaigner for people bereaved through substance use, Joan was a key inspiration for the research on which these guidelines are based, a member of both the research team for the project as a whole and of the working group that produced these guidelines. These Guidelines are a lasting memorial to her and her achievements.

Why we developed these Guidelines and their relevance to you

Welcome to your copy of these Guidelines, which are for all those whose paid or voluntary work brings them into contact with adults bereaved through a drug or alcohol-related death. By adult we mean any family member, colleague or friend (including those who use drugs and alcohol themselves) bereaved in this way. This easy-to-follow guide shows how best to respond to these bereaved people, enhancing both your work and their well-being.

The Guidelines are based on the first large scale research project in Britain into the experiences of adults who have been bereaved through a drug or alcohol-related death. The research found that these deaths, not at all unusual in the UK, are particularly difficult to cope with and that those left behind have mixed experiences of the services they have to deal with. While some people reported positive experiences, others experienced poor, unkind, often stigmatising responses, which added to their distress and left them feeling alone, confused, hurt and angry at an already very difficult time. Much poor practice resulted from practitioners not understanding this kind of death and the issues involved.

These Guidelines share what we have learnt of good practice. Their authors are a Working Group of your peers, including members of the police; the coroner's court; drug and alcohol services; a GP; a paramedic; a funeral director; a university chaplain; and a bereavement counsellor. Some of us have had personal experience of bereavement through substance use. As practitioners, some of us have made the kind of mistakes highlighted by the research.

These Guidelines cover the work of a range of organisations, so they mostly offer general guidance. Therefore we recommend that you implement what you consider relevant to your work. We hope you will share these Guidelines with your colleagues; you could identify someone to lead on implementing them in your team or organisation. Working with bereavement can be demanding and stressful, and it may re-stimulate our own grief for those we have lost. So it is important that you look after yourself as well.

The Guidelines are based on five key messages identified from research interviews with 106 bereaved adults and focus groups attended by 40 workers and bereaved adults. Therefore the guidance is for adults, although we list some resources for helping bereaved children at the end. Each message is illustrated by quotes from the interviews, questions for you to consider and our suggestions to support your work. They apply at any time, even years after the death.

What is bereavement?

Bereavement is the experience we go through following the death of someone we have been close to. It is usually distressing and often stressful. Contrary to popular belief, a major bereavement is not something we 'get over'. Rather we revisit it over the years, although the frequency typically lessens, and we gradually build a new life. How we respond to this experience depends on how we grieve and how we cope; support from family, friends and our wider community; and on the responses of a potentially wide range of practitioners, including people like yourself.

However, being able to draw on these personal and social resources may be more difficult with deaths, like those resulting from substance use, that are stigmatised because of the behaviour of the person who died. Rather than sympathy and support, bereaved people often meet with stigmatising responses, which leaves them feeling that their grief is unacknowledged and they have nowhere to turn. This may be on top of their ability to cope with the bereavement being depleted by many years of the stress of living with the person's substance use.

What are substance use and addiction?

'Substance use' means taking any substance to change how we feel, think or behave, e.g. to relax, to heighten enjoyment of music etc. This includes alcohol; illegal drugs like heroin; new psychoactive substances, often called 'legal highs'; misusing medicines like valium; and misusing products like lighter fuel. People can use these substances in a range of ways from experimenting, to regular use, through to problematic use like 'binging', and, for some people, ultimately to dependence, also known as addiction.

The word addiction (or dependency) is emotive and often misunderstood. So to clarify: addiction is habitual and compulsive behaviour to achieve a desired reward, where the person loses control over this behaviour so that it becomes excessive, despite adverse consequences for their health and relationships. It is sometimes thought of as a disease or an illness. Whether or not you share that view, addiction is not just a life-style choice or being weak willed.

When bereavement and substance use come together

Not everyone who dies from substance use is addicted and these deaths may occur in various ways. Examples include a young person dying after experimenting with a drug; someone dying from liver failure or some other long-term consequence of alcohol use; over-dosing on a drug after a relapse; and accident, suicide or murder/manslaughter.

The death comes as a shock, even if expected. Some of those left behind may not have known before that the person used drugs or how much alcohol they drank. In other families, some members may have known and others not, which can lead to conflict between them. Some families may have been coping with the frustration, stress and pain of the person's substance use for many years, and long ago 'lost' the person they previously knew. Other families may have given up on, or lost contact with, the person who used substances. It is also the case that some bereaved people will use substances themselves. What all these bereavements can have in common are:

1. Both the substance use and the death may be considered taboo and stigmatising, leaving the bereaved person feeling shame and alienated at what might be the worst time of their life.
2. These bereavements are likely to be complicated by:
 - A belief that the death was premature and could have been prevented.
 - Circumstances of the death, including not knowing exactly how the person died or how much they suffered.
 - Feelings of guilt that they were not able to help the person.
 - A difficult relationship with the person and their substance use before the death.
 - Involvement with police, the wider criminal justice system and the coroner's court or (in Scotland) the procurator fiscal service.
 - The loss of hope that the person would one day stop using substances.
 - Sensational and judgemental media coverage.

Such things easily combine to produce particularly severe bereavements. This places you in a key position to provide a kind, helpful and supportive response, countering the stigma and misunderstanding that those bereaved by substance use may otherwise meet. Your response needs to appreciate the reality of these bereavements, including how easily bereaved people can be put off from engaging with you and the high level of need they may have. We believe these Guidelines will equip you to make that response.

Key message 1 – Show kindness and compassion

Guidance to show kindness and compassion is probably unsurprising and they may be difficult to show when busy, stressed, and you have a job to do and protocols to follow. However, the research shows that kindness and compassion can make a huge difference, especially when we first meet the bereaved person.

Consider these two contrasting experiences reported by two bereaved mothers:

“He was known to the police because he had been an addict...that’s awful as a mother...you feel like society looks down on you...[but] I didn’t get that sense. [The police] couldn’t have been more helpful.”
(Mother talking about son)

“I thought at the time that [things] could have been dealt with later... How do you expect me to answer questions when I’ve just been told my son has died?... You are going to tell a mother that her son just died, it doesn’t matter what kind of person she is or what kind of person he was, you try and show a bit of compassion. You don’t just go in as if it is an ordinary run of the mill thing.”
(Mother talking about the police)

Notice how these situations were made harder because a substance-related death is stigmatising, unlike a death from say cancer or a heart attack.

Take a moment to consider what it would be like for you to go and talk to a worker or professional about what you believe is a difficult and shameful thing in your life. What would that be like?

You may often come across these deaths in your work and may even be desensitised to them. However, for the bereaved person you work with this is their loved one, not ‘another’ drug or alcohol-related death. Remember, you could be dealing with someone at one of the worst times in their life. Therefore approach them as you would anyone who had lost a loved one in difficult circumstances, such as a road traffic accident. The circumstances are different, but the underlying loss is the same.

Good practice

- A first impression can be a lasting one. Therefore take a moment to prepare yourself before meeting a bereaved person for the first time to ensure you convey kindness and compassion. It might help to think ‘ABC’ – for Attitude, Behaviour, Communication.
- Offer your condolences, just as you would to anyone else, e.g. *‘I’m sorry to hear about the death of your son’*.
- Your attitude is as important as the amount of time you give someone. No matter how brief, time well spent can mean a lot and really help.
- Your kindness and compassion need to be genuine, not put on for the occasion. Do not try too hard to convey kindness and compassion - that can appear fake.
- Talk *with* the bereaved person and not *to* them. Show your understanding and humanity. Sometimes they just need someone to be there and listen.
- If possible, switch off mobile phones, radios and other communication devices. If not, turn the volume down or put them on ‘silent’ or ‘vibrate’ and take a moment to explain to the bereaved person why they cannot be switched off.

- People who are recently bereaved may be in shock and confused, they may be raw with grief, so will not take in everything you say. Therefore you may need to repeat things, although do so sensitively without bombarding them with information - stay focused on what really matters at that time. Write key information down so they can look at it later.
- Your professional judgement of a situation is necessary, but personal judgements of individuals and their conduct are unhelpful. Remember, you could be making assumptions, as you will not know everything about the person involved. Give people the benefit of the doubt and treat both the person who died and the bereaved with dignity and respect.
- There may be occasions when you do not have the time to give. Please give what you are able and arrange another time to speak. If not, then apologise and ensure they know about others who are able to give more, in such a way that they understand you are not pushing them away (see key message 5).
- Regardless of how often you work with the bereaved person, continue to be kind and compassionate.

An idea for you to consider

We suggest you adopt the six 'Cs' often used in the NHS: care, compassion, competence, communication, courage and commitment. See [The 6Cs england.nhs.uk/wp-content/uploads/2012/12/6c-a5-leaflet.pdf](https://www.england.nhs.uk/wp-content/uploads/2012/12/6c-a5-leaflet.pdf)



Key message 2 – Language is important

Our language shapes how we see the world and the people within it, and how other people see us. This has implications for us in our work. Consider for example the impact of words like ‘junkie’ or ‘drunk’ used to describe someone who has died. Though commonly used, these words may be experienced as judgmental, stigmatising and hurtful by a bereaved person. Language is important, as these two quotes illustrate:

“And it is just a horrible stigma, you get a label on you, you are labelled...it is as if when she died ‘Oh another one bites the dust’. That’s the impression we got you know when it all happened, it was just horrible.”
(Mother talking about son)

“The doctor in A&E who signed his death certificate... he 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’, you know.”
(Parent talking about son)

Consider how these bereaved people felt. Think of a time when you had to talk to a worker or professional about a personal matter you found emotive. When they spoke to you, what kind of language and attitude helped you, and what did not?

Research has shown that language used to describe substance use affects attitudes towards people who use substances and their families, in both positive and negative ways (for example, Kelly & Westerhoff, 2009). Using language like ‘substance abuser’ risks defining the person by their substance use and obscuring other aspects of their character and identity - aspects the bereaved may well cherish.

Many bereaved people will already have felt judged and stigmatised before the death, and may even judge and stigmatise themselves - as do parents who ask themselves ‘where did I go wrong?’ They will be acutely aware of your language and the attitude it implies. The risk is that they disengage from you and other organisations to avoid being stigmatised or judged again. This undermines the job of ensuring they get help, so the language you use is particularly important. Usually poor language is caused by our lack of thought, rather than by deliberate insensitivity.

Good practice

- Use the same language you would expect if it were your loved one who had died.
- Aim to use language that mentions the person before describing their behaviour, as we have in these Guidelines, e.g. ‘*person who died of drug use*’ rather than ‘*dead drug user*’.
- Be respectful and ask the bereaved person how to refer to them and to the person who died. Or use terms like ‘*Mr./Ms...*’ or ‘*Sir/Madam*’ for the bereaved and ‘*your son/daughter*’ for the person who has died.
- Simplify your language and avoid organisational terminology. Explain any processes, formal/official words and acronyms, and do not assume people know what these are. Check they understand what you have told them and it can be really helpful to provide written information as well.
- If possible, ask if they would prefer to talk face-to-face or by phone. If you have to say difficult things over the phone, then acknowledge this and check if it is possible for someone to be with them.
- How you say things can be as important as what you say, so consider your attitude, manner, tone of voice, facial expressions and body language. For example, sit down when speaking to a bereaved person rather than standing over them, and ask for somewhere private to talk.
- Consider your language when writing and also when speaking to colleagues.
- You may try too hard not to cause upset, which could inhibit you, sound patronising, or lead to you saying more than is appropriate. Trust yourself to gauge a situation. Say ‘*sorry*’ if you get something wrong; people are usually forgiving if they sense your good intention.
- If you work in the media, the Samaritans media guide for reporting a death through suicide is also relevant to substance use deaths (see Resources section).

We do not want to tell you what you can and cannot say or to use politically correct language - language varies between organisations. Instead we offer you examples of language that we believe are helpful and unhelpful, and leave you to decide how to use these.

Kelly, J. F. and Westerhoff, C. M. (2009) Does it matter how we refer to individuals with substance-related conditions? A randomized study of two commonly used terms, *International Journal of Drug Policy*, 21, pp202-207

Some things we suggest you avoid saying

- Avoid using terms like *'junkie'* or *'alcy'*, or labels like *'addict'* or *'drug abuser'*. Everyone deserves dignity and respect in death.
- If the bereaved person uses judgmental or stigmatising language, do not use it yourself.
- Avoid saying *'I know how you feel'*. We acknowledge the good intention here, but you may not know, and it can anger bereaved people whose experiences and circumstances will be different. Perhaps be honest and sensitively say *'I don't know how you feel'*. Also avoid saying *'You shouldn't blame yourself'* or similar comments that deny what the bereaved person is saying (although do not agree either, as they are almost certainly not to blame).
- The bereaved person may say that their nightmare of coping with substance use is over or that the person who died is spared further torment. However, do not raise this yourself, as the person you are working with may not feel this. Even if they do, they are still having to cope with a bereavement.

Some things we suggest you could say

- As a rough guide, use the same language as the bereaved person, unless it is judgemental or stigmatising.
- When referring to the person who died, acknowledge them by using their name, or at least a term like *'son'* or *'wife'*, rather than impersonal labels like *'the deceased'*.
- Use the terms *'drug use'* or *'alcohol use'* when referring to someone's substance use.



Key message 3 – Every bereaved person is an individual

Substance use affects people in a wide range of ways, and deaths resulting from alcohol or drugs can be equally diverse. Therefore be prepared for a wide range of reactions, emotions and situations. There is no 'one size fits all' response. Though it may be easier to categorise or pigeon-hole someone, taking on the challenge of responding to them as an individual is ultimately more successful.

Substance-related deaths may be familiar, you may even have become de-sensitised to them, but this will probably not be the experience of the bereaved person you are working with. Therefore, be mindful that every bereaved person is an individual and has different wants and needs. It is also important to remember that every person who died through substance use is also an individual.

Consider the following contrasting experiences:

"...some acknowledgement also that this was a different kind of death... There is a need not to make presumptions about how people might be... It is really, really important that you pay attention to how they are rather than how you think they should be."

(Mother talking about son)

"[The police] were as considerate as they could be in the circumstances. They gave me my place as his wife but didn't push anything on me... Every time I said to them I am not his next of kin any more, they accepted that and didn't push that at all, they just took his brother's name from me and were quite happy to go with that.. The police... were probably the best that could have been in the circumstances."

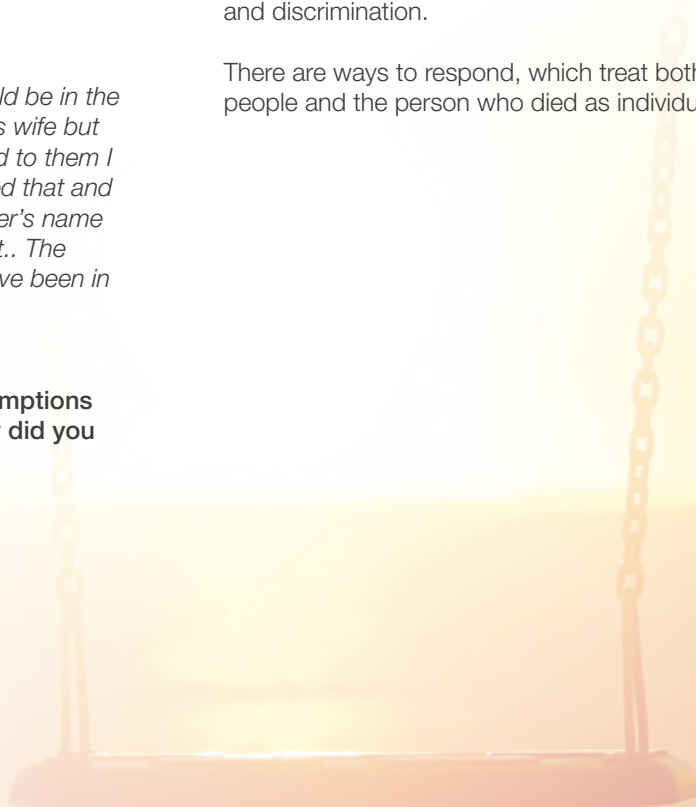
(Wife talking about ex-husband)

Think of a time when someone made assumptions about you and what you were saying. How did you feel? How did it affect the conversation?

A death affects everyone who knew the person - family, friends, extended family, colleagues etc. However, each of these people will grieve differently and their expressions of grief will fluctuate and change over time, perhaps for years. A bereaved person may not act as they normally would. Additionally, family members may be from different religions and cultures. Therefore people bereaved by the same death can react in a wide range of ways, including sadness, anger, depression, anxiety, shame, confusion, guilt, panic, blame, withdrawal, trauma and even relief (which can lead to feelings of guilt and remorse).

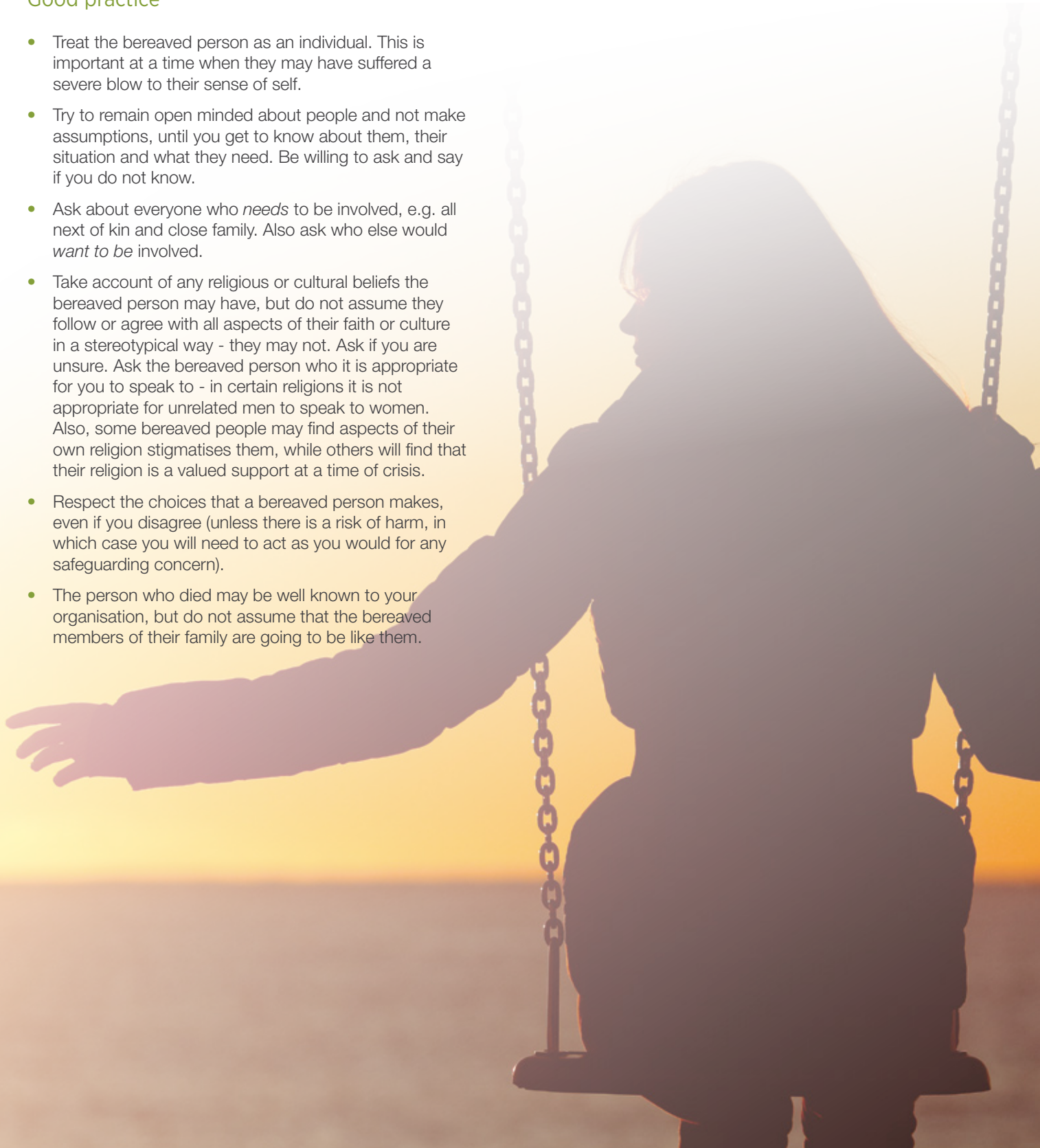
Furthermore, a situation can be complicated: The person who died may have a complex family network, including multiple partners. There may be more than one next of kin. The family may dislike the police and other official organisations. Families may have experienced domestic abuse from the person who died. Some people may not know that the deceased used substances, and others who do know might not want others to know. Some families can even split apart after a shocking and difficult death. Some of the bereaved may know nothing about drug use and be confused and frightened by it. Finally, some bereaved people may use drugs or alcohol themselves. They may have witnessed the death, feel guilty for sharing or using with the person who died, and now face stigma and discrimination.

There are ways to respond, which treat both bereaved people and the person who died as individuals.



Good practice

- Treat the bereaved person as an individual. This is important at a time when they may have suffered a severe blow to their sense of self.
- Try to remain open minded about people and not make assumptions, until you get to know about them, their situation and what they need. Be willing to ask and say if you do not know.
- Ask about everyone who *needs* to be involved, e.g. all next of kin and close family. Also ask who else would *want to be* involved.
- Take account of any religious or cultural beliefs the bereaved person may have, but do not assume they follow or agree with all aspects of their faith or culture in a stereotypical way - they may not. Ask if you are unsure. Ask the bereaved person who it is appropriate for you to speak to - in certain religions it is not appropriate for unrelated men to speak to women. Also, some bereaved people may find aspects of their own religion stigmatises them, while others will find that their religion is a valued support at a time of crisis.
- Respect the choices that a bereaved person makes, even if you disagree (unless there is a risk of harm, in which case you will need to act as you would for any safeguarding concern).
- The person who died may be well known to your organisation, but do not assume that the bereaved members of their family are going to be like them.



Key message 4 – Everyone can make a contribution

This message involves taking responsibility for the contribution you can make. It follows the same approach that is used for safeguarding children and vulnerable adults (Safeguarding Vulnerable Groups Act, 2006). This does not commit you to going beyond your role, but rather is a reminder to do all that you can, like when safeguarding a child or vulnerable adult.

If you have worked with a person bereaved through a substance-related death look back now and consider if you did all that you could in the circumstances? If you have not worked with someone yet, take a moment to consider all that you could do and how you would do that. Next, consider how you would feel following these two experiences.

“The fact of the matter is I did feel desperately let down...a young man fighting for his life and surely somebody in that A&E department would have had the decency to say, ‘Well I think he needs next of kin,’ but no, they didn’t...”
(Mother talking about son)

“The police were great; they couldn’t have been any nicer. They really couldn’t. The liaison officer I think it was, there was a man and a woman and the two of them they really were awful, awful nice. They couldn’t do enough to help us...”
(Mother talking about son)

These quotes illustrate the importance of the contribution we can all make to helping a bereaved person and how our contributions can affect their grieving.

Good practice

- Do not be afraid of speaking to the bereaved person about the death; it is often worse for them when it is not acknowledged. Also, you may need to know certain details to do your job.
- Take a moment to explain your job and any procedures or processes when you first meet. Avoid overloading people with information and jargon. If you have more than one role, such as police officers who may inform someone of the death and then take a statement, explain these roles too. Where possible back up what you say with written information, a leaflet or websites.
- Use the thoughts and ideas you had in response to our question above to consider the contribution you can make, what you can actually do, even if that is limited. Consider what will help you to be able to do that.
- Ask the bereaved person what will help and what they want of you. Be willing to really listen. Do not assume that someone else will help and support them.
- If the task of breaking the bad news falls to you, bear in mind that how you do so will have a lasting impact on the bereaved person and set the tone for any later communication. The NHS, BMA and the Police have produced guidelines for handling this as sensitively as possible, e.g. *Brake Family Liaison Officer Handbook: Breaking the bad news*. These include offering to contact someone the bereaved person wants to be with them and support them initially.
- If you are worried about a bereaved person, e.g. they seem severely shocked, very disorientated, or in a very low mood, follow your organisation’s safeguarding policy. Do not be afraid to ask them ‘has it been so bad that you have wanted to kill yourself?’ Any suicidal ideas need to be taken seriously by you and acted upon as any other safeguarding concern.
- Avoid appearing to put your role or your own professional reputation before doing your job in a way that is sensitive to the bereaved person, e.g. being defensive if you make a mistake.
- It is obvious, but avoid saying how busy you are, or making commitments you cannot keep.
- Identify local and national organisations so you can ‘signpost’ the bereaved person to further help (see key message 5).
- If practical in your job, give the bereaved person your contact name, phone number and email so that if they have any questions later they will not need to describe the situation all over again to a stranger.

If you work with the same bereaved person many times

- Plan ahead, ideally with the bereaved person, and be clear about how long you can work with them. Pace your interventions, especially when the bereavement is new, so as not to overload the person. Consider whether your work tasks can happen one at a time rather than all at the same time. The latter could well be harder for a bereaved person to cope with, so we suggest avoiding that approach if possible, e.g. a police officer needing to both inform someone of the death and take a statement could arrange to come back on another occasion to take the statement.
- As time goes by provide updates on what is happening, even if it is to say that there is no news at the moment. Offer information about help and support again, because the person's needs may have changed or they may not have remembered what you have previously told them. If appropriate to your role, be mindful of key dates, like an inquest or court case, or the anniversary of the death.
- Make sure the bereaved person is aware of who will assist them when you have completed your own work; this will make the support they receive continuous.
- Consider how you will end your work with the bereaved person. Be mindful that you may have been their lifeline and that losing you could be emotionally difficult for them. Give plenty of warning of the end, avoid appearing to 'pass the buck', and actually say 'goodbye' in your own way.



Key message 5 – Working together

The research which informed these Guidelines highlighted that it is really difficult for bereaved people to access help and support when organisations do not work together. It is challenging for practitioners to be familiar with all the national and local services which are available, and with their processes and procedures.

Consider for a moment the impact these experiences had on the bereaved people concerned:

“If it is 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 do not fit anywhere either... So you feel like you fall between everything and there is nothing that I can see particularly for families where it has been drugs.”
(Mother talking about son)

“[The police] just came in, stood in the middle of the room, told me [my son was dead], stayed for two minutes and then went.”
(Mother talking about son)

Have you dealt with a person bereaved through substance use before? If you have, do you consider you worked well with other organisations, or can you see now that more could have been done? If you have not worked with someone before, give a little time right now to consider who you would need to work with.

Good practice

- As a minimum, identify all the local and national organisations (see Resources section) that could help, so that you can effectively ‘signpost’ bereaved people to further help. This will help you by spreading the workload and it is only by working with other organisations that you can be fully effective. Have contact details to hand and check regularly that these are up-to-date.
- While there are few services across the UK to support people bereaved by substance use, there are some excellent examples of good practice, e.g. the Adfam-Cruse project, Bereavement Through Addiction, DrugFAM, Family Addiction Support Service, Scottish Families Affected by Alcohol and Drugs and Spoda (see Resources section). Identify the organisations that are relevant for your area and include them in the information you give.
- When referring on to another organisation it helps if you know a bit about it and even have named contacts who you or the bereaved person can speak to. However avoid giving the impression that you are ‘passing the buck’.
- Have a ‘tell us once’ (see Resources section) approach, where one person in your organisation takes responsibility for the bereaved person – could that be you? This person would ideally co-ordinate with other organisations so there is a joined-up approach. In the absence of this, consider how you can work with other organisations to ensure the bereaved person is at the centre of things.
- Take account of any joint-working protocols your organisation has, such as about sharing confidential information. Do you know about these and do you use them? Often there can be a gap between policies and actual working practice.
- Funeral Directors can be a key resource when dealing with bereavement issues, such as knowing about relevant services and organisations.

Going beyond the basics

- One way to make it easier to work together is for local services, the police and legal representatives to collaborate to produce an information leaflet for bereaved people, explaining the procedures that these organisations need to follow and giving details of local organisations that offer further support. For an excellent example of such a leaflet, see the Family Addiction Support Service (FASS) in the Resources section.
- Regardless of how familiar you are with this type of bereavement, it may be helpful for you (and your colleagues) to contact national or local organisations that work with families affected by substance use and listen to their experiences, including where deaths have occurred. This will provide insight into the effect that these deaths often have on a family, the complex issues involved and how the right support can really help. Over the longer term, consider continuing professional development in this area and forging strong, regular and effective links with other organisations.



Guidance for particular circumstances you may encounter

You or your organisation worked with the person who died

If you have known the person who died in a working capacity, your thoughts and feelings about what happened may be very different from those of the bereaved person you are working with.

The bereaved may criticise you or your organisation for not doing more to stop the death occurring. Indeed, you may even share their view. It usually helps defuse the situation by acknowledging how they feel, e.g. *'I understand just how angry you are about...'* (Notice how this does not include taking responsibility for something you did or did not do). In bereavement, anger can be misplaced away from the individual who died and onto others or onto organisations. If you feel guilty and assume some responsibility for the death, such as being the paramedic or the dead person's drug worker, remember that guilt is often a normal reaction even though you are not responsible or did all you could in the circumstances. If this happens, we encourage you to take advantage of any help to enable you to cope with the impact on you.

If the person who died was well known to you in your professional or private life, it might not be appropriate for you to work with the people bereaved.

Circumstances of the death and how the person was found

This may be particularly distressing or confusing for the bereaved, e.g. the body may have been discovered outside or there may have been long delays before the bereaved could see the body. Establishing how and why someone died is an essential part of bereavement. Therefore:

- Say what you know and explain any procedures, as far as your role allows.
- Bereaved people are typically distressed, frustrated and confused when the circumstances of the death are not investigated fully and questions are left unanswered. This can prolong and complicate their bereavement. If it is part of your job to investigate the circumstances of the death, be aware of this and regularly update the bereaved on progress with, or delays to, the investigation.

Seeing and touching the person who died

For many bereaved people it is really helpful if they can see and touch their loved one, and they may also want to dress the body for the funeral. However, following some deaths it is not possible to touch the body because of infection control policies and occasionally it is not possible to see the body. This can be made worse when bereaved people are not told why.

We recognise that hospital mortuaries and funeral directors have obligations, such as infection control policies and confidentiality, and will also want to be helpful to the bereaved. Good practice involves:

- Balancing your obligations with compassion.
- Maximising the possibility of the bereaved person seeing and ideally touching the person who died, if they wish, by working together, using your influence, sharing as much information as you can with other organisations and following local infection control procedures.
- If relevant, talking to the bereaved person about what this will involve (particularly if the body is in a poor condition) and offering them support to decide whether they want to see them.
- Where relevant, explaining in an open and honest way why there needs to be limited, or no, contact with the person who died and acknowledging to the bereaved person that you understand the impact that this has on them.
- Being willing to ask for help and guidance in situations with which you are unfamiliar.

Confidentiality of the person who died

The person who died is still entitled to the same confidentiality about their medical history and treatment as when they were alive. If you have to keep certain information about the dead person confidential, this will limit what you can say to a bereaved person. Good practice involves:

- Taking time to say why confidentiality is necessary.
- Acknowledging the bereaved person's response, e.g. *'I appreciate how frustrating confidentiality is for you'*.
- Balancing the limits on what you can say with compassion and a willingness to explain.
- Avoiding giving the impression you are hiding behind confidentiality. If you are unsure of how much you can say then seek advice.

Official investigations relating to the death

Many, but not all, substance-related deaths require a post-mortem and official investigation by the police and legal authorities (the coroner in England, Wales and Northern Ireland and the procurator fiscal in Scotland). There may also be a criminal investigation resulting in a court case, e.g. if someone else was involved with the death. Bereaved people can be shocked, stressed and distressed by these official procedures and how long they take. So do offer information, including:

- In England, Wales and Northern Ireland relatives can appoint their own doctor or medical person to be present at the post-mortem investigation. While in Scotland this is not an option, in a criminal case the accused can ask for a second post-mortem with an independent pathologist after the initial post-mortem.
- Relatives are entitled to see post-mortem and toxicology reports, and in England, Wales and Northern Ireland transcripts of the inquest. However, remember that the graphic content and the impersonal, formal style of these documents can be shocking and very distressing for bereaved people. In Scotland there is no charge for access to any documentation, although charges may apply elsewhere in the UK.

In other words, do all you can, and work with others, to inform and to help minimise delays to these procedures (see Resources section).

Paying for a funeral

For some bereaved people the cost of the funeral can present a significant difficulty. Though there is state support from the Department for Work and Pensions' Funeral Payment (see Resources section), applying for a Funeral Payment can be onerous and stressful. If the application succeeds, the amount is often far short of the total cost of the funeral. Also, the Funeral Payment decision may not be made until after the person has paid up front for the funeral, risking a fall into debt. Some funeral directors may agree to wait for payment.

Bereavement Payment

Someone under state pension age whose husband, wife or civil partner has died may be able to get a Bereavement Payment. This is a one-off, tax-free, lump-sum payment of £2,000 (see gov.uk/bereavement-payment).

Some local and national resources for adults bereaved through substance use

Adfam and Cruse joint project for those bereaved through substance use. From 2015, this project will train and support bereaved people as 'experts by experience' who then provide help and support through a befriending scheme, structured phone support using counselling skills, and delivering peer support groups in the community. See below for Adfam and Cruse websites.

Adfam adfam.org.uk Has listings of local groups and services for people affected by someone else's substance use, most of which are not exclusively for bereavement.

Alcohol Concern alcoholconcern.org.uk Free factsheet on their website on alcohol and bereavement.

ALISS aliss.org A local information system for Scotland that signposts support.

Benefits and death gov.uk/browse/benefits/bereavement Information on state benefits.

Bereavement payment gov.uk/bereavement-payment. Potential one-off payment for those aged under 65.

Bereavement Through Addiction bereavementthroughaddiction.com Provides support groups, a helpline and an annual memorial service in Bristol.

Coroner's Court guide gov.uk/government/publications/guide-to-coroner-services-and-coroner-investigations-a-short-guide Information on the Coroner's Court and Inquests in England and Wales.

Crown Office and Procurator Fiscal (Scotland) copfs.gov.uk/investigating-deaths. Information on the investigation of deaths in Scotland that require further explanation.

Coroners Service for Northern Ireland courtsni.gov.uk/en-GB/Services/Coroners/Pages Information on the investigation of deaths in Northern Ireland that happened in sudden or unexplained circumstances.

Cruse Bereavement Care cruse.org.uk/drugs-and-alcohol Provides bereavement support.

Cruse Bereavement Care Scotland crusescotland.org.uk Bereavement support for people in Scotland.

DrugFAM drugfam.co.uk Free 'Bereaved by Addiction' handbook; a support project for bereaved young people aged 18-30; an annual conference for people bereaved by substance use; a quarterly support group; one to one support; befriending visits; and telephone, Skype and email support.

FASS (Family Addiction Support Service) fassglasgow.org Supports families in Glasgow affected by substance use, including bereavement counselling. Peer support groups including bereavement. Yearly memorial service. Information leaflet produced in partnership with Police Scotland, email info@fassglasgow.org for a copy.

Funeral payments gov.uk/funeral-payments/overview Possible financial help with funeral costs.

Inquest inquest.org.uk Free advice to people bereaved by a death in custody.

Media guidelines on reporting suicide Written for death through suicide, this pdf contains much relevant guidance for the media
samaritans.org/sites/default/files/kcfinder/files/press/Samaritans%20Media%20Guidelines%202013%20UK.pdf

Ministry of Justice justice.gov.uk/downloads/burials-and-coroners/guide-charter-coroner.pdf Booklet on Coroner's and Inquests.

Samaritans samaritans.org Help with any difficulty, including suicidal thoughts.

Scottish Families Affected by Alcohol and Drugs (SFAD) sfad.org.uk From June 2015 offers specialist bereavement counselling and information following a substance-related death. Also provides links to groups supporting those bereaved by substance use. SFAD are working with Edinburgh University to research families/close others who have been affected by alcohol and other drugs, in order to improve support services in Scotland.

Support After Murder & Manslaughter samm.org.uk Support for families bereaved by murder and manslaughter; also provides advice and training for other agencies.

Survivors Of Bereavement Through Suicide (SOBS) uk-sobs.org.uk Support for people bereaved through suicide.

The Compassionate Friends (TCF) tcf.org.uk Provides a helpline and local support groups, as well as various online resources, for bereaved parents and siblings.

Tell us once gov.uk/after-a-death/organisations-you-need-to-contact-and-tell-us-once A government service to report a death to most government organisations in one go.

Resources for children and young people bereaved through substance use

ChildLine childline.org.uk Confidential service for children and young people up to the age of 19.

Hope Again hopeagain.org.uk Cruse's free on-line service for bereaved young people up to the age of 18 and a helpline for young people up to the age of 25 (0808 808 1677).

Winston's Wish winstonswish.org.uk A charity for bereaved children.

Further Reading

1. Orford et al. (2005) *Coping with Alcohol and Drug problems: The experiences of family members in three contrasting cultures*, London, Taylor and Francis
2. Valentine, C., Bauld, L. and Walter, T. (forthcoming 2016) Bereavement following substance misuse: A disenfranchised grief. *Omega Journal of Death Studies*.

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Project Summary

'Understanding and Responding to Families and Individuals Bereaved by a Drug or Alcohol-related Death'

Funded by the Economic & Social Research Council, this is the first large-scale study of a largely neglected though sizeable population of bereaved people. Based in the University of Bath's Centre for Death and Society, and in collaboration with the University of Stirling, the study has combined the expertise of bereavement researchers, substance use researchers and a bereaved family member advisor. The researchers interviewed 106 bereaved adult family members and conducted 6 focus groups with 40 practitioners, some of whom were also bereaved through substance use. The interviews and focus groups identified both the challenges bereaved people face in their contact with various organisations and agencies, and the pressures and constraints under which workers and professional often work. These findings informed a Working Group of 12 practitioners (some also bereaved) tasked with developing these Guidelines.

go.bath.ac.uk/bereavementresearch

Reference

Peter Cartwright, *Bereaved Through Substance Use: Guidelines for those whose work brings them into contact with adults bereaved after a drug or alcohol-related death*. University of Bath, 2015.

Further copies of these Guidelines are available from the Centre for Death and Society (CDAS), at <http://www.bath.ac.uk/cdas/>

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