

# Supporting suddenly bereaved children and young people

This report highlights research and best practice as presented at two Sudden seminars on supporting suddenly bereaved children and young people, in July and November 2013. The seminars were sponsored by Fentons Solicitors. This report is produced for the benefit of Sudden subscribers and event participants.

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## Brake's work supporting suddenly bereaved children and young people

**Louise MacRae, support service manager, Brake**

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A sudden death is devastating for children and their families. There is no time to prepare or say goodbye. In many cases the death is violent and horrific, such as when someone dies in a road crash or commits suicide. Children and young people respond to shock in a similar way to adults but they may express their emotions differently. They will also grieve in different ways at different times.

Common reactions include: difficulty comprehending death; denial; shock and physical symptoms; and a need for information and questions answered. Brake support for suddenly bereaved children Brake provides support for suddenly bereaved children through its Amy & Tom project and associated literature, other support guides, and through its helpline for UK-based families affected by road crashes. Information for professionals about these services can be found on the Sudden website. Full details on these services for victims are available online at [www.brake.org.uk/victims](http://www.brake.org.uk/victims).

### Helpline case study

A woman whose husband had been killed in a crash called the helpline. She had separated from her husband prior to the crash and had a 13 year-old daughter. Following the crash the husband's family fell out with the woman, and took his possessions from their home without her consent. The woman had severe financial difficulties, and was affected by gossip and accusations by her husband's family and the local community. She struggled to support her daughter through her grief, due to her own conflicted feelings towards her husband and his family.

### About this report

This guidance report is one of a series for support professionals produced by Sudden, a not for profit initiative providing information and guidance to assist people who have been suddenly bereaved, including help for professionals supporting those people.



These reports highlight research and best practice from papers presented at Sudden events and from other relevant sources, and aim to help raise the professional standards of people who care for those bereaved by sudden death.

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She was also concerned her daughter was being bullied.

After she contacted the helpline, Brake was able to assist in a number of ways:

- encouraged discussions with the school over what had happened and the bullying her daughter was suffering;
- reassured the woman about her legal rights with regards to her husband's possessions;
- arranged for specialist legal support to ensure financial security;
- helped arrange specialist therapy for the woman and her daughter; and
- assisted her in supporting her daughter through her grief.

### Volunteer case study: Emily Carvin

Emily Carvin is a Brake volunteer whose mother, Zoe, was killed in a road crash in February 2006, when Emily was 11 years old.

On the day her mother died, Emily returned home from school to find her father already home and waiting for her. She was surprised as he usually worked long hours so was rarely home during the day. He had come home early after he heard reports of a crash nearby, and became worried that he couldn't get hold of Zoe on the phone. Minutes before Emily came home, the police had arrived to give him the terrible news that Zoe had been killed in the crash. As Emily arrived her father told her what had happened, then the two of them had to tell her older brother as well when he returned later that afternoon from football practice.

Zoe's car had been in a queue at a temporary traffic light, when a truck driver who was texting on his mobile phone failed to see the stationary traffic and ploughed into the back of Zoe's car. Zoe was killed instantly; her mother, who had been driving, suffered serious injuries but has now recovered from the physical trauma of the crash.

Emily felt initially empty and numb, rather than sad. She felt constantly isolated, even though she was surrounded by family and friends and never actually left alone. She says her reaction differed greatly from her brother's, who was openly, visibly distressed.

Emily had some counselling about six months after the crash with someone her dad knew. She didn't 'click' with the counsellor so she felt put off and didn't pursue counselling. She thinks family counselling or support might have been helpful had it been offered, and support should have been offered to her dad; instead he had to look for it. She says she would have been interested in group counselling with other bereaved young people, but she had no idea it was available to her. She did receive unofficial support from a sympathetic teacher. Emily started having counselling in 2012, six years on from the crash, and felt it helped her then.

When Emily returned to school after the crash her closest friends supported her, but many others avoided her as they didn't know what to say or how to react. She thinks if the school had offered support to her classmates on dealing with their own feelings of shock, they might have been better able to cope and she would have felt less excluded.

Some of Emily's teachers were made aware of her situation but not all of them. This led to several difficult situations, for example a psychology teacher who asked Emily repeated questions about people's relationships with their mothers, without being aware that Emily's mother had died.

### Key learning points:

- communicating news of a child's bereavement to all their teachers helps to avoid upsetting situations later on, but the child should have a say in what information is given to other teachers, staff and pupils;
- ensure appropriate support is available and offered to the bereaved child; and
- offer support to the child's friends and classmates too, as they may not have dealt with a bereavement before and will need to know how they can help their friend.

### Volunteer case study: Louise Cox

Louise Cox is a Brake volunteer whose parents were both killed in a road crash in November 1998 when Louise was 15 and her brother, David, was 17. Louise was taking part in a modelling course. She was very excited about this opportunity, and her parents had wanted to take her there, and bring her back, so they could support her.

When her parents didn't arrive to pick her up at the end of the day, Louise was worried as her parents were usually early, not late. Eventually she called her aunt from the reception office. Her cousin answered the phone and delivered the devastating news that Louise's parents had both been killed in a crash. They had been on a dual carriageway, at a point where two lanes merged into one. An unlicensed driver with a car full of passengers was driving too fast to merge safely and slammed into the back of their car. Both of Louise's parents died at the scene. The other driver was convicted of careless driving, but never served a prison sentence.

Louise and her brother felt largely unsupported by family during the months following the crash. They managed to live independently in their parents' house, paying the bills and getting through their exams. She felt her aunts blamed her for her parents' death, and she found herself acting almost as a parent to her brother, who wasn't coping. She found it very difficult to access counselling, as she was too old for child services but not old enough for adult counselling. She did feel her school provided fantastic support and helped her through this incredibly difficult time.

The aftermath of the crash was made more difficult following the trial, at which the driver who had killed her parents showed no remorse. Louise felt justice wasn't done, as the driver was not jailed. She also feels she didn't get enough information from police over what had happened: she didn't know the full story of the crash until she requested extra information in 2012; 14 years after the crash had taken place.

Louise is still seeking counselling for her bereavement. She feels that because she was put in a position of having to take care of her brother immediately after the crash she pushed her feelings away rather than dealing with them, and is suffering from delayed trauma.

### Key learning points:

- sudden bereavement is not a short-term problem; the effects can last for years;
- schools have an important role to play in offering reassurance, a listening ear and a safe place for a bereaved young person;

- being flexible following a bereavement, for example around coursework deadlines and exams can help young people; and
- receiving accurate information is essential to being able to process and deal with a traumatic event.

## The ripple effect: how complex bereavement affects whole families

**Arlene Healey, consultant family therapist and manager of the Belfast Family Trauma Centre**

Bereavement is a normal part of the life cycle. Losing someone you love will always involve a natural longing for them, which should not be treated using therapy. However, many struggle after loss and need help to find ways to cope.

Persistent Complex Bereavement Disorder (or simply “complex bereavement”)<sup>1</sup> is different to “normal” bereavement. It is more intense and tends to last longer. Normal grief is often painful and disruptive, but people gradually find it possible to get on with their lives. Sudden death at an “unacceptable” stage of life is more often associated with complex bereavement.

Risk factors for prolonged bereavement or complex grief include<sup>2</sup>:

- nature of the event, particularly if it was sudden, violent or traumatic, or involved multiple deaths;
- high closeness, support and dependency in the relationship with the deceased;
- public nature of the death or deaths (for example, high-profile tragedies such as the Hillsborough Stadium disaster in 1989); or
- no sense of justice or legal justice.

The need for a bereaved family’s involvement in any legal process can prolong or prevent healing; they may feel unable to move on until it is resolved. This prolonging can also exacerbate the situation as the family is likely to have less social support as time goes on.

A person may be diagnosed with complex bereavement if they experience at least four out of the following eight symptoms in a marked, overwhelming or extreme way:

- trouble accepting the death;
- inability to trust others since the death;
- excessive bitterness or anger about the death;
- feeling uneasy about moving on;
- feeling emotionally numb or detached from others since the death;

- feeling life is empty or meaningless without the deceased;
- feeling the future holds no meaning or prospect for fulfilment without the deceased; and
- feeling agitated, jumpy or on edge since the death.

The symptoms must cause disruption or marked dysfunction in social or work settings for at least six months to fit the criteria for diagnosis.

Complex grief is associated with<sup>3</sup>:

- increased risk of physical and psychological problems;
- increased risk of cancer, heart problems and suicidal thoughts;
- decline in functioning in social, family and occupational life;
- increase in hospital admissions;
- negative health behaviours (such as an increase in alcohol use); and
- reduced quality of life.

### Impact on families and children

Complex bereavement has a “ripple effect” on entire families and communities, not just those closest to the deceased. Breakdown in communication is often experienced in the family, as all family members struggle to adjust to the new reality without their loved one and their new roles within the changed family dynamic. Some family members may blame each other.

Parents may struggle to meet their children’s emotional needs due to their own grief, which can feel to the child like another loss. Parental styles can also change, either in response to their own grief or to compensate for the changed family structure, particularly if it was one of the parents that died. Parents may become overprotective of their children as part of their own grief reaction and fear of another loss.

Grief will affect the child’s confidence and their expectations of their living environment, which may feel unsafe following a sudden bereavement. This can have a long-term impact on the child’s attainment and development, and lead to difficulties in relationships and their social, academic and professional life.

### Treatment

As complex bereavement affects whole families, systemic family therapy can be a useful approach. This approach<sup>4</sup> enables family members to explore difficult thoughts and emotions in a safe way, work together to understand each other’s experiences and views, and support each other in the context of their family relationship<sup>5</sup>. Couples therapy may also be recommended if the loss has impacted severely on the parents’ relationship.

The aim of therapy should be to help the family build a coherent narrative of what has happened. In the aftermath of a sudden, traumatic death such a narrative is often confused, making it harder for the family to process the event and move on with their lives. By way of a careful review of what happened, the family can build the event into a story and start to see a way to rebuild their lives together. Going over the event again will be distressing, so all family members and any support professionals helping them should be prepared for this.

Symptoms of trauma must be treated before any further counselling is initiated. Individual trauma-focused treatment can be helpful, such as cognitive behavioural therapy (see the paper from David Trickey, below, for further details on trauma support).

## Post-traumatic stress disorder following traumatic bereavement in children and young people

**David Trickey, lead consultant clinical psychologist, Child Bereavement & Trauma Service**

Approximately one third of children and young people will develop post-traumatic stress disorder (PTSD) after traumatic events<sup>6</sup>. The symptoms<sup>7</sup> consist of three clusters of difficulties:

- re-experiencing the event: intrusive memories; nightmares; flashbacks; repetitive play
- over-arousal: difficulty falling or staying asleep; irritability or outbursts of anger; difficulty concentrating; jumpy and always on the lookout
- avoidance and numbness: avoiding anything associated with the event; memory loss; loss of interest in activities; feeling different from others; sense of foreshortened future

The above symptoms may be common in any bereavement, but are classed as PTSD if they persist for more than one month, or if clinician and patient agree they are "clinically significant", i.e. causing distress or impairment in day to day life.

It is difficult to predict who will suffer from PTSD, but it seems that the child or young person's emotional response and interpretation of why or how it happened is more important than any objective measure of trauma severity. How they understand the event is more important than how much of it (if any) they actually witnessed<sup>8</sup>.

Symptoms of PTSD, particularly intrusive memories and avoidance, can hinder the grieving process: children in particular may have been too horrified by the event to begin to be saddened by their loss. Traumatic deaths are often accompanied by a number of other factors that

further complicate the adjustment of those bereaved, such as a coroner's inquest or a criminal trial, which can affect the ability of adult carers to look after bereaved children. In some circumstances where children were witnesses to the death they may be involved directly in a trial.

### Treatment

Trauma-focussed cognitive behavioural therapy (TF-CBT) is the only intervention recommended by the UK National Institute for Health and Care Excellence (NICE) for children and young people with PTSD<sup>9</sup>. TF-CBT consists of some or all of three core components<sup>10</sup>:

- bringing the event to mind to create a coherent narrative and "process" the memory;
- developing a meaning of the event that is both truthful and useful; and
- reducing avoidant coping strategies.

TF-CBT should only be provided by clinicians who are trained as cognitive behavioural therapists. There are national bodies that accredit CBT therapists, including the British Association of Behavioural and Cognitive Psychotherapists and the National Association of Cognitive Behavioural Therapists in the USA, although accreditation is not compulsory.

Parents, carers and support workers seeking to arrange appropriate intervention for a child should first discuss the problem with the child's family doctor, who can arrange referral to an appropriately qualified clinician.

There is also some evidence that an approach called eye movement desensitisation and reprocessing (EMDR) can be effective for children with PTSD<sup>11</sup>. Treatment involves the patient making side-to-side eye movements following the therapist's hands (or other left-to-right stimulation, including hand-tapping or sounds), while recalling the traumatic incident. The way in which this treatment works is still subject to debate, but while EMDR is yet to be recommended by NICE in the UK for children and young people, it is recommended for adults. EMDR should only be provided by clinicians who have been trained in its use on a course approved by the EMDR Institute.

### Non-clinical support and treatment

Support practitioners who are not trained in CBT or EMDR can also help people at risk of developing PTSD by supporting them to talk through their traumatic experience as and when they are ready and wish to do so, ensuring they feel safe. This will help create a 'narrative' (or 'normal') memory of their experience, to replace the 'sensory' memory (sights, sounds, smells, etc.) laid down at the time of trauma. This sensory memory creates the feeling that the event is still happening, leading to the intrusive thoughts and anxiety that symptomise PTSD.

## Legal support for families following a sudden death in the UK

**Nigel Smith, solicitor, and Etala Anderson, solicitor, Fentons**

Following a sudden death or life-changing injury, the family may be entitled to make a compensation claim under UK law. The aim is not to replace what they have lost – no amount of money could ever compensate for the loss of a loved one – but to put them back, in financial terms, to where they would have been had the incident never happened.

A solicitor will act as a guide to the complex legal process. While the family may not want to initiate a claim immediately following the bereavement, it can be useful to contact a solicitor as soon as possible to find out what the options might be. Brake's helpline can give information on what kind of legal support may be available and direct families to reputable solicitors if appropriate.

The role of a personal injury lawyer is to: explain the procedure; obtain the evidence and build the case; protect the family from distressing evidence (such as photos or medical reports); represent the family at the inquest if required; assist in dealing with bad news; and deal with the media on the family's behalf. They will give professional and honest advice about the prospects of success in a claim, and help to obtain early, appropriate treatment if needed. Ultimately their role is to achieve the best results to allow an injured person or bereaved family to move on with their lives.

### Compensation and dependency claims

A compensation claim can provide financial support for the bereaved person, and fund any necessary treatment. Treatment could include physical injury or scarring, as well as psychological injury such as post-traumatic stress and grief counselling. Financial support can cover costs for care, loss of a parent's income, funeral costs, and costs for dependants.

To make a dependency claim, the bereaved person must be able to show they were financially dependent on the deceased, or were likely to become so (for example, an elderly parent who was planning to move in with their adult son or daughter on retirement). The claim should consider the income of the deceased person, as well as the monetary value of any care or services they provided (for example, child care or DIY). Dependency claims can be made by spouses and ex-spouses, common law and same-sex partners (if they had lived together for a minimum of two years), parents, children, siblings, or other relatives or dependants.

A claim must be brought within three years of the death. For a claim to be successful, it must be proved that someone else was to blame for the death, due to negligence. However, criminal charges do not need to have been brought for a civil claim to succeed.

### Bereavement awards

A bereavement award is a fixed amount of £12,980, payable to fixed categories of relatives. Under the Fatal Accidents Act 1976, a bereavement award is payable to the wife or husband of the deceased, if they were over 18 and married. If the deceased was under 18, bereavement damages can be claimed by his /her parents, or his /her mother if the deceased was illegitimate. A bereavement award is payable in addition to any other damages awarded.

### Case study

Zoe's mother, Jill, was killed in a road traffic collision. Zoe was 21 at the time of the crash. She has a severe form of cerebral palsy, is wheelchair dependant, partially blind, and has no movement in her left arm. She also has an Autistic Spectrum disorder and severe learning difficulties. Jill was her sole carer prior to the crash.

After the crash Zoe's aunt had tried to move into the council home where Jill and Zoe had lived together, but social services refused and Zoe was placed in a care home, where she was the youngest resident by 30 years. Both Zoe and her aunt felt this was completely inappropriate and were very distressed at this outcome.

In assessing Zoe's claim, Fentons identified that she had lost her: home; main carer; means of transport; and someone to manage her finances. They initiated a successful claim for her to reinstate some of the things she had lost. Zoe was able to move into a shared house with two other young adults with special needs, with plans to use her damages eventually to buy her a house of her own and pay for 24 hour care. She will be appointed with a Court of Protection deputy to manage her money, and a case manager to organise the staff who care for her.

## Supporting pre-school children after a sudden death

**Liz Koole, family services team leader, Winston's Wish**

Most children can't understand the physical concept of death until they are about six years old<sup>12</sup>. Pre-school children (birth to five years old) can't comprehend the permanence of death, so may ask questions about when their deceased loved one is coming home. They may be initially upset by strong displays of emotions from their parent or carer, but it is important to show feelings so the child understands it is normal to be sad and to cry, and not something they need to hide.

A child's understanding can be gauged by listening carefully to what they say, answering questions honestly and explaining any misunderstandings in clear and simple terms. Avoid using euphemisms like "passed away" "lost" or "gone to sleep", which can confuse or distress young children. For example, a young child told their parent has been "lost" may be upset that no one is

trying to find them. Using the words “death” and “dying” avoid this confusion and make it easier for children to understand. However, pre-school children may learn to use these words without understanding them, so it is important to listen to how children talk about the death to determine whether they have actually understood.

Children who suffer bereavement when very young often continue to grieve many years later. This may be the case even if the child was too young to remember the person who died. As they grow older, children can be “given memories” by other family members and friends sharing their own stories, which will help the child to process their loss.

### Common reactions

Most children repeat questions over and over, as they need this reinforcement to develop their understanding. Pre-school children may not have the cognitive development or emotional literacy to ask questions, so parents and carers need to look out for things they may be worried or upset by and explain these as they go along.

Children may be very sad or distressed one minute and talking and playing normally the next. This is because it is hard for children to handle strong emotions for sustained periods.

Other common reactions include:

- clinginess and separation anxiety;
- unable to cope with any changes to routine;
- temper tantrums, as a way of expressing frustration, anxiety, or confusion;
- fears or anxiety about themselves or others around them;
- physical symptoms such as tiredness or illness;
- assuming the death was their fault;
- seeking attention from adults of same gender as the dead parent; or
- upset by loss of the ‘whole family’ and making requests to find a new parent.

### What helps

Children need love, comfort and reassurance that they are cared for to help them feel safe again. If a pre-school child is suffering from separation anxiety, giving them objects such as pieces of their carer’s clothing or jewellery can calm them during short periods of separation, and help them to understand their carer is coming back.

All children are different, but some or all of the following is helpful to most pre-school children:

- giving the child something that belonged to the dead person;
- talking about the person who died and what they did together;
- keeping routines and boundaries;
- voicing emotions for them if the child is too young to find the words themselves, for example “You might be feeling worried Daddy might die as well as Mummy”; and
- learning how the death affects other people, to help them learn to express their own feelings and feel less alone.

### Funerals

Many families worry pre-school children will find funerals frightening or upsetting. However, funerals are a chance to acknowledge the death and say goodbye, and

pre-school children need this as much as everyone else. Adults who were bereaved as young children often report feeling regret at not being allowed to attend the funeral of their loved one<sup>13</sup>. If the child is to attend they should be told exactly what will happen there and what to expect, so nothing comes as a surprise, and should be given the choice to not attend if they don’t want to. If the child will not attend the funeral, the family should consider holding some kind of personal ritual the child can attend.

### Supporting children and young people bereaved by suicide

**Claire Stableford, facilitator, and Julie Ellison, training development facilitator, Child Bereavement UK**

Bereavement by suicide is often viewed differently to other forms of sudden death: there is still a stigma attached to suicide, formed by religious beliefs, family honour and even criminal legislation. It can leave the family of the deceased with feelings of guilt and self-reproach, isolation and abandonment. People bereaved by suicide often report being ignored by friends and colleagues, who are afraid of saying the wrong thing so say nothing at all.

In 2011 the rate of recorded suicides in the UK rose for the first time in a decade. This is thought to be linked to economic recession and pressures on individuals struggling to remain in employment or facing financial hardship. There were 6,045 suicides in 2011 of people aged 15 years and over, three in four of whom were men. The highest suicide rate was among men aged between 30 and 44, but there has been a significant increase of suicide amongst men aged between 45 and 59. The highest suicide rate for women was in the 45-59 age range<sup>14</sup>.

Telling a child their loved one decided to end their own life is incredibly daunting. Adults often seek to protect

children from the harsh truth, which can result in children being excluded from the information sharing process. Children are often given inadequate explanations, or the information is kept from them entirely<sup>15</sup>. This is an understandable impulse, but ultimately harmful. Children may well find out the details from other children, from the local media, or from social media. When the child eventually learns the truth of what has happened they may lose trust in the parent or carer who lied to them. Attempting to protect children from the truth also robs them of the chance to process and come to terms with what has happened.

Children experience the same sorts of emotional reactions as adults to a suicide, but may express them in different ways. Some common emotions and reactions include:

- anger: may be expressed through challenging behaviour, or may be repressed and lead to depression;
- isolation: people may avoid talking to the child or expressing sympathy due to the stigma associated with suicide, which can affect children as much as adults;
- pain: the child may feel abandoned, and believe the adult who killed themselves didn't love them;
- confusion: the suicide may have followed years of depression or other mental illness, and even prior suicide attempts, which will have affected the child's relationship with the person who died and may leave them with conflicted feelings about their death;
- guilt: the child may believe it was their fault, or that they could have prevented the suicide; and
- denial: the child may have difficulty accepting what has happened, especially if people around them refuse to talk about it, as many do following a suicide.

Children need to be told the truth in an age-appropriate way, to be given simple and honest answers to questions, and to be listened to. Most importantly, they need to know they are not to blame, they have somebody who is there for them and will look after them, and they can talk about difficult feelings as well as good memories they have of the person who died.

It can be useful to take a structured approach to giving information, explaining in stages and expanding gradually on what the child needs to know. This should be taken at the child's pace, checking what they understand and if they want any more information at each stage. Stages in talking to a child about a suicide can include:

- explain honestly and in simple terms that the person has died;
- give simple general details about how and where the person died;

- explain that the person killed themselves;
- provide more detail about how the person died; and
- explore possible reasons why the person killed themselves.

Children should be encouraged to talk about their feelings and to focus on positive rather than negative emotions. This can be done in creative ways, through drawings and play, and age-appropriate books which explore the topic.

The child's teachers should be made aware of what has happened, but children should have a say in how much a teacher can tell other teachers, school staff and pupils about the death. The child will need supportive teachers who aren't afraid to ask how the child is feeling or talk about the person who has died, and who the child can feel comfortable in going to at any time. Teachers should also be aware of where planned lessons may be difficult for the child, and agree with them how this should be handled: for example, allowing the child to leave the room if necessary, or arranging different activities with support. Difficult feelings related to the suicide may come up at any time, even years later, so teachers need to be aware of and understand any behavioural issues or difficulty concentrating or completing work on time, within appropriate boundaries.

## End notes

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