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# I Understanding Childhood Death

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# 1 A Family's Journey

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ANN CHALMERS

'Ondine lived for nearly seven months and then died suddenly one night . . . The horror and shock and desperation of that discovery are difficult to describe. But in barely an hour we were transformed from a normal blessed family to three crushed individuals at the beginning of a journey of grief of which we knew nothing.'

Madeleine

The sudden and unexpected death of a child is something for which no parent can ever be prepared. Parents expect to be able to watch their children grow and develop into adulthood, and when a child's life is abruptly ended, whatever the cause, the anguish is immense. As professionals coming into contact with families at this time and in whatever capacity, we are faced with the most tragic of situations that cannot be made better. This does not mean, however, that we cannot make a difference to those families in a time of tragedy.

A parent's natural instinct is to protect their child, and the sudden and unexpected death of that child can give rise to powerful feelings of responsibility and failure as a parent, however irrational these may seem. Whilst most deaths are likely to be from natural causes, the fact that an investigation may be necessary inevitably adds to that burden of responsibility. It is paramount that parents are handled with respect, sensitivity and understanding throughout the investigative process.

The death of a child at any age is always a death out of time. As parents, our perfectly reasonable expectation is that our children will survive us. It is interesting that this expectation is so firmly entrenched in us all that no single word exists to denote a parent who has lost a child, whereas there are words for other situations of bereavement, such as for those who have lost a spouse and for a child who is left without parents.

Parents often feel a sense of stigma in relation to their child's death. The death of a child threatens the security of everyone who comes into contact with the family – concrete evidence of every parent's worst nightmare. At one extreme, the extent of their grief can be so great that others may avoid them, finding it unbearable even to come close to a situation where this has happened. At the other end of the spectrum, assumptions may be made that a little amount of life, measured by time, equates to a little amount of loss.

Professionals have an important role in acknowledging the significance of the parents' experience. Referring to their child by name acknowledges their child and the reality of what has happened.

When a child dies, the parents' lives are forever changed. Their child is still, and always will be, part of their family. There will be a gap that can never be filled. The death of a child represents not only the loss of a past with that child, but the loss of a future that will never be fulfilled, and the loss of all hopes, dreams and expectations associated with that child. The grief is not only for the loss of what was, but for what can now never be.

'As we held her that night, we were acutely aware that nothing could ever be the same again. Up until then had been normal life, and from that moment on represented our changed lives, which would never feel normal again. I think that this is probably a pivotal moment common to all bereaved parents. Life will go on and must go on, but it will always be different. You can resume routine over the weeks and months but your loss will permeate everything.'

Madeleine

The parents' ability to survive emotionally will be impacted by what has gone before in their lives, by their own childhood experience of parenting and by what they have invested in their relationship with this child. This may have been the longed-for boy in the family, the child who caused the least trouble, the child with whom a mother was going to develop the kind of relationship never experienced with her own parents. Parents are faced with the monumental task of learning to live life without their child, and to survive this experience as best they can.

There is no 'right' way to grieve. Understanding what is happening to them in relation to what happens to anyone facing significant loss can help parents to feel 'normal' in their grief, when so many fear they are 'going mad'. Parents find it helpful to know that grief can be felt physically as well as emotionally, and is exhausting. Grief also has much anxiety and fear attached to it; one family were greatly helped by their Health Visitor who explained that people often feel frightened in grief. Part of grieving is struggling to accept the reality of what has happened. Believing it to be real and reaching any acceptance that you will live every day of your life without your child feels almost impossible to achieve, but families have been helped by professionals who avoid jargon and are honest. This helps parents accept the reality.

Each parent will grieve in their own way in their own time. Grieving the death of a child is a solitary experience. Although this is the one loss in life that, as parents of the dead child, they may share equally, each parent will have had their own unique relationship with that child and their grief may be very different in its expression and duration. Couples often experience an inability to communicate with each another and to express their overwhelming feelings. As a result, each can feel alone and isolated in their grief, particularly if partners are unable to share with each other what this loss means for them. This

can drive a wedge in a relationship from which some may not recover, particularly if there were difficulties before the death happened. Others who find a way of sharing their feelings may find themselves drawn together in this shared tragedy.

Men and women often behave differently in grief. Women naturally tend to focus on the loss and are more concerned with their emotions; men in contrast are more likely to be restorative, wanting things to return to 'normal' as soon as possible. Unhelpful assumptions can be made, with women sometimes misinterpreting their partner's response as not caring about their child. Because a restorative response does not involve the 'expected' way of grieving, professionals may also place unhelpful interpretations on a person's behaviour. Yet getting in touch with the emotions associated with a loss and doing things that take you away from the enormity of that experience for a time are both very necessary components of a healthy grieving process. Men need to find ways to express their feelings about their child's death, and women need to develop ways of being restorative if they are to move forward.

Through memories the dead child remains a member of the family. Everything surrounding their child's death, including their interactions with professionals they encounter at that time, will be part of that precious memory bank for parents. Even the most difficult aspects of investigating a child's sudden death can be managed positively.

'The hospital staff, from the Paediatrician who told us Ondine was dead, to the nurses who regularly checked on us, were gentle and sensitive to our needs. Even the police, who had to come and ask questions, were dignified and kind enough to agree with me that yes, she was a beautiful baby. We could not fault anyone that night.'

Madeleine

Parents tell us that the professionals who make a real difference to them are those who do not hide behind some professional façade, but who are able to be congruent and let their own humanity shine through in their interactions with the family.

'We were fortunate to be supported by many wonderful people in those early weeks and months. Family and old friends of course, but others too, more surprising and unexpected: the funeral director whose dignity and sorrow were palpable, whose respectful hands would wash and dress our baby with a mother's tender touch; the surgery staff nurse who visited us and spoke of her vivid memories of Ondine and who even came to her funeral; the coroner's assistant who gently guided us through the inquest; the Paediatrician who spoke with such understanding and honesty.'

Madeleine

Acknowledgement of the significance of their loss is vitally important to parents, as is the feeling that others really understand the depth of the tragedy they are facing. Often, because it can seem so impossible to find 'the right

words' to say, we may say nothing. A simple expression of sorrow at what has happened can go a long way.

'An understandably difficult encounter was with the Paediatric Pathologist. We were shocked by how unfeeling she seemed. We could acknowledge that her job was one of scientific investigation, but felt bemused as to why the few words of condolence which would have put us at our ease were never spoken.'

Madeleine

In contrast, Rachel and Simon were helped by a member of the mortuary staff who explained she would take great care of the body of their little son, Ben, and that they were to think of her as their babysitter.

Memories of time spent with their child after death can be very precious. Sensitively preparing parents for what their child might look like is important, as is affording them the opportunity to do things that matter to them. Sarah greatly appreciated the mortuary technician who gently and willingly made her little child's body available for her to see each day before the funeral so she could read her stories, and the interest the technician took in the books she brought.

Parents have seldom had anything but positive feelings towards professionals who have been visibly moved by what has happened. They are often helped by seeing the professionals' reactions to the death of their child; this makes the death real and can also give parents the permission they may need to show their emotions.

'It was important that people saw our beautiful son and thought that this was the worst thing in the world that could have happened.'

Andrea<sup>1</sup>

The 'system' that swings into action when a sudden death occurs can leave parents feeling powerless, with everything out of their control. Where a coroner's post-mortem examination is to take place, having no say as parents in whether or not their child undergoes the examination can be experienced as a huge violation. Unfortunately, when a death is to be referred to a coroner, the temptation for professionals in contact with the family at that time can be to present this as a *fait accompli*, believing that the less the parents have to think about this, the better it will be for them. Arguably, however, in cases of sudden death there is even more reason to ensure that clear explanations and information are given to parents at each stage of the process.

However well intentioned, keeping people in the dark usually only serves to increase their anxiety. Explaining gently to parents that the examination is being done to help understand why their child died, giving them the name of the pathologist who will be carrying out the examination and details of where and when it will be carried out, reassuring them that nothing will be retained

<sup>1</sup>From: *Paediatric Post Mortem: Communicating with Grieving Families* (Video/CD-Rom 2004) The Child Bereavement Trust

without them knowing why and for how long, and informing them what the arrangements will be if they wish to see their child afterwards can help alleviate concerns.

Another important area is making sure that parents are fully informed of the process where there is to be an inquest. If members of the press are present, families need help in understanding that aspects of the inquest may be made public. Media interest can be difficult for families to manage. While Lucy found it deeply shocking to see her daughter's picture on the front page of newspapers which were blowing around a wet and windy petrol station forecourt, Louise and Paul were helped by a sensitive coroner who allowed them to leave the inquest by the back door to avoid the waiting press.

Parents have greatly appreciated those professionals who have afforded them the opportunity to ask questions, and who have sensitively answered those questions honestly and openly. Telling parents that certain things are 'not possible' or 'not advisable' without any explanation as to why leaves them wondering and fuels their imagination, often leading them to conclusions that may be a far cry from the reality of the situation.

'When I asked if I could pick her up, the funeral director said he wouldn't advise it.'

Natasha<sup>2</sup>

This left Natasha with concerns as to what had happened during the post-mortem examination, whereas a sensitive explanation of what could be expected would have been much more helpful.

Professionals need to take their lead from the family. Information should be available for those who want it. It is important not to assume that information will be too difficult for parents to manage, but equally important not to force unwanted information on them. Sensitivity is the key. Often, parents will appreciate knowing what the next stage in the process is. They have also been grateful to be given the contact number of someone they can get in touch with should they later have any questions.

Parenting instincts are not extinguished by death; they may never have spent any time apart from their child during the child's lifetime and knowing where their child is, who is with their child, being helped to understand what is and is not possible under the circumstances, and what the course of events is likely to be can be extremely helpful in lessening their understandable anxiety in being separated from their child. They need time to absorb what has happened; in their distress, information may need to be repeated several times. It can be helpful to provide some clear information in writing to back up what has been given verbally, and for professionals to take responsibility for checking whether parents have understood what they have been told.

<sup>2</sup>From: *Paediatric Post Mortem: Communicating with Grieving Families* (Video/CD-Rom 2004) The Child Bereavement Trust

Parents have appreciated being offered the choice of being involved in all aspects of their child's care, even when very difficult. Lucy and Mark watched the attempts to resuscitate their daughter Hazel, and appreciated that everything possible had been done. Supporting parents by communicating what is happening, and why, is important.

'I got there in time to see them working on Hazel, which is something I'll never forget – they were trying everything. Lucy had been there for 25 minutes. I arrived with new hope and thought everyone around me wasn't so hopeful, because I didn't realise.'

Mark<sup>3</sup>

Even the most difficult of subjects, if broached sensitively, can be raised with families. When Peter and Andrea's son, Thomas, died suddenly and unexpectedly, the sensitivity of the nursing staff in raising the subject of organ donation helped them consider this choice without any pressure or agenda on the part of the staff. In fact, three adults and two other children benefited from Thomas's organs, and Andrea and Peter had some precious extra days with Thomas while recipients were found.

A major source of concern for parents whose child has died suddenly and unexpectedly is explaining to their other children what has happened. Most parents will never have had any cause to think about how they might do this, and will appreciate guidance from informed professionals.

'What about our surviving children? How do we explain to them something we do not understand ourselves?'

Louise

Every parent's natural instinct is likely to be to protect siblings, but the issue is not whether or not to talk to them, but how this can be managed. Even very young children are aware when something significant is happening within the family, and will notice what is going on around them. Professionals can play an important role in supporting parents with this difficult task by making time to discuss with them their worries and anxieties and helping them think about how they might include siblings around their brother's or sister's death.

Acknowledging that it is natural for parents to want to protect their children, but that children tell us they want to know and be included, can be supportive of parents in parenting their other children when a tragedy has happened in the family. Very young children may have difficulty in understanding the permanence of death, but simple explanations such as 'when you're dead, your body doesn't work any more' can help children understand that death is different to being asleep (when your body works very well) and why, if they touch someone who has died, their body will feel very cold.

<sup>3</sup>From: *A Child Dies: Parents' Grief* (DVD 2006) The Child Bereavement Trust



If children are to be involved, preparing them for what they will see – avoiding euphemisms and using words appropriate to their level of understanding – is crucial.

No answer will ever be adequate to justify to parents why their child was taken from them; the 'why' will never be satisfactorily answered, regardless of whether or not a definitive cause of death is ultimately established. Parents are rendered powerless in the face of death, regardless of when or how that death occurs. Those feelings of powerlessness are not infrequently mirrored in the professionals who come into contact with the family.

Working to understand the needs of grieving families who experience their child's sudden death can aid us in offering appropriate support. We learn constantly from families; each one is unique and that family's 'culture' will determine their responses and actions. Similarly, as professionals, our own family culture will determine our responses to issues of death and dying, and will inevitably impact on our interactions with bereaved families. It is essential, therefore, if we are to be effective in caring for bereaved families, that we are self aware and recognise that we will bring our own feelings about our own life experiences to any encounter with grieving families. These can give us the sensitivity to engage with families. Conversely, if we do not recognise where our own feelings come from, the potential for them to get in the way is significant.

Self awareness requires us not only to be willing and able to look at what has happened in our own lives, but to recognise how those experiences have affected us, and what aspects of those experiences we might carry into our work. It also involves us looking at the impact of this work on ourselves. Emotional pain can be catching, and accessing support for our needs is vital. If we are willing to look at these things for ourselves, we will undoubtedly be better equipped to come alongside bereaved families and afford them the care they deserve.