



## **Drug and alcohol related bereavement project**

**Scoping review – October 2014**

### **The purpose of this review**

Adfam and Cruse Bereavement Care are carrying out a four year drug and alcohol related bereavement project funded by the National Lottery and running from 2010-14. The purpose of this review is to create a solid evidence-base from which the project can develop a useful and timely network of peer support and associated resources for people who are bereaved in this way. This review maps the context of this bereavement type through the available literature, reviewing findings and illustrating gaps in the research which have yet to be filled.

### **1. Drug and alcohol related deaths: Statistical findings**

#### **Headline findings**

- Alcohol deaths have been fairly stable since 2008, following a sharp rise from 1993 onwards;
- Drug deaths from opiates are still the main group of drug death but this is decreasing;
- Drug deaths from novel psychoactive substances (including 'legal highs') are increasing;
- More men die from both drug and alcohol use than women;
- There is a strong correlation between drug/alcohol mortality and social inequalities;
- There is a strong bias in drug deaths towards least socially privileged areas – the North East and the North West routinely higher than London, the East of England and the South East

#### **The background**

The Office of National Statistics (ONS) publishes comprehensive figures on drug and alcohol related deaths. The most up-to-date figures are contained in ONS, 2013 and 2014. In all, there were 2,597 drug deaths in England and Wales and 8,367 alcohol deaths registered in 2012.

#### **Definitions**

It is worth noting that different agencies employ differing definitions, which sometimes causes confusion when attempting to compare statistics and data-sets. The issue is significant enough that

it inspired Corkery to write a paper specifically considering such definitions.<sup>1</sup> He identifies five definitions in the UK literature: one used by the Office for National Statistics; one in the UK Drug Strategy; two used by the European Monitoring Centre for Drugs and Drug Addiction; and one adopted by the National Programme on Substance Abuse Deaths (np-SAD).

The ONS definition of a drug death is: *'A death where the underlying cause is poisoning, drug abuse or drug dependence and where any of the substances controlled under the Misuse of Drugs Act (1971) are used'*<sup>2</sup>. The National Treatment Agency for Substance Misuse (NTA) note that *'some partnerships use a local definition, which gives them the opportunity to include a wider range of deaths, such as volatile substance abuse cases and deaths in cars while intoxicated'*<sup>3</sup>.

The Drug Poisoning statistics encompass all drug poisoning incidents for all drugs - legal and illegal (including medicines). This includes suicides, accidental overdose and the long term effects of drug addiction, but does not include deaths resulting from adverse reactions to drugs, such as anaphylactic shock. 'Drug deaths' are taken not to include deaths where the main cause was alcohol (whilst alcohol clearly is a drug, it isn't considered as such within the literature), although many - 27.7%<sup>4</sup> - drug deaths also list alcohol as a contributing factor.

It is worth noting that official statistics on alcohol deaths usually reflect 'alcohol related deaths' and not 'alcohol attributable deaths', which may include suicide whilst under the effect of alcohol and road traffic accidents. 'Alcohol deaths' here are taken to mean deaths where alcohol was identified as the main cause, although other drugs may also have been mentioned as involved.

Official figures on drug and alcohol deaths may not reflect the real numbers who die from these causes because some deaths are not recorded or categorised as being alcohol or drug-related (by coroners wishing to 'protect' the family for instance) and definitions of these types of deaths tend to vary as we have seen.

## **Gender**

The ONS figures indicate that of those who die from drug use 2/3 are typically men and 1/3 are women, with 1,706 male deaths and 891 female deaths in 2012<sup>5</sup>. There has been a slight decreasing trend in male deaths and a slight increasing trend in female deaths over the past few years, leading to greater parity.

## **Age**

Drug related deaths are a leading cause of death for young people; accounting for one in eight deaths, in 2012, of those in their 20s and 30s<sup>6</sup>. Despite this, the most common age group for drug deaths is 30-39, followed by 40-49, with 55-59 the most common age group for alcohol deaths.

An age-based trend worth noting is the regular amount of deaths amongst older heroin users, especially men. *'The fastest rise in recent years has been among older, male heroin users. This group*

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<sup>1</sup> Corkery (2008)

<sup>2</sup> NTA (2011)

<sup>3</sup> *Ibid*

<sup>4</sup> Ghodse *et. al.* (2013)

<sup>5</sup> ONS (2013b)

<sup>6</sup> *Ibid*

is increasingly vulnerable to the adverse effect of risky drug-taking behaviours. Prolonged heroin use causes chronic physical and psychological problems,' the NTA note.<sup>7</sup>

### **Ethnicity**

For 2011 drug deaths 'where ethnicity was known (n = 894), the vast majority were White (95.4%); with the remainder Asian (1.9%); Black (1.6%); and Chinese and other ethnicities (1.1%)'<sup>8</sup>.

### **Region**

Drug deaths were significantly higher in Wales (45.8 per million) than England (25.4 per million). Within England there is a marked bias, with levels in the North West (41 per million) and the North East (37.4 per million) much higher than London (17.2 per million).

Alcohol deaths are similarly distributed, with higher rates in Wales than England (95 versus 76 per million for females and 170 versus 159 for males). Within England, most are seen in the North West (229 per million for males and 108 per million for females) and the least in London (53 per million for females) and the East of England (118 per million for males).

In exploring the geographical trends of alcohol deaths in the UK, the ONS noted, 'Breakwell *et al.* (2007) examined geographical variation in the number of alcohol-related deaths between 1991 and 2004 and found a strong association between death rates and deprivation in England and Wales'<sup>9</sup>.

### **Death type**

The most common type of drug death for males is accidental poisoning (overdose) at 65%, next is deliberate drug poisoning (suicide) at 31%, with 'mental and behavioural disorders due to drug use' the least common by far.<sup>10</sup> For females, accidental and deliberate drug poisoning are of equal prevalence, with both accounting for just under 50% of deaths. The remaining deaths (around 1%) fall under the 'mental and behavioural disorders' category.<sup>11</sup>

### **Drug type**

The ONS findings show that it is not always straightforward telling which drugs are implicated in deaths: 12% of deaths are recorded under generic terms such as 'drug overdose' or 'multiple drug toxicity'; 31% of drug death records specifically mention more than one drug; and 30% also mention alcohol in combination with a drug.<sup>12</sup>

In 2012, over half (52%) of all drug deaths were related to an opiate, with heroin or morphine implicated in 579 deaths. Methadone was implicated in 414 deaths, cocaine in 139, the amphetamine family (including ecstasy) in 97 deaths and novel psychoactive substances (NPS) in 52 (mainly cathinones). Fifty-eight deaths made mention of helium, and 182 involved paracetamol – both drugs frequently used in suicides.<sup>13</sup>

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<sup>7</sup> NTA (2011)

<sup>8</sup> Ghodse *et. al.* (2013)

<sup>9</sup> ONS (2013a)

<sup>10</sup> ONS (2013b)

<sup>11</sup> *Ibid*

<sup>12</sup> *Ibid*

<sup>13</sup> *Ibid*

Additionally, there are quite noticeable drug trends in relation to gender. The most commonly identified drugs in male deaths in 2011 were heroin/morphine (34%), alcohol-in-combination (23%) and methadone (30%). For female deaths, it was anti-depressants (43%), other opiates/opioid analgesics (35%) and hypnotics/sedatives; for instance, benzodiazepines prescribed for anxiety or insomnia (24%).<sup>14</sup>

Of increasing importance is the inclusion of drugs – covered variously, and partly, by the terms legal highs, research chemicals, bath salts and new psychoactive substances (NPS) – which are not controlled under the Misuse of Drugs Act 1971. These include a diverse and ever evolving group of compounds, often stimulants chemically similar to amphetamines or cathinones, which have not been legislated against but which may, in time, come to be covered by the law. The market supplying these drugs reacts very quickly, and there is a good deal of confusion over the exact chemical make-up and neuro-pharmacological effects of the substances which are often not clearly labelled or marketed. The problem of toxicology tests not being sophisticated enough to identify these drugs should be borne in mind.

Ghodse *et.al.* note, '*As in 2010, there was a substantial number of deaths reported involving novel psychoactive substances such as mephedrone and other methcathinones, and the benzodiazepine phenazepam... The speed with which these and other new substances are continuing to replace established recreational drugs means it is important that surveillance and monitoring of the situation continues*'.<sup>15</sup>

### **After the death**

There is a marked difference in the speed and manner with which drug and alcohol deaths are processed. Deaths must be registered within five days unless there is a good reason. However, deaths which are considered unexpected, accidental or suspicious go to the coroner for inquest, which necessarily delays their registration. All drug and alcohol death statistics are therefore a reflection of the number of deaths *registered* in the year, rather than the ones that actually took place that year.

In 2012, 61% of alcohol related deaths were registered within five days – against 76% registered for all deaths – with 83% of alcohol related deaths registered within a month and only 4.9% going beyond the six month mark.<sup>16</sup>

In comparison, the picture is quite different for drug related deaths. Just over half of the deaths registered in 2012 did not take place that year. The average delay in registering drug deaths is now 170 days, although this has gone up substantially since 1993 when it was just 70 days. This may be partially explained by an increase in all deaths referred to a coroner – from 22% in 1993 to nearly 40% in 2010.<sup>17</sup>

This delay in registration, and the associated processes of working with the coroner, inevitably puts additional stresses on bereaved families who just wish to grieve in private and with dignity.

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<sup>14</sup> Ghodse *et. al.* (2013)

<sup>15</sup> Ghodse *et. al.* (2013)

<sup>16</sup> ONS (2014)

<sup>17</sup> ONS (2013b)

It is worth noting that some families may find the inquest to be an important part of making sense of the death. They may have high expectations of the inquest and believe that many of the questions they have around the death, and 'why' the person died, will be answered. Often this will lead to disappointment, since the coroner's remit covers only the 'how' and not the 'why', i.e. the exact facts and physiological causes of death.

## 2. Bereavement

### Headline findings

- Grief resulting from a significant loss is a normal process;
- Certain deaths are more likely to trigger more complicated grief reactions;
- Disenfranchised or stigmatising grief can drastically impede grief reactions;
- Complicated grief means the bereavement and grieving process is delayed or protracted, placing a stress on the mental health and wellbeing of a bereaved person

Whilst there are several reports produced on bereavements through drugs or alcohol, much research and development in this field pertains to how the bereaved person experiences and copes with bereavement, regardless of the type of death that has caused it. It may be useful to summarise the main therapeutic models of bereavement, looking at factors which may complicate the grieving process, before examining literature related to drugs and alcohol deaths in particular.

### The process of grieving

Bereavement can be defined as the process that includes grief and mourning, over the loss of a significant attachment or relationship. Mourning refers to the rituals and customs that a person or their culture practices. Grief as '*a normal reaction of intense sorrow, following... the loss of an emotionally significant person*'<sup>18</sup> is the emotional journey or process that a bereaved person must go through when a loved one dies, and it is one which is dependent on the bereaved person's attitudes, resources, experiences and also those of the community around them. The journey through grief begins when a bereavement occurs and progresses through to a point where it is resolved and integrated into the bereaved person's life experience. Grief is something to be encouraged and fostered, as its suppression can lead to complications which can have far-reaching effects on the bereaved person:

*'People should not be deprived of an opportunity to experience grief, which can ultimately be a rewarding and maturing process. Grief cannot be permanently postponed, for it will reach expression in some way... the more sustained the inhibition of feelings, the more intense are they likely to be when finally expressed'*<sup>19</sup>.

There are several models which map grieving as a process resulting from the emotionally disruptive event of bereavement. Parkes developed his Phases of Grief Model<sup>20</sup>, which denotes the key stages

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<sup>18</sup> Stewart (2005)

<sup>19</sup> *Ibid*

<sup>20</sup> Murray Parkes (2010)

of grief as: shock; separation and pain; despair; acceptance; and resolution and reorganisation. Similarly, Worden considers grief work in his Tasks of Mourning<sup>21</sup>:

1. accept the reality of the loss
2. work through the pain of grief
3. adjust to an environment where the deceased is missing
4. find an enduring connection with the deceased while embarking upon a new life.

Stroebe and Schut focus on the multiple stressors that bereavement incorporates and proposed the Dual Process model<sup>22</sup>, whereby the bereaved person oscillates between coming to terms with their loss and the completion of restoration-related work.

The length of this process will depend on various factors including the relationship to the deceased (the death of a child or a partner can be the most devastating) and the resources available to the bereaved person: both their own internal coping mechanisms and resilience; and also external support, whether it is family, friends, community, medical or therapeutic.

### **Beyond 'normal' grief**

Katherine Shear argues that *'many people resist the notion that grief could be considered a mental disorder, but the depth of some bereaved people's distress can mean they experience great difficulty in progressing through the natural healing process'*<sup>23</sup>. This illustrates the point, that whilst grief may need to run its course, there are several factors which can complicate the grieving process making it more difficult for the bereaved person to navigate.

### **Complicated grief**

For most people, grief never goes away completely but, with time, it will become less intense as the restorative process leads the bereaved person back towards engagement with life, as is demonstrated in Tonkin's *Growing Around Grief Model*.<sup>24</sup> However, for some people, grief remains the dominant aspect and they find themselves unable to get beyond it. This is termed complicated grief and it refers to factors which interfere with the normal grieving process. Such factors can include the individual's personal responses to their life circumstances (their resilience, coping mechanisms, adaptability and previous life experiences) and also external factors including the nature of the relationship to the deceased, circumstances around the death, or their community's response to the death. People who experience complicated grief, often report feeling 'stuck'.

It is not yet known what specifically causes complicated grief, though researchers point to a group of factors which may increase the risk of developing it. They are:

- An unexpected or violent death
- Suicide of a loved one
- Lack of a support system or friendships
- Traumatic childhood experiences, such as abuse, neglect or separation anxiety
- Close or dependent relationship to the deceased person

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<sup>21</sup> Worden (2009)

<sup>22</sup> Stroebe and Schut (1996)

<sup>23</sup> Shear (2010)

<sup>24</sup> Tonkin (2010)

- Being unprepared for the death
- Lack of resilience or adaptability to life changes<sup>25</sup>

Cruse has found that contributory factors also include:

- The presence of any anticipatory grieving or high pre-death distress
- High post-bereavement distress that restricts the use of coping strategies
- The physical, emotional and psychological health of the bereaved person
- The cultural context in which the bereaved person lives and its influence on the expression of grief

### **Traumatic deaths**

The word 'trauma' comes from Greek and is defined as '*to pierce or puncture armour*'. The nature of [traumatic] incidents is that they have the potential for 'piercing' usual coping defence methods<sup>26</sup>. Gibson's definition aptly encapsulates the effect a traumatic event can have in getting beyond our usual resilience. And it is this ability of getting past our normal defences that can result in traumatic stress, although it is to be noted, in the first instance, such symptoms can be normal reactions to a devastating event:

*'While most disorders are irrational or unrealistic (for example, people with phobias generally recognise that their fear doesn't make sense), trauma is perfectly understandable...Why wouldn't you be terribly upset or 'traumatised' when life presents you with this kind of shock?'*<sup>27</sup>

While such normal reactions to a traumatic event are to be expected, it is when these reactions stay with the bereaved person that complicated grief becomes salient. The effect of a traumatic bereavement can impact severely on all members of a family and their community and as Bloom reports, the problem can be exacerbated

*'...when the emergency measures that have been activated to protect family survival operate long past the time when they are necessary. Separated from their original purposes, these emergency measures become family styles of interacting, family belief systems that rapidly become impermeable to change.'*<sup>28</sup>

Traumatic deaths are often linked with survivor syndrome, the notion of surviving a traumatic event which is often perceived as being random, unfair or irrational. Perreault, Fitton and McGovern reported that in their study, '*the experience of survivorship was one of bewilderment that HIV and death seem to randomly pick some people and not others.*'<sup>29</sup> As with a traumatic incident, it is this very sense of bereavement being *unjust* that makes it harder to process.

### **Disenfranchised and stigmatizing grief**

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<sup>25</sup> Centre for Complicated Grief (2014)

<sup>26</sup> Gibson (2006)

<sup>27</sup> Callahan (2001)

<sup>28</sup> Bloom (1997)

<sup>29</sup> Perreault *et. al.* (2010)

Disenfranchised grief is defined as grief that is not openly acknowledged, socially accepted, or publicly mourned. The relationship, the loss, the griever are unrecognised. The bereaved are cut off from social supports and are therefore denied the opportunity to address or express their grief, and as such, are often unable to reach a resolution stage. Disenfranchised or stigmatising grief often occurs with deaths which society finds harder to deal with, such as suicide, preventable deaths, abortion, stillbirth, or sudden infant deaths. Similarly, this type of grief can occur when society deems the perceived status of the deceased to be more complex or difficult to deal with, such as the deaths of criminals, those with HIV or AIDs, drug/alcohol users or in the LGBT community. Stigmatising grief is rarely evidenced without thoughts or feelings of shame.

Perreault *et al* note in their research that *'participants, particularly those who were connected to a marginalised community, described stigma and lack of societal support as additional losses'*:

*'I never believed I would feel so alone when my son died of AIDS – I thought people in my church would support a mother losing a child, no matter what the child did or died of, but I was wrong'*<sup>30</sup>.

Again, research undertaken with couples bereaved through still birth, (*Finding the positive in loss: still birth and its potential for parental empowerment*) Murphy reflects the notion of 'felt stigma' in relation to particular types of bereavement:

*'While the term stigma was rarely referred to, the participants in this study certainly used language that would be associated with a stigmatised identity: they recounted experiences which suggested that relationships with others had been changed irrevocably and that other people's attitudes towards them had altered too. Crucially... their perception of themselves had changed too'*<sup>31</sup>.

Murphy quotes a participant to highlight this:

*'I think I was sort of ashamed to tell other people that I hadn't, um, I had failed, you see. I had, had failed again. I'm sure it's that failure thing, I'd failed to produce a baby and I'd failed to notice when the baby was in distress'*<sup>32</sup>.

Disenfranchised, stigmatising or traumatic deaths are those which are more likely to result in complicated grief, or the inability to progress through grief and find the capacity to re-invest in life. It is this group of bereavements, by definition, which are more likely to cause more suffering and distress.

### **3. How drug and alcohol use affects families**

#### **Headline findings**

- Addiction is a journey taken by the whole family. When an individual uses substances, the impacts on the family can be wide-ranging and destructive;
- Families can feel a multitude of different emotions and suffer from a range of both physical and psychological impacts as a result of their loved one's addiction;

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<sup>30</sup> *Ibid*

<sup>31</sup> Murphy (2012)

<sup>32</sup> *Ibid*

- Stigma is not only experienced by the user but also their family, and is a particular and prominent feature of drug and alcohol addiction;
- Different families will adopt different approaches to coping with addiction in the family
- The ways families access support, as well as the support itself, varies greatly

In order to gain a deeper understanding of drug and alcohol bereavement, it is necessary to briefly consider the way that drug and alcohol use affects the family of the substance user and the relationships between them. The level of engagement the families have with their loved one, their drug or alcohol use and their treatment (if any occurs) may influence the way they react and the coping mechanisms they employ following a bereavement.

More recent years have seen an increase in recognition of the various and severe impacts that an individual's substance use can have on those around them, particularly family members. Addiction can affect the very core of family dynamics and relationships, as well as impacting upon individual family members' health, employment, finances and general wellbeing. Families commonly report experiencing a wide-range of emotions, including guilt, shame, concern, fear, anger, stress, betrayal and isolation. Often, family members feel angry with their loved one for putting them in such a situation or for having betrayed their trust and expectations. They may also feel angry with themselves for having failed to prevent it, or for their collusion with the situation by, for example, giving the user money. Some feel that they are being forced to betray the user by not being able to support their actions, or for imposing extreme sanctions, such as making them homeless.

Similarly, families often feel a deep sense of shame about what is happening, and struggle to speak to others about the problems out of fear that they will lose respect in their community or of admitting 'failure'. If they are ostracized by the wider family, friends and neighbours, families are cut off from crucial sources of practical, emotional and financial support. A loss of self-confidence and self-esteem can accompany this, leaving families feeling unable to participate in normal social activities and serving to isolate themselves further.

In addition to this overwhelming mixture of emotions, families affected by a loved one's addiction experience, sometimes serious, adverse effects to their physical and psychological health and wellbeing. Common complaints include: sleep problems, symptoms of anxiety and depression and physical symptoms such as hypertension, pains and migraines. In fact, it has been found that families are more likely to be diagnosed with their own medical conditions than non-drug using families to levels of serious comparable to psychiatric outpatients.<sup>33</sup> The stress-related symptoms they suffer have also been found to sometimes be severe and long-lasting and, as such, these families are associated with high usage of primary care services.<sup>34</sup> Another study found that exposure to heavy drinkers reduces personal wellbeing and utility health scores, particularly in relation to reductions in usual activities, increased pain and discomfort and higher levels of anxiety and depression.<sup>35</sup>

Yet another impact of drug use in the family is the financial one. For instance, criminality can be extremely costly – most obviously due to theft of property or money to fund the user's drug or alcohol habit. Families will often also 'bail out' the user; paying off drug debts or fines, or providing

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<sup>33</sup> Adfam, *Supporting families affected by drug and alcohol use: Adfam evidence pack*

<sup>34</sup> Copello et al (2010) 'The 5-Step Method: Evidence of gains for affected family members,' *17 Drugs, Education, Prevention and Policy* 100

<sup>35</sup> Copello et. al. (2010) 'The impact of addiction on the family: Estimates of prevalence and costs,' *17 Drugs: education, prevention and policy* 63

them with money for rent, food etc. The UKDPC has estimated that crime costs family members £2,840 per annum, not including costs incurred by the criminal justice system.<sup>36</sup>

Stigma also often serves to complicate the matter. Stigma comes from an assumption about an individual or group, so that they are treated simply as a stereotype and places them outside the normal reach of society. Families as well as the user are stigmatised; often thought to be partly responsible for their loved one's choices based on concepts of 'bad families' or beliefs that 'it's the parents' fault'. This can commonly lead to feelings of shame and isolation, which can result in or add to already fraught relationships between the user and their families. Family members may also be judged for supporting their loved one – *'why don't you just kick them out?'* On the other hand, however, when families choose to disassociate themselves from the user, because of the impact on their own health for example, families have reported similar judgmental attitudes – *'I would never turn my back on my son!'*<sup>37</sup>

Evidently, while some families will strive to support and encourage the user throughout their addiction regardless of negative impacts on themselves, others simply cannot cope and may choose to disassociate themselves from the user and their chaotic lifestyle – at least until the situation improves. All of the above can and does have serious implications for family harmony, dynamics and relationships and will inform how the family reacts to a drug or alcohol related bereavement.

## 4. Drug and alcohol bereavement

### Headline findings

- The available literature on drug and alcohol related bereavement is scant;
- The available literature specifically on alcohol related bereavement is non-existent;
- Drug and alcohol related deaths are more often less acceptable in society, with these deaths commonly considered unnatural or 'out of time';
- Drug and alcohol related deaths are also less accepted because they are linked to societal perceptions and judgements around immoral living or illegal activities;
- Due to experiences of stigma and shame as a result of society's reactions, the grief of the families left behind may be disenfranchised;
- This type of bereavement can cause huge damage to families and destroy relationships and previously held certainties, making families question their own capabilities;
- Media intrusion and sensationalist coverage can also make things harder;
- Legal processes following a drug or alcohol related death (such as an inquest) can often add to the trauma of this type of bereavement

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<sup>36</sup> UKDPC (2009) *Adult family members and carers of dependent drug users: prevalence, social cost, resource savings and treatment responses*

<sup>37</sup> Adfam's 30<sup>th</sup> birthday campaign (2014)

## The background

The literature available specifically on drug and alcohol related bereavement is not extensive. Four academic papers have been identified which cover the topic – two British papers, based on the same set of data, and written or co-written by Philip Guy;<sup>38</sup> a third paper by American academics William Feigelman, John Jordan and Bernard Gorman;<sup>39</sup> and a Brazilian paper, written by E.A. da Silva, A.R. Noto and M.L. Formigoni.<sup>40</sup> Feigelman et. al. also wrote a book entitled, *Devastating Losses: how parents cope with the death of a child from suicide or drugs*;<sup>41</sup> which offers an overview of the research on this topic. Furthermore, a book edited by Kenneth Doka<sup>42</sup> looks at the grief resulting from various ‘bad’ deaths and how it is processed by families and friends.

### Drug deaths are different to other deaths (including, often, alcohol)

Drug deaths are ‘qualitatively different’, Guy suggests: *‘the reasons for this include the often unexpected nature of the deaths and the young age at which they tend to occur. These deaths result from an activity that is illegal and is regarded as deviant or carries social censure... [they] occur in a context that might be poorly understood by those close to the user. The death itself might reveal a relative or friend as drug user for the first time’*.<sup>43</sup>

The experience of drug and alcohol related bereavement can most closely be compared to another of society’s most prominent ‘bad’ deaths – suicide. The American research conducted by Feigelman et. al. found *‘no appreciable differences...between the suicide bereaved parents and those losing children to drug-related deaths’*. However, compared to accidental and natural death, both these groups were *‘more troubled by grief and mental health problems’*.<sup>44</sup>

Sudden drug deaths are also ‘different’ in another way: they may take place in the public realm, away from hospitals and hospices where death is normalised, institutionalised, and taken out of the public gaze. People who die at home, or in the homes of friends and family, may be discovered by loved ones – something which naturally adds a significant factor of shock and emotional distress to the situation. Alternatively, those who die from fatal drug overdoses may do so whilst using with their peers – which, naturally, would prove to be a highly traumatic experience for the friends or associates who witness the death.

The full impact of ‘bad’ drug (and perhaps alcohol) deaths is profound. *‘For the bereaved family and friends a drug-related death often results in the breakdown of self-identity, calls into question the reliability of persons and things, destroys the reference points in their lives and overturns perceptions of reality’*.<sup>45</sup> Effects may go beyond deep unhappiness, to states of mental and emotional breakdown or existential crisis. Recovery from any traumatic experience will necessarily incorporate grief reactions which call into question what we believe, how we view life and perceive ourselves.<sup>46</sup>

### Social stigma – deviant or bad deaths

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<sup>38</sup> Guy (2004) and (2007)

<sup>39</sup> Feigelman et. al. (2011)

<sup>40</sup> Silva et. al. (2007)

<sup>41</sup> Feigelman et. al. (2012)

<sup>42</sup> Doka (2002)

<sup>43</sup> Guy (2004)

<sup>44</sup> Feigelman et. al. (2011)

<sup>45</sup> Guy and Holloway (2007)

<sup>46</sup> Herman (2001)

The illegality of drug use and the associated social stigma makes it difficult for families to grieve. They may feel that the deaths they are dealing with are not 'good' in the eyes of society; that they were not noble, did not involve a brave struggle against an illness, but rather, were pointless, self-induced, 'bad', dirty or deviant. Da Silva et. al. describe drug deaths as, '*loaded with social/moral stigmas, secrecy, shame and denial*'.<sup>47</sup>

Variation of attitudes within the family may make the processing of grief even more difficult – Guy suggests that some people with whom he spoke struggled with the attitude of a surviving family member in dealing with a drug death. Some people may choose to 'sweep it under the carpet', whilst others wish to commemorate and mourn the sibling, child or parent they loved and have lost. This will clearly be compounded by practical issues, such as police interviews, autopsies, inquests etc.

### **Disenfranchised grief**

This term, used by Guy and Holloway,<sup>48</sup> was first coined by Doka in the book he edited of the same name. It was initially used to describe the grief felt by those in relationships which were not recognised by society; gay relationships, for example. Since then, he has expanded the term to cover the grief resulting from types of death not fully recognised or accepted by society, including deaths related to substance use.

The term goes some way in explaining how the social stigma around drug and alcohol deaths leads to a sense that families do not have a socially-legitimised space in which to grieve – that '*grief in these circumstances is somehow wrong*'.<sup>49</sup> This lack of a socially-endorsed model of grief leads to a range of effects, from the prolonged mental health and wellbeing issues for the family members, to a distorted presentation of the actual death by family members within their families and communities. Feigelman et. al. assert that, '*drug-overdose death bereaved parents routinely misrepresent the cause of a family member's death to other close family members, co-workers, and friends, fearing that the person's reputation will be greatly diminished by the revelation of their death cause*'.<sup>50</sup>

Disenfranchised grief may leave family members feeling that they cannot or should not seek help and support from their friends, families or even professionals – and even when families do get a response of some kind from society, it nonetheless '*may exacerbate rather than ameliorate the pain*'.<sup>51</sup> Some will face these challenges in dealing with their grief and will not know how to talk about it or broach the subject.

These barriers to grief may affect the 'remembering' process and the ability of the bereaved to take comfort from fond memories of the deceased, which can be shared with others. Some may feel that the deceased's memory has been spoiled – something also linked to media representations of substance use deaths and how, through them, we as a society remember those who die from drug or alcohol related causes. Clearly, this has a huge impact on the capacity for a bereaved person to normalise grief, come through the grieving process and work towards restoration.

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<sup>47</sup> Da Silva, Noto, Formigone (2007)

<sup>48</sup> Guy and Holloway (2007)

<sup>49</sup> Guy (2004)

<sup>50</sup> Feigelman et. al. (2011)

<sup>51</sup> Guy and Holloway (2007)

## **Drug deaths are often sudden deaths – alcohol deaths less so**

Given that drug deaths usually occur from either accidental or purposeful poisoning (overdose), they are often sudden. Sudden deaths do not allow for any period of preparation for family members, where they can think about the death or cultivate skills or attitudes that will help them after the bereavement. *'Sudden death is a traumatic event that haunts the survivors for a long time, hindering the mourning process,*<sup>52</sup> Da Silva, Noto and Formigoni note.

Another factor which might come into play for families, compounding the sudden and horrific reality that a son, daughter, friend or parent has died from drug or alcohol use, is actually discovering the existence or true scale of their loved one's substance use. Some family members may have no idea that the person used drugs at all: *'Death by drug overdose is brutal, sudden, my family lost it, we felt angry, ashamed, guilty, cheated. Nobody at home knew that he used drugs; we only knew it after he died. Our anger increased,*<sup>53</sup> one family member said. On the other hand, where families were fully aware of the person's drug use, especially if they were engaged in high-risk behaviour such as intravenous opiate use, it may be asserted that the element of surprise that comes with such sudden deaths is somewhat curtailed.

### **Families blame themselves**

Inevitably, perhaps, family members can blame themselves for the deaths of their loved ones. *'Where did I go wrong?' one parent asked himself. 'I spent all that time blaming myself...what have I done to deserve all this? I've always worked, I'm not very educated, but I've always given my children everything I had.'*<sup>54</sup>

Similarly, Guy and Holloway describe a mother they interviewed: *'The death of her eldest daughter has resulted in a reappraisal of her success as a mother...Jane now feels that the performance as mother fell short of the standards she set for herself and thought she had achieved'*<sup>55</sup>.

The idea of blame is one which is commonplace in complicated grief and one which prevents the bereaved from moving on with their lives: as Shear articulated, *'bereaved people with [complicated grief] may find themselves ruminating about what they could have done to prevent this death, or how someone else was responsible for the death. They may resist acceptance of the finality of the loss, focusing instead on how their loved one should never have died this way.'*<sup>56</sup>

### **Drugs, alcohol, medicine – or suicide?**

A lack of clarity around the exact cause of the death itself may provide an additional barrier to grief for family members. Indeed, *'there is often a daunting challenge for medical examiners to ascertain whether a given individual's death was intentional suicide or an accidental drug overdose... [they]*

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<sup>52</sup> Da Silva, Noto, Formigone (2007)

<sup>53</sup> *Ibid*

<sup>54</sup> *Ibid*

<sup>55</sup> Guy and Holloway (2007)

<sup>56</sup> Shear (2010)

*struggle greatly with the cases that straddle the ambiguous line*.<sup>57</sup> . Sometimes multiple drugs are found in autopsies – some of which family members may have had no idea the deceased ever used – with alcohol also implicated in a large number of drug deaths. This uncertainty around the cause of death is often coupled with an uncertainty around legal processes - again making it more difficult for the bereaved to grieve healthily.

## **Media**

The available literature clearly demonstrates that media coverage of drug deaths is not always fair and objective: it has its own narrative, which is pursued to increase sales. For example, Guy found that, *'the popular press focus almost exclusively on young, good-looking women*,<sup>58</sup> whilst another angle that clearly emerges from the media's cooperation with parents or other family members is to use the death as a warning or educational message to drug users. From the family's perspective, Guy suggests this may be, *'an attempt by [the family] to maintain a self-image of having been good parents, so good in fact that they will sacrifice privacy and dignity*,<sup>59</sup> and consequently part of the grieving process.

Guy and Holloway use interviews with bereaved family members to explore themes in their work. One parent's experiences of his son's death was described: *'John's son died after taking a combination of heroin, alcohol and methadone. The body was found in a public lavatory. This was a point made repeatedly in the press reporting, as if to add a sordid and salacious twist to the tragedy*.<sup>60</sup> They also cite headlines such as, *'Lorna boils to death on super-strength ecstasy'* as adding to the insensitive and sensationalist mood<sup>61</sup>.

### **If the person is seriously ill or deeply unhappy when they die, the death can bring mixed feelings**

For some families, they may find the death in some (often unvoiced) way a release or relief. Some people with drug and alcohol problems are so helplessly addicted or are in such severe physical ill health that families find their eventual death restores some order or security to their own lives. One parent said, *'when my son died I had ambivalent sensations: on one hand immeasurable pain, the pain of irreparable loss; on the other hand, relief. Relief from his suffering as well as ours. The year that preceded his death was terrible, we expected the worst every day*'.<sup>62</sup>

It is worth considering if this is more likely to occur where the person was addicted to alcohol and certain drugs and had long-term chronic health conditions rather than in relation all drug deaths. Although heroin and crack addiction doubtlessly lead to severe long-term health problems, some other drug deaths (for instance, MDMA, GBL/GHB or other club drug related) may be much more unexpected and unaccompanied by preceding chronic health issues.

### **There is a strong correlation between drug / alcohol deaths and social inequality**

Social inequality will also have an impact on the capacity a bereaved person has to recover from a death. For example, it may be contested that those who are most socially disadvantaged are less

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<sup>57</sup> Feigelman et. al. (2011)

<sup>58</sup> Guy (2004)

<sup>59</sup> Guy (2004)

<sup>60</sup> Guy and Holloway (2007)

<sup>61</sup> Guy and Holloway (2007)

<sup>62</sup> Da Silva, Noto, Formigone (2007)

likely to ask for support for any bereavement type, and they are at a higher risk given their lack of good coping mechanisms to help them through such a difficult time.

Also, social inequality can bring into question the very definition of 'normal experience': qualitative findings from Cruse's work with prisoners revealed that many prisoners who use/have used drugs consider it entirely normal to use drugs on a daily basis. The concept of 'being clean' can mean, for this group at least, that they are not taking drugs like heroin but that they still 'smoke joints' or misuse prescription drugs.

Interestingly, bereavement through drugs or alcohol is one of the most common types of bereavement reported within the Cruse Prison Support Project, along with other traumatic deaths such as suicide, homicide and road deaths. Research also shows that prisoners may be able to accept support while incarcerated, but that they will usually revert to older, and perhaps less efficient, methods of coping when they return to their communities:

*'Chitsabesan et al. (2006) found that young people in the secure estate (i.e. prisons and other secure accommodation) had better health, including mental health, than the offenders they sampled who were on community sentences. Crucially, though, these apparent gains were lost when they were released.'*<sup>63</sup>

This points to poor levels of support, education and coping mechanisms in their community life; which will have a great impact on their ability to grieve well. It would also suggest the need for information and capacity building at a grass roots level in areas of social deprivation, where there is a higher occurrence of deaths due to drugs or alcohol.

## **5. Conclusion**

Whilst there exists a wealth of information around bereavement, drug and alcohol use and its impact on families, there is little literature which specifically considers bereavement through drugs or alcohol. This review has shown that people bereaved through drugs or alcohol are often at a higher risk of developing chronic grief issues; with blame, anger, trauma, the suddenness of the death, and society's attitude towards and acceptance of this kind of bereavement all playing a part.

Existing bereavement theory and research tends to fall into specific overall categories - complicated, traumatic, disenfranchised grief – which have been useful in thinking about drug and alcohol related bereavement. However there is some way to go before a comprehensive discourse or evidence base exists on the topic.

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<sup>63</sup> Durcan (2008)

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