

BEAD
Bereaved through
Alcohol and Drugs

Consultation findings for the

BEAD project

BEAD: Bereaved through
Alcohol and Drugs

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The BEAD project is a partnership between
Cruse Bereavement Care and Adfam



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Overview

Adfam and Cruse Bereavement

Care undertook an exploration of the experiences of families and friends bereaved through drug and/or alcohol use, with the aim of developing a range of peer support services and targeted information specifically for people bereaved in this way, as part of a Big Lottery funded partnership.

People bereaved through substance use face a unique set of complex emotional and practical problems. However, despite the unique challenges presented by drug and alcohol-related bereavement, and the many thousands of people affected by it each year, this is an under-researched area and one where available services, support and relevant information are extremely limited.

Background

This report outlines and discusses findings from a consultation conducted by Cruse and Adfam in 2014 into the experiences and views of people bereaved through drug and alcohol use. Its purpose was to find out more about the support this group of bereaved people had or had not received, both immediately after their loved one died and in the longer term, as well as asking what support they felt would be most beneficial. This has closely informed the direction Cruse and Adfam's BEAD project is now taking. Cruse and Adfam would like to record their thanks to all those who responded to the survey and/or took part in phone interviews and consultation workshops as well as the organisations which promoted the consultation, in particular the University of Bath and DrugFAM.

Whilst all types of bereavement can be very difficult and painful for loved ones, there are certain factors which can complicate and exacerbate the grieving process when the bereavement is related to drugs and alcohol. Family members' responses showed that the following factors are particularly important:

- Drug and alcohol-related bereavement can cause immense damage to families and to relationships within the family, and an inability to grieve can lead to prolonged mental health issues.
- It is not uncommon for families to blame themselves, and if the person who died was seriously ill or deeply unhappy before their death, this can evoke many conflicting feelings for those left behind.
- A lack of information about their loved one's treatment and incredibly difficult choices about how to support their loved one before they died can make the experience of grieving very complicated. Family members are often left with many unanswered and sometimes unanswerable questions.

- The circumstances of death can be particularly traumatic.
- Attitudes by professionals, authorities and wider society to drug and alcohol deaths can lead to a feeling of stigmatisation for bereaved family and friends.
- Drug and alcohol deaths are often viewed as less acceptable by society, due to perceptions and judgements around immorality, illegality, poor choices and deficient parenting.
- The shame and stigma that result from these attitudes can present an obstacle in seeking informal and professional support.
- Media attention and sensationalist coverage of the bereavement can exacerbate the challenges facing families, as well as delays in processing the death due to legal formalities.

Family members felt that in order to be effective, support needed to be non-judgemental and well-informed, and many welcomed the idea of support from peers, i.e. others who had been through a similar experience.

This report outlines the views of this group of bereaved family members in more detail. An in-depth exploration of relevant concepts from bereavement theory and research, and the ways in which families can be affected by substance use (including the impact of stigma) can be found in Adfam and Cruse's literature review of drug and alcohol bereavement, also produced as part of this project.¹

1. This can be seen online at www.adfam.org.uk/cms/docs/Adfam-Cruse_Drug_and_alcohol_related_bereavement_Scoping_review_-_October_2014.pdf and www.cruse.org.uk/drugs-and-alcohol

Consultation

1. Methodology

The findings in this study are derived from the following sources of data:

1. An online survey of 100 respondents

- The survey contained 31 questions; some of which were multiple choice (with optional comments) and others open-ended

2. Ten semi-structured phone interviews

3. Two additional materials provided by research respondents:

- A phone interviewee's account of her interaction with the Coroner's office
- A speech for a professional conference on the subject of the survey respondent's bereavement

The online survey was promoted through Adfam and Cruse national networks, websites and social media (including Adfam's policy briefing and Cruse's newsletter), as well as through project Advisory Group members: DrugFAM, Bereaved Through Addiction and the Centre for Death and Society at the University of Bath. The survey was open to families, friends and carers affected by drug and alcohol related bereavement.

Of the 48 participants who recorded how they came to hear about the survey, 90% stated that this was through Adfam.

Those who indicated a willingness in the survey to have further involvement with the project were contacted to see if they would like to participate in a phone interview. Interviews were held with seven survey participants, a woman referred through Cruse and a further two interviews were conducted with men referred directly through DrugFAM, to ensure a better balance of interviewee gender.

Percentages used in this report have been rounded to the nearest whole number.

1.1 Limitations

Given that participants were self-selected, the survey was vulnerable to sampling bias. In order to complete it, respondents must have been aware of the survey (and by proxy, at least one of the channels through which it was promoted), as well as having the capacity and desire to participate. This gives rise to common limitations when using convenience sampling: the sample cannot accurately be said to be representative of the entire population with experience of drug and alcohol related bereavement. Nonetheless, the findings are presented without assumption or adjustment.

Survey questions were not compulsory and respondents were able to choose whether or not to answer a given question. This means that every question has a different number of responses, and that percentages are therefore calculated from a different sized sample for each question.

2. The respondents

Gender

The majority of the 100 survey respondents were female (84%); whilst of the 10 telephone interviews conducted, seven interviewees were female and three male. This gender disparity is reflective of the typical profile of people who access support services. For example: one piece of research into gender differences in health and medication information seeking behaviour found that women are more likely to seek information than men,² whilst another study into help seeking behaviours in people with mental health problems (a group which often does not seek professional help) similarly found that men were less likely to seek help for their disorder than women.³ Various Adfam projects also corroborate this assertion that women access support services more readily than men.⁴

Age

The age-group to which the largest group of respondents belonged was 51–60 (28%), closely followed by 61–70 (27%). 19% were between 41–50, 12% were 31–40, 6% were over 70 years old and 5% were between the ages of 26–30. Only 3.6% of respondents were under the age of 25, with 1% under 16.

Sexual orientation

Of the 78 respondents to this question, 99% identified themselves as heterosexual and 1% as bisexual.

Disability

82 respondents answered this question, of which 84% did not consider themselves to have a disability as defined by The Disability Discrimination Act 1995.

Ethnicity

The majority of respondents (98%) identified as white. White British made up 56%; with 26% identifying as White English, 6% White Welsh, 4% White Scottish, and 4% White Irish. Three respondents identified as mixed race and one identified as Chinese: the lack of ethnic diversity is again typical of the profile of those accessing family support services in the UK, as evidenced in numerous Adfam projects.

Religion

Of the 77 who answered this question, 65% were Christian and 1% Buddhist. 34% did not belong to any religion.

Location

34% of respondents were from the South East of England; 18% from the South West; 12% London and less than 10% from each of the other regions.⁵ One respondent was based in Belgium.

Multiple bereavements

Respondents were asked whether they had experienced more than one drug or alcohol related bereavement. Only 25 respondents answered this question and, of these, 13 had experienced more than one drug or alcohol bereavement in the family, and seven in their friendship group.

2. Tong et al. (2014) 'Gender differences in health and medication information seeking behaviour – A review,' 20 *Journal of the Malta College of Pharmacy Practice* 14

3. Oliver et al. (2005) 'Help-seeking behaviour in men and women with common mental health problems: cross-sectional study,' 186(4) *The British Journal of Psychiatry* 297

4. For example Adfam's Family Champions project in Greenwich and the thirtieth birthday campaign

5. The nine Governmental regions of England

Prior support

In response to whether respondents had been receiving support prior to the bereavement, 77% of the 79 respondents to the question said they had not. 18% had been receiving peer support from a drug and alcohol family support group, and 9% had been receiving one-to-one support. Some respondents who had not been receiving support had not done so because they were either unaware of their loved ones' substance use or of the level to which it had escalated.

Personal drug/alcohol use

Although 21% of respondents said they had been using drugs or alcohol prior to their bereavement, this was usually in the context of using alcohol socially rather than drug or alcohol dependence, and only 9% reported having sought help for their own drug or alcohol use in the past.

When asked whether their bereavement had caused a change in attitudes towards drugs and alcohol, 54% of respondents replied in the affirmative; with many referring to their improved knowledge of the effects of drugs, alcohol and dependence. Several said that they were now more aware of the amount of alcohol they consume: for example, one respondent said the bereavement had led her to completely refrain from alcohol out of fear of the impact on her children.

3. Findings

3.1 The bereavement

Relation

Almost half the respondents to the online survey had lost a child (49%), whilst 19% had lost a spouse or partner, 15% a parent and 10% a sibling. Other relations noted included: extended family member (3%), friend (3%), grandchild (1%) and grandparent (1%). Similarly, five of the 10 phone interviewees had lost a child, two a partner and the remaining three had lost a friend, nephew and parent respectively. The nature of the relationship is not always an indication of the impact that death may have on a family member or friend – an important factor to bear in mind when offering support and information.

Time passed since bereavement

Many of the survey respondents had experienced bereavement within the past two to five years (35%), followed by 26% having been bereaved in the last five to 10 years. 23% had lost a loved one within the year prior to the survey.

Substance

Of the survey respondents, 40% had experienced a drug-related bereavement, compared with 34% for alcohol; whilst 29% of respondents noted that both drugs and alcohol had been involved. Five phone interviewees had been bereaved through alcohol, four through drugs and one bereavement was attributed to both drugs and alcohol.

Receipt of treatment

59% of survey respondents said their loved one had not been receiving treatment at the time of death. However, many noted that they were unaware as to whether their loved one had been receiving treatment or not, due to the fact that they had been estranged at the time of death. Of those who had been receiving support, responses indicate that this was primarily through drug

and alcohol treatment services, although mental health and psychiatric services were mentioned by several respondents. Some had also been in receipt of opioid substitution treatment (whereby illegal opioids such as heroin are replaced by longer-lasting but less euphoric opioids such as methadone and buprenorphine) prior to their death.

It was not always clear from phone interviewees whether their relative had been in treatment at the time of death. However, it seemed that the majority had been in contact with treatment services or health professionals at some point prior to their death, albeit possibly not at the time.

Age

Bereavements most often occurred when the person who died was aged between 26 and 50, with 31–40 being the most common age group. Only 1% had lost a loved one who was under 16 or over 70 years old. This tells us that whilst the majority of survey respondents had lost a child through drug or alcohol bereavement, these were adult children. 11% had lost a loved one who was between the ages of 16 and 20 at the time they died.

Cause of bereavement

The most common cause of death reported was overdose (45%), followed jointly by long-term chronic illnesses and sudden, unexpected health issues (20% respectively). Others had lost a loved one through suicide whilst under the influence of drugs or alcohol (14%), due to an accident whilst intoxicated (11%) or as a result of short-term illness (2%). In the accompanying comments section, respondents were invited to expand upon their replies: there were several references to cirrhosis of the liver, organ failure and accidental death as explanatory causes.

Of the phone interviewees, four had been bereaved due to overdose and two due to a long-term health condition. A further two respondents noted the cause of death had been a sudden, unexpected health issue. One respondent's relative committed suicide under the influence of drugs and alcohol, and the other died following an accident while under the influence of alcohol.

3.2 The effectiveness of support

The focus of the research was primarily to obtain a clear picture of the support available to and accessed by those bereaved through drugs and alcohol, and their experiences of this support where it was accessed. Respondents were asked to identify sources of support with which they had contact immediately following and in the long-term after their bereavement, and to rate their effectiveness and sensitivity on a five point scale: 1 being 'not at all effective or sensitive', and 5 being 'very effective and sensitive'.

Overall, family and friends were considered the most effective and sensitive sources of support in the immediate aftermath and longer term; offering practical and emotional support and providing an opportunity to discuss the deceased together (something which respondents indicated was helpful in coming to terms with their bereavement). In the immediate aftermath, 58% of respondents rated their own family's effectiveness (as a source of support) and sensitivity between 4 and 5 on the scale; which reduced to 51% in the longer-term. Approximately a quarter (26%) of respondents considered their family had been ineffective and insensitive (rating between 1 and 2). Similarly, 57% rated friends between 4 and 5 in the immediate aftermath, but this fell to 47% in the longer-term. The family of the person who died were also found by many respondents to have been effective and sensitive: 45% in the immediate aftermath and 41% longer-term.

In terms of professional services, experiences of support varied greatly both amongst respondents and the sources of support accessed. In the immediate aftermath, counsellors and coroners were considered to be the most effective and sensitive, with 46% and 44% respectively rating them between 4 and 5 on the scale. GPs and counsellors received mixed ratings: 31% reported GPs had been effective and sensitive (between 4 and 5) and 39% said they had not been at all effective or sensitive (rating of 1); whilst 46% thought counsellors had been effective and sensitive and 27% thought they had been 'not at all effective or sensitive.'

Many professional services received negative ratings overall: 76% of respondents rated drug treatment services as 'not at all effective or sensitive', 74% afforded social services the same rating, and hospitals, paramedics, bereavement peer support groups and family support services were all rated as 'not at all effective or sensitive' by more than 50% of respondents. The majority of respondents were also dissatisfied with their contact with the police in the immediate aftermath, with 61% either affording them a rating of 1 or 2. However, when we consider the comments relating to drug treatment services and social services (the agencies which fared most negatively in the ratings), it appears that rather than having had bad experiences with these services, the poor ratings may reflect a lack of involvement: many commenters said they had received little (if any) contact with these two services in particular.

In considering the effectiveness and sensitivity of professional services in the longer term, drug and alcohol family support groups, GPs and bereavement helplines or groups were rated most highly (53%, 44% and 43% of respondents respectively rating the services either 4 or 5 on the scale). In fact, a higher percentage of respondents rated drug and alcohol family support groups between 4 and 5 than their own family and friends; although, only 11% said their family and 13% said their friends had not been at all effective or sensitive, whilst 32% said so of drug and alcohol family support groups. Other services were considered less effective: 90% of respondents thought the police had been ‘not at all effective or sensitive’, as well as 89% for social services, 83% for drug treatment services and 50% for bereavement peer support. Several respondents stated that bereavement peer support had either not been offered or was not available, and all 15 respondents who rated victim support considered it had been ‘not at all effective or sensitive.’

Again, the accompanying comments, taken together with the highly negative scores for certain services, suggest that those agencies rated very badly were those with which respondents were either not involved or from which they had very little contact. As such, these scores may be at least partially attributable to an absence of contact with these services, rather than a lived negative experience. In other cases, negative ratings may be due to insensitivity and experiences of stigma from professional services, coupled with a lack of understanding around substance use in some services, and drug and alcohol-related bereavement in others – and sometimes both. Generally, professional support fared more negatively than informal sources in the short and long term following bereavement.

3.3 An analysis of experiences of support

Research respondents received varying levels of contact and support from informal sources (such as family and friends) and professional services – and their experiences will inevitably greatly differ. Nevertheless, whilst each person’s experience of drug and alcohol bereavement is unique to them, a review of the responses and comments highlights a number of common points.

3.3.1 Stigma and a lack of understanding: what difference does the involvement of drugs and alcohol make to experiences of bereavement and support?

Pervasive throughout the examination of consultation responses is the lack of understanding around drug and alcohol use and drug and alcohol related bereavement in professional services and wider society. This was thought by respondents to be fuelled by the stigma associated with substance use. When asked about their negative experiences, respondents referred to hurtful comments from friends, family members, neighbours and colleagues, which they attributed to their lack of understanding of and, in turn, compassion towards drug and alcohol dependence.

“If the wider public understood more about the process of addiction, maybe friends would have better understood what I was going through and felt less inclined to apportion blame.”

(Ex-husband, Survey Respondent)

A number of respondents described instances where friends and family members would assume the death was ‘expected’ and that respondents, therefore, should be relieved:

“People assumed that because he was a junkie it was to be expected and, therefore, not such a shock. I was very aware of the stigma attached to being a partner of someone with a drug problem.”

(Wife, Survey Respondent)

The evidence suggests that irrespective of whether someone has actually experienced prejudicial attitudes first-hand, the stigma surrounding substance use is so well-acknowledged and pervasive throughout society that its impact will nonetheless be felt: several respondents reported a reluctance to speak openly about the bereavement and seek support, out of fear or presumption that others will be judgmental or cruel. The debilitating effects of stigma additionally meant that respondents commonly experienced deep feelings of shame.

“Friends didn’t understand and I also felt awkward in talking with them about the bereavement.”
(Daughter, Survey Respondent)

“The problem I had was my own shame, I suppose, in admitting the cause of my son’s death.”
(Mother, Survey Respondent)

Respondents similarly criticised professional services for insensitivity and even discriminatory attitudes: the police, coroners, medical professionals and hospitals were all, to varying degrees, said to have been uncompassionate and judgemental. One interviewee, whose nephew had been badly beaten prior to his death from a heroin overdose, described her contact with the police following the bereavement:

“I tried to pursue the assault committed against him, but he was a dead heroin addict, so who cares? He was just another junkie off the streets – that was the pattern from everyone.”
(Aunt, Phone Interviewee)

Another survey respondent wanted to get this message across to professionals:

“With a drug death, society doesn’t want to know. It happens to someone else, not me. There’s a sense that parents don’t care or weren’t looking after them...and [it] is not always about deprivation.”
(Father, Phone Interviewee)

Stigma was also reported in family support, drug treatment, and bereavement services: one survey respondent who accessed a particular bereavement service explained that because of the relationship with drugs, the group was extremely judgemental and would often ‘push people out of the group’ if they had experienced a drug-related death.

The impact of stigma on the bereaved becomes truly evident when taking account of both the consistency and volume of comments highlighting this particular issue as a key barrier to accessing support – and as a central reason for negative reports of support.

Upon being asked to outline a critical message for professionals and, later, to note any further comments, respondents repeatedly made explicit and implicit references to stigma. Many drew attention to the perception of drug and alcohol related deaths as ‘illegitimate’, and called for equal treatment to people bereaved through more ‘legitimate’ reasons, such as illness or road traffic accidents. Some comments included:

“We deserve to be treated like families who have lost someone to cancer.”
(Mother-in-law, Survey Respondent)

“I felt stigmatised by services. Health and social care services treated me well until they found out the cause of my mother’s death. Then I was treated differently.”
(Daughter, Survey Respondent)

This stigma is a major contributor to respondents’ belief that drug and alcohol bereavements are unique – and that services are so far failing to sufficiently understand and appreciate the specificity and uniqueness of drug and alcohol related bereavements.

“It affects everything, the support we received, society treats drug users as scum, this perpetuates their use, when something does happen to them their stigma continues for us.”
(Aunt, Phone Interviewee)

3.3.2 The crucial elements of support: what should support look like?

“The point about dealing with bereavement is not about ploughing them full of pills, but to know that somebody cares.”

(Brother, Phone Interviewee)

Based on respondents’ accounts of positive and negative experiences of support in the aftermath of a drug or alcohol related bereavement, it is possible to form a picture of what might constitute effective and sensitive support from the perspective of those bereaved in this way.

Targeted support from peers

Comments indicated that in order to feel effectively supported, it was necessary to feel able to talk about the deceased and ‘keep their memory alive’, whilst also feeling sufficiently comfortable to be able to ‘let it all out’, without being judged. Respondents more often than not simply wanted ‘someone to listen.’

The need to feel able to openly discuss the bereavement and the complex feelings around it, to feel understood, not feel judged and to have someone to listen, suggests that targeted support could be highly effective for those struggling with this type of bereavement. Many respondents were categorical in their belief that drug and alcohol bereavement is a unique and specific type of bereavement, warranting targeted support – and this desire was elicited by some in the form of peer support:

“I think I would have benefited from more contact with others in the same situation. More peer support groups would be good.”

(Mother, Survey Respondent)

“I would love to join a support group specifically for widows of addicts. It can be really difficult sharing with those who were bereaved through other illness or accident. It also brings up a lot more complex grief, I think.”

(Wife, Phone Interviewee)

Whilst the majority of respondents had not accessed peer support, some had been in contact with Al-Anon (an organisation which runs peer support groups for families affected by a loved one’s alcohol use) and had found it enormously helpful. One participant described having met someone who had also lost their father to alcohol problems at an Al-Anon meeting:

“The relief of being able to sit down and talk to him – someone other than close friends or husband – without feeling like they’d look at you as if you had eight heads was enormous. I wanted that one-to-one connection with someone who had been through it.”

(Daughter, Phone interviewee)

Of the few other respondents who had accessed peer support, this was not always face-to-face: some respondents had sought telephone and online peer support to help cope with the bereavement. Although, one phone interviewee who had accessed peer support online forums stated that she would have preferred ‘personal support’ had it been available. This gap in provision drove at least two respondents to set up their own peer support group following their bereavement, and another facilitated a peer support group on behalf of a third party organisation. Respondents when asked what they would have benefited from and what had helped during their bereavement, a significant number talked about meeting others who had been through a drug and alcohol related bereavement, and who were thus understanding and non-judgemental.

The demand for peer support – or ‘targeted support’ generally – was clearly illustrated throughout the survey.

Providing information about substance use and about drug and alcohol related bereavement

The provision of reliable and accurate information around substance use and dependency was repeatedly raised by respondents. Firstly, many voiced their frustration at not having been provided with relevant information relating to the risks associated with drug and alcohol dependency prior to the bereavement: for example, one respondent, who had been in contact with her son's treatment service still struggled to accept that she was not given any practical information about his dependency issues:

"If we had been given more information about [son's] medical condition in the months prior to his death, we would have done things differently."
Mother, Survey Respondent)

This left respondents feeling that they had been kept 'in the dark' when they should have been informed and consulted. A number of people stated that the lack of consultation with the family before the death (usually based on confidentiality agreements or concerns) actually compounded their distress in the aftermath of the death. One woman who had not been informed of the extent of her son's problems and, as such, went on holiday and was out of the country when her son died, said:

"I've never experienced alcoholism. I was never explained to or told it could happen quickly. If someone had sat us down and said, 'This is a possible scenario, this is your son's case, it's a possibility he could die' ...I can't get over that: nobody said this could happen. There's no way I would have left in that case."
(Mother, Phone Interviewee)

It would appear that the provision of information around drug and alcohol bereavement would be highly beneficial for those experiencing a drug or alcohol bereavement for a number of reasons, including to encourage people to manage any feelings of self-blame, guilt and a multitude of other negative emotions:

"Information about bereavement following drug-related deaths [would have been helpful]. I felt very alone and ashamed of what had happened. I felt guilty and a bad parent."
(Mother, Phone Interviewee)

Other respondents also noted how, as a result of learning more about dependency since their bereavement, they felt more able to understand the choices made by the deceased and, in turn, were provided with a sense of comfort.

"I found learning more about addiction enormously helpful in understanding my father and also myself."
(Daughter, Phone Interviewee)

Specialist, non-judgemental support from professionals

As noted above, stigma, fear of judgement and discrimination and the resulting isolation, shame and guilt are significant impediments to accessing effective support services. To help combat these issues, some respondents recommended that professionals receive training to be able to appropriately and sensitively deal with people bereaved through drug or alcohol use and offer suitable forms of support:

"The police simply had no idea. They should receive better training on how to deal with families in our situation."
(Father, Survey Respondent)

Several respondents noted a lack of experience particularly amongst police officers and GPs, as well as professional services without specialism in drugs and alcohol and/or bereavement. Again, comments indicated a desire for the provision of training to those services not directly involved in drug treatment, family or bereavement support to be able to effectively engage and support people bereaved in difficult circumstances, including through substance use. Where positive experiences were captured, professionals were described as ‘compassionate’, ‘non-judgmental’ and being in regular communication.

“What if it was your child, your mother, your sister? You need to imagine it and feel it for yourself. You need to ask ‘how you would like to be treated if it happened to you?’ You can’t assume that person was bad. The main thing is empathy. What if it was your child?”

(Aunt, Phone Interviewee)

As with peer support, targeted professional support in the context of drug and alcohol related bereavements seemed patchy from respondents’ accounts. Speaking of her contact with a bereavement support service, one respondent said: “The counsellor was helpful but remarked that she’d had no experience of drug related deaths.” An interviewee who lost her father due to alcohol-related illness also explained that despite being ‘reasonably familiar’ with the agencies involved in substance use, she was unable to find support for coping with the bereavement. Upon then finding a bereavement support group not specialising in drugs and alcohol, the same respondent said,

“I wanted that connection with someone who understood the challenge of dealing with a substance use disorder, but bereavement-wise it was lacking. A separate group would have been helpful.”

Indeed, whilst drug and alcohol family support groups can be unsure of knowing how to address the impact of the bereavement, bereavement services can lack specialist knowledge around drugs and alcohol; thus leaving a significant gap in service provision.

A parallel project by the Universities of Bath and Stirling has led to the publication of guidelines specifically for professionals who come into contact with people bereaved through substance use, which represent a significant step forward in addressing this issue and one which the BEAD project wholeheartedly supports.

Increasing the availability of support

The vast majority of respondents reported that they had not been offered any support following their bereavement, despite having come into contact with several different services. GPs are in a prime position to ensure that people are made aware of and directed towards appropriate support services, given the often ongoing relationship and regular contact. Unfortunately however, many respondents said they had no contact with their GP following the bereavement. Moreover, others who did have contact with their GP likewise reported not having been offered or directed towards support. A lack of support and understanding from employers was also apparent: several respondents described having experienced judgemental and unhelpful attitudes from their employers, who had shown a lack of compassion and inflexibility around working arrangements.

As illustrated by the comments below, not being offered support seemed to be especially common amongst relatives other than the parents of the deceased:

“All attention was directed at my sister, as it was her son who had passed. No one acknowledged or understood my parental role in his life or how hard his passing was on me... Long-term, apart from DrugFAM, I received zero support from anyone and that continues to this day.”

(Aunt, Survey Respondent)

“I was ‘just’ her best friend... I felt like if I got professional support I would be seen as overreacting.”

(Friend, Survey Respondent)

In order to increase the number of people who access support following drug or alcohol related bereavements – and to prevent bereaved people from struggling to cope, unaided – respondents felt it was imperative to offer support to all those who want it, regardless of their relationship to the deceased.

3.4 The circumstances of bereavement

It was sought to determine whether experiences differed amongst respondents, depending on the circumstances of the death, i.e. whether it had been a sudden, unexpected death or due to longer-term health issues. It is important to acknowledge that some deaths were not as a result of long-term dependent drug or alcohol use, but as a result of experimentation or bingeing; which brings a different set of issues and a particularly strong sense of shock.

Some of those who had experienced a sudden bereavement spoke of hiding their loved one’s cause of death from others, whilst a substantial number described feelings of guilt and regret at not having done things differently or not having intervened at an earlier stage of the dependency. Respondents’ dissatisfaction with the effectiveness of drug and alcohol treatment services whilst their relative was alive was evident. A phone interviewee put it simply:

“Really, I wish the support had been there to stop them from dying in the first place.”

(Wife, Phone Interviewee)

Descriptions of feeling as if their lives were ‘on hold’ in the period before the bereavement were plentiful; both where deaths were sudden and as a result of known, longer-term conditions. This was due to the fact that even where deaths were unexpected, those close to the deceased had often been grappling with the challenges brought about by the substance use and the consequent chaotic lifestyle for some time prior. This comment depicts a typical scenario:

“My life was just on hold. And in a way, we were anticipating the grief that was to come... it came that every time the phone rang I would be a shaky, quivering wreck because ‘what was this call going to be?’”

(Mother, Phone Interviewee)

Respondents' disappointment with the quality and level of support provided to themselves and their loved ones prior to the bereavement was clear. Consequently, some respondents expressed a desire for pre-bereavement support in appropriate circumstances:

"The biggest problem was the lack of coordinated support before her death... There needs to be something around pre-bereavement. It was difficult in the months leading up to her death and when she was in hospital."

(Ex-husband, Phone Interviewee)

These respondents also described the guilt in the aftermath of bereavement and feeling conflicted: on one hand, feeling angry with the person who died for their reluctance to seek help for their dependency, and on the other trying to understand the extent to which the problem was out of their control and trying to forgive.

Interestingly, many of our research respondents described being expected to behave in a certain way: to 'get over it' quickly or, on the other end of the spectrum, to outwardly project an image of devastation for quite some time after the bereavement. Both expectations were considered unhelpful and insensitive. Survey participants bereaved in all circumstances also spoke of a sense of relief following the bereavement; relief that their loved one was no longer suffering, and for themselves to be able to regain control of their lives and reintroduce stability and order. This, however, could increase the guilt and confusion felt by respondents.

Discussion

The findings outlined in this briefing provide an insight into drug and alcohol-related bereavement, the unique difficulties of coping with it, the complications that can arise in the grieving process and the urgent need to plug the gap in targeted support for this group of bereaved people. Whilst it cannot claim to be a comprehensive review of all the issues associated with drug and alcohol-related bereavement, the findings nonetheless identify a number of key points and also chime with existing evidence of the impact of drug and alcohol use on families, their experiences of support and professional services, and research into complicated and disenfranchised grief.

In terms of what distinguishes a drug or alcohol related bereavement from other bereavements, this research suggests that the key differences are the challenges of living with drug and/or alcohol dependency prior to the death; the intense and complicated emotions this can lead to after the death; the stigma and consequent isolation felt by family members; and the lack of support and understanding for those bereaved in this way. The findings suggest that stigma leaves families afraid of seeking support from informal and professional sources – and when they do seek support, they are sometimes confronted with discriminatory attitudes and hurtful experiences. Findings also indicate that a lack of information and knowledge around drugs, alcohol and dependency is unhelpful and could increase distress both before and after the death.

Based on these findings, a number of suggested actions can be identified:

- Providing accurate information around drug and alcohol use and the practical and emotional issues concerning drug and alcohol-related bereavement;

- Creating opportunities for peer support, given the unique challenges of this kind of bereavement, and thereby providing a safe space where family members can talk and be listened to without judgement or blame;
- Addressing the stigma family members feel about being bereaved through substance use;
- Encouraging non-judgemental attitudes amongst professionals, focusing on developing compassion and sensitivity and on combating discriminatory attitudes and misguided views;
- Improving the availability of information and the signposting to sources of support.

As a result of this consultation and further research, Cruse and Adfam are now setting up an innovative programme, called the BEAD project (Bereaved through Alcohol and Drugs), with an emphasis on developing peer-led support. A team of peer support volunteers is being trained throughout 2015 to offer three different types of support: informal befriending; telephone bereavement support; and support groups.

Cruse and Adfam are also developing a microsite and other information resources to plug the gap in targeted information for people bereaved in this way.

More information is available at www.cruse.org.uk/drugs-and-alcohol and at www.adfam.org.uk/professionals/latest_information_and_events/current_projects/bereavement

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