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Bereavement through drugs and alcohol

Helen Lawton, James Gilbert and Fiona Turnbull

Bereavement through a friend or relative's drug or alcohol use is a devastating, challenging and often isolating experience. Despite many different circumstances, those bereaved through drugs or alcohol share many experiences. In this article Helen Lawton and James Gilbert share their stories of bereavement, and Fiona Turnbull's commentary draws out some common elements found in drug and alcohol related bereavement.

Helen's story

Our son, Matthew, died in April 2001 from a heroin overdose. He was thirty years old. He was the middle one of three boys and he had begun experimenting with drugs and alcohol probably in his early teens. His behaviour changed drastically then, but it can be hard to know the difference between 'normal' teenage behaviour and drug use. And he was the last child one would imagine to try drugs — he loved sport, had lots of friends, detested people smoking and knew about the dangers.

So all through the long years of Matthew's addiction to drugs there was the hope that one day, eventually, he would – he <u>must</u> – recover. It seemed impossible that the son who had been the most beautiful and loving of children could be lost forever to the nightmare world that he – and we – now inhabited.

When he died it was the end of that hope, and more devastating than I could ever have imagined. For of course I <u>had</u> imagined and dreaded it, had lived with that fear for nearly fifteen years, but the reality, the absolute finality, was beyond any imagining.

I'd always thought I would be one of the parents who wrote publicly about their child, campaigned against drugs, raised money to help others. In fact I did none of these things. I struggled with the most mundane everyday tasks — it took all my energy simply to get through each day. So Matthew's death rocked my own self-image — I wasn't the person I'd imagined myself to be, and I no longer had the purpose which had driven me for so many years.

During those terrible early months I was helped more than anything by the love and support of our other sons and their partners, as well as my sisters — they all loved Matthew too. We all needed to stay strong and caring for his daughter, who was only eight years old. There was also Matthew's dog! I certainly didn't want a dog at the time, but after three months, when no-one else could care for her, she came to us, and having to go

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out twice a day for long country walks probably did more than anything else to calm me.

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Later on, around the end of the first year, I found help from The Compassionate Friends, a most wonderful organisation for bereaved parents. Not through their support groups, but through the website and 'meeting' other parents there. I think the reason I didn't want to attend a group was mainly because of the way Matthew died. I felt, rightly or wrongly, that it could be hard for parents who had lost a child through illness or accident to empathise with the loss of a child through drugs. I think I myself might have felt this way in the past. And I didn't want to feel ashamed of Matthew – that was the last thing I needed. Through the TCF website I found parents with the same experience, and many, many others whose children had died in different circumstances, but who were still able to reach out to me with compassion and understanding. It's been wonderful to actually meet and talk with some of these friends during the years since.

The 'Growing around grief' model is often shared online, see http:// www.loistonkin.com/growing-around-grief.html

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One of the postings which most resonated with me was a description of "The Circle of Grief". It describes a mother's perception of the way her life was and has become since her child died. She describes how at first, grief consumed her totally, filling every part of her life, awake or asleep. She had imagined that as time went by the grief would shrink, although she knew it would never go away completely. But what happened was different. The grief stayed just as big but her life grew around it. There were particular times, dates, or moments which reminded her of her child, when her grief felt just as intense as it ever had. But increasingly she was able to experience life in the larger circle. The description explains: 'This model relieves the expectation that the grief should largely go away. It explains the dark days and also explains the richness and depth that the experience of grief had given to the woman's life'.

Almost fifteen years on this has proved true – for me at any rate. Life does continue, with other joys and sadnesses. There is no recovery from losing Matthew, but there is a need to keep his memory alive and perhaps help or influence others in however small a way.

I've stopped looking for reasons as I did continually in the early days, the thoughts and questions going round and round in my mind, with no resolution or relief. I've stopped trying to make sense of it all because there isn't any. He was a child, and his brain was still forming, and he was in the wrong place at the wrong time in his life. He wasn't abandoned by his family — he was loved and cared about, but still it happened. He experimented, as many teenagers do, and he could never have expected that taking those stupid risks would lead to such a terrible end. It was an accident, like taking the wrong turn on a mountain top or diving into shallow water.

The death of a child changes one's life as profoundly as their birth and we can never be the person we once were. There is no escape from the grief – it is still often overwhelming – but there is no option but to live with it, and so it becomes part of life. In the words of another dear friend: 'The yearning comes and goes, and I expect it now, like the tides'.

James' story

My dad's alcohol use got worse through my teens as he moved in with his partner, who herself was/became an alcoholic, and my relationship with him suffered badly. It's hard to connect meaningfully with someone who is drunk whenever you interact, and he was drunk almost every time we stayed with him while we were in secondary school. On the odd occasion he was sober, I got along with him very well. We had similar senses of humour and enjoyed spending time together.

But generally spending time with them was horrible and their house was disgusting. My sister and I wouldn't eat anything prepared there, use the toilet and eventually wouldn't even sit down other than on our jackets/bags on the sofa. Living with an alcoholic parent is also embarrassing — any time spent with him/them and other people was always embarrassing as no one else

ever behaved like they did. It was a real sign of his problem that he couldn't contain his drinking to private situations or when he was at home.

After his death I was just in total shock. We never believed that this would happen; we had never even considered it. His decline between first being admitted to hospital in October and dying in March was so rapid we didn't have time to get used to the idea. I still haven't found the words to describe how I felt after that. Devastated probably comes closest but still doesn't go anywhere near capturing it. Our uncle (dad's brother) said he felt like a part of himself had been lost, which I think is quite a good description. When I think about what happened, I get a feeling that is sometimes so strong it feels like a real physical force in the room.

His funeral was two weeks after his death. It was a terribly sad day — I cried from the first moment of the service to the last — but also got some comfort as there were many special moments with family and friends brought together, despite it being such a sad occasion. Soon after the funeral I went back to university as my exams started six weeks later. I channelled a lot of energy through studying and found throwing myself into studying helped me deal with how I was feeling.

The contribution of alcohol left me feeling angry, which is probably common. To not die, all he had to do was stop drinking. But he wouldn't. That's such a frustrating thought and everyone who deals with a preventable bereavement probably experiences something similar. It's also sad to think that he had demons or problems that were so hard to deal with that he didn't feel like he could do anything but drink – the angry thoughts often turn to a sadness for him because of this. There's also a huge amount of regret; regret that we didn't know what would happen and that we didn't do more to stop him drinking.

Family and friends were very important in dealing with the loss. A lot of people contacted us to offer support, often people we weren't hugely close with, and their support and wishes made a massive difference. I really found kindness a great counter to the sadness. Some of these moments were truly special and ones I cherish.

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A close bereavement is the biggest test of character many will have faced when losing their first parent and it's impossible to know how you will deal with it. It was a such a sad time for all the family but I always felt like letting the death do damage that could be prevented would be one final blow to my dad, myself and our relationship. I wanted to deal with it as positively as possible and using that approach I just did the best I could. I think people

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are stronger than they give themselves credit for. The sadness doesn't go away, but it definitely makes you stronger and with time you become more able to deal with it.

Having this kind of experience gives you an insight that other people don't have, including many young people who are lucky enough to have two living parents. I have used my experience and insight to help friends who have suffered difficult circumstances since then, particularly bereavements but also depression. Every situation is different but there are some things in common that I've used to form really strong connections with people who are having tough times of their own. This has also helped me find some peace with his death.

The sadness itself hasn't really changed after nearly four years. It still hurts and is just as painful. I still haven't come to terms with how we (myself, himself and the rest of the family) let him drink to the extent he did. Thoughts of his death have decreased steadily and don't dominate any more, which is a natural part of the grieving process. A sadness like this is obviously painful but it is so pure and simple that it is kind of beautiful in its own way. Sadness is also the best connection I have left with him, and I cherish it in a strange way. Another important thing to come from his life and death is the lesson we have all learned; alcohol is a very dangerous drug and society doesn't treat it with enough respect. I am determined that I won't let the same thing happen to any other friends or family members in the future.



James as a boy with his father

Commentary

I have been deeply moved by reading Helen's account of grieving for her son, Matthew, in the years following his death from a heroin overdose, and James's reflections on the loss of his father to alcohol.

Emotional intensity

The emotional intensity of a drug or alcohol related bereavement cannot be underestimated. Helen's description of the acute pain she felt after losing Matthew and James's sense of grief as a physical force as well as his enduring sadness about his father's death resonate strongly with what we hear from so many of the people who approach the BEAD project, a new peer support service set up by Cruse Bereavement Care in partnership with Adfam, specifically for those bereaved through alcohol or drugs.

Intense feelings of guilt, helplessness, regret and self-blame can be experienced, often made all the more painful by a belief that the death could have been prevented or that they have let the person who died down. Anger towards their loved one – for 'loving drugs or alcohol more than me', for 'everything they put us through', or for 'dying and leaving me' – is not unusual but this often makes feelings of guilt stronger as bereaved people tell themselves they are wrong to feel angry.

Drugs and alcohol in family life

Both Helen and James describe how the turmoil and anguish of living with drugs or alcohol in the family before the person has died becomes another thread in the process of grieving. The traumatic, stressful and sometimes frightening experiences that many families have lived with leave an emotional legacy that can combine with the impact of grief in an often overwhelming way. Living with addiction can have a serious impact on all aspects of life, such as physical and mental health, financial security and family relationships (Adfam, 2012): many of these issues continue to be an ongoing source of difficulty for family and friends long after the death.

Moreover, when the person suffered from a long-term addiction, family members and friends often feel they began to lose their loved one even before they died, describing the experience as a 'living bereavement'. And as Helen so poignantly describes, Matthew's death brought a further devastating loss: the loss of hope of recovery.

Shock

Some families and friends, by contrast, may have been unaware that their loved one was using drugs or alcohol at all or did not know the extent of their use and so, with their death, comes the additional shock of discovery. The person who died may have been using occasionally or experimenting: the disbelief that occasional or even first-time use has proved fatal can feel unbearably tragic. Even when drug or alcohol use is known, or the death is feared and perhaps expected, for example when

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families and friends have witnessed previous overdoses, shock is still present, something James describes very powerfully.

Stigma and isolation

Like many other forms of disenfranchised grief, such as suicide and homicide, those bereaved through drugs or alcohol often feel that a substance-related death carries a heavy stigma and that their grief is not socially acceptable, even feeling they do not have a right to mourn or that the person who died is no longer recognised as an individual person but merely defined as a user or addict. Bereaved people may either directly experience or indirectly fear judgement from the people around them, from professionals they have contact with or indeed from wider society.

This can lead to devastating feelings of isolation and loneliness, just at a time when support, care and understanding are what bereaved people are likely to need. New guidelines for professionals who come into contact with those bereaved through substance use emphasise the importance of treating them with kindness and compassion and taking care to avoid any stigmatising language or attitudes (CDAS, 2015).

Support and help

I found it heartening to read in both James and Helen's accounts about the support and love that they received from family and those around them and, for Helen, how therapeutic she found the peer support she engaged with. James also describes how he has found a degree of solace by taking what he has experienced and using it in support of others — this is something the peer support volunteers at the BEAD project, all of whom have had personal experience of a drug or alcohol related bereavement, frequently identify with.

Conclusion

There are many other dimensions of drug and alcohol related bereavement which can add to the burden bereaved families and friends face. The death itself is often traumatic; there may well always remain unanswered questions; the involvement of officials such as police and coroners is highly likely; and the possibility exists of intrusive, insensitive and sensationalist media coverage, including on social media.

Drug and alcohol related bereavements are complex and distinctive. Yet on another level they are no different from any other bereavement: a person who was loved and cherished has died and those who are left behind are thrust into a long journey of grief. I believe passionately that those bereaved through alcohol or drugs are entitled to grieve without fear of being judged and to receive the support they need, just like anyone else.

The palpable feelings of loss, sadness, pain, and love that are woven through Helen and James's stories are a powerful reminder of the human cost and profound impact of drug and alcohol related bereavement. Thank you to both writers for being willing to share them with a wider audience.

Fiona Turnbull

Fiona Turnbull is a freelance project consultant and writer specialising in bereavement, and a trainee psychotherapist. She worked for Cruse Bereavement Care as the project manager for the BEAD project in partnership with Adfam until March 2016. fionajturnbull@gmail.com

The BEAD project has been set up by Cruse Bereavement Care and Adfam to offer one-to-one telephone support for people bereaved through alcohol or drugs. A peer support group has also been set up in London and a second group will be launching in Birmingham later this year. All volunteers with the project have personal experience of being bereaved through substance use and have been specially trained to offer support to others going through similar experiences. A BEAD website is also due to launch later this year.

For more information about the BEAD project and to read the scoping review and consultation findings, go to www.cruse.org. uk/drugs-and-alcohol or www.adfam.org.uk/professionals/latest_information_and_events/current_projects/bereavement

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