



Supporting Families

"No one should ever suffer the unexpected death of their child, like I did. But it happens and what we can do, what you can do, is make sure that the routines and procedures that are put in place to explain that unexpected death are the best they can be. For the parents and family. And for the child. You can help."

Gabrielle Osrin, bereaved parent

There is no perfect or "right" way to work with a family following the death of a child, but what we hope to here are some pointers to support good practice. Even small acts of compassion can make a big difference to grieving parents, and a sensitive caring approach, far from interfering with any investigation, goes a long way to ensuring a thorough evaluation of the death.

The process of grieving

Grieving is not a one-off event nor even a specific process leading to a predetermined outcome, but rather an on-going and varied state that can be felt physically as well as emotionally and socially. It is important to recognise that there is no "right" way to grieve and that each individual is likely to feel and express their grief differently at different times. Grieving is exhausting; it can affect a couple's ability to communicate with each other; it can affect concentration and ability to work; it can also be a time of great anxiety and fear. Often, but not exclusively, women will be more expressive in their grief, and focus more on their emotions; in contrast, men often tend to be more restorative, acting to get things back to normal. However, both these are important aspects of grieving and both men and women may need help to express their emotions and to develop ways of being restorative in order to move forwards.

The unexpectedness of a child's death may lead to shock or disbelief, which may last for several days or weeks. Parents may react with anger directed against others, including the team responding to the death or other professionals who may be accused of negligent care. Many parents, particularly mothers, will express feelings of guilt, that somehow they have caused or contributed to the child's death. Such expressions need to be handled sensitively, not jumping to conclusions but trying to gather all the information in order to fully understand the circumstances of death; not unduly apportioning blame, but not offering false reassurances or denying factors that may have contributed to the child's death.

Practical steps to helping grieving families

Stewart and Dent¹ (2007) offer 6 pointers to helping families:

- **Careful listening:** learning to be quiet and listen to what parents and other family members are saying can help us to respond in an appropriate way.
- **Acknowledging** that the child has died and that this is a loss for the family. Speaking of the child by name; expressing our condolences; and listening to a family's tales of their child are all ways of acknowledging that the child was precious and that his or her death has left a hole in the family.
- **Recognising** that the family define who they are and what their needs are; not imposing our views on them or prejudging their needs.
- **Informing:** providing the family with information is one of the most important aspects of our response to an unexpected death. The family have a right to know what is happening to their child, and to know the outcomes of any investigations. Again sensitivity is important, and we should not force information (for example details of what happens at autopsy) on parents who do not want to know, but our starting point should always be one of seeking to involve and inform the family at all stages.
- **Negotiating Social Support:** finding out who the family members can turn to for support and helping them to do so; this may involve contacting bereavement counsellors or religious leaders; putting them in touch with self-help and support groups; phoning other family members. For some families, professionals may be one of the key sources of social support, offering both practical and emotional help.
- **Getting in touch with ourselves:** In our work with families we need to recognise that our own interactions will be influenced by our beliefs, past experiences and culture. Awareness of those influences can help us to be sensitive in the way we engage with grieving families.

Immediate care

The concept of the "golden hour" has as much meaning in bereavement support as it does in gathering evidence for a criminal investigation. Attention to supporting families in the hours immediately following their child's death will help in the longer term process of grieving. On arrival at hospital, one nurse should be assigned to the family as a support nurse, to help them through the process. Although it will not always be possible, because of changing shifts or other demands, for the same nurse to stay with the family for the whole of the time they are in the department, whenever any change is required, or new staff members take over, there should be a thorough handover and the new staff should be personally

¹Stewart A, Dent A (2007) *Supporting Families When A Child Dies Suddenly*. In P Sidebotham and P Fleming (Eds) *Unexpected death in childhood: a handbook for professionals*. Chichester:Wiley

introduced to the family. It will often be helpful, after breaking the news of the death to allow the family some time alone with their child; in some situations this may require careful handling with sensitive non-intrusive supervision, but rarely will it be necessary to deny the parents this right. Family members may want to wash their child, or to provide their own clothes for the child to wear. They should be offered the option of photographs or other mementos such as hand and foot prints or a lock of hair. Although there may be time constraints on some of the processes occurring after a child's death, as far as possible the family should be allowed to take things at their own pace, and that our professional responses fit around the family's needs. Parents should be given clear information about who to contact to find out what is happening to their child or if they want to spend time with their child. Following the autopsy, they may need help and support to understand the changes that occur and how their child may look different.

Sharing information

At the time of presentation of an unexpected death, it will often not be possible to give the parents a cause of death and it is important not to hazard a guess at the cause or offer assurances that may not be correct. If there are clear pointers towards a specific cause of death, it is appropriate to tell parents that this seems the most likely explanation, although even in these circumstances, it must be emphasised that a full investigation is still required to determine the cause of death. For infants, it is important to explain that it is not always possible to identify a specific cause. As information becomes available through the process of the investigation, that information should be shared with the family, but this must always be discussed with the coroner first and agreement sought on what information can be shared, when, and by whom.

Parents also need a full explanation of the process of the rapid response, who will be involved and why this is necessary. Most families seem to understand and find this approach helpful, and feedback from bereaved families suggests that they don't find the joint presence of police and paediatricians in the emergency room or at the home visit intrusive, but rather that this can be very supportive and reassures them that their child's death is being evaluated thoroughly. Parents need to be informed that a post-mortem examination will be required, where and when this is likely to take place, what will happen to their child before and after the autopsy and what arrangements there are for them to visit and spend time with their child.

Practical arrangements

Parents may need help in caring for themselves and others physically; eating and sleeping regularly; getting regular exercise. Some parents may require short term sleeping tablets or other medication and should be referred to their GP for support. Breast feeding mothers may need medication or support to suppress breast milk following a sudden infant death.

Registering the death – all deaths need to be registered with the Registrar of Births, deaths and marriages; the process will differ according to whether the death was expected and a death certificate has been issued, or unexpected and referred to the coroner. The website www.statistics.gov.uk/registration provides details about the processes and contact details for all registrars.

Families should be encouraged to contact a funeral director at an early stage, even if there is to be an autopsy which may affect the timing of the funeral. Many funeral directors will charge a minimal or no fee for the funeral of a baby or young child. The funeral director will be able to help with all arrangements around transporting their child, arranging the funeral itself, cremation or burial, and other practical issues. If the family expresses a particular faith, they can be put in touch with religious leaders of that faith. Most religious leaders will also be willing to offer support to members of other faiths or those who profess no faith.

Helping children and other family members

As children grow, their understanding and responses to a sibling's death vary. Young infants may not be aware of or able to understand the death, but will pick up that something is happening in the family and this may lead to behavioural responses that can add to a parent's stress. Pre-school children typically have difficulties in understanding the permanence of death; but also tend to have vivid imaginations, and may feel that they are responsible for the death, thus compounding their sense of loss and isolation. With a limited ability to express themselves verbally, grief may manifest in a whole range of behaviours including aggressive, clingy or withdrawn behaviour. As the child grows through school age to adolescence their thinking becomes more concrete, finally progressing to allow abstract and deeper thought processes.

Professionals can play an important role in supporting parents with the difficult task of explaining the death to their other children, and coping with the realities of ongoing family life. Explaining the death to the child in an age appropriate way, avoiding euphemisms or ambiguous phrases, and involving the child in the restorative processes of the funeral, building memories, and rebuilding a family life and routine can all help children in coping with their grief.

It is not just parents and siblings who are affected by the death of a child, but grandparents, other wider family members and the child's friends and school mates.

Resources for families

There are a wide range of organisations offering support for bereaved families, along with various books and other resources. All professionals involved in responding to child deaths should familiarise themselves with local sources of bereavement support. Some key national organisations are listed here, others can be found through searching the internet.

Child Bereavement Trust

Tel: 01494 446648

Website: www.childbereavement.org.uk

Childhood Bereavement Network

Tel: 020 7843 6309

www.childhoodbereavementnetwork.org.uk

Cruse Bereavement Care

Tel: 0844 477 9400

Young people's support line: 0808 808 1677

Website: www.crusebereavementcare.org.uk

Youth Involvement Project www.rd4u.org.uk

Foundation for the Study of Infant Deaths (FSID)

Tel: 0870 787 0885

Help-line 020 7233 2090

Website: www.sids.org.uk

SANDS (Stillbirth and Neonatal Death Society)

Tel: 020 7436 5881

Website: www.uk-sands.org

