

the death of a baby or child



How professionals communicate with and support parents at the time of a bereavement can profoundly affect their experience of the death of their child. The information in this article is based on what parents have said they need at this traumatic time.

"It is now recognised that providing bereavement support and involving parents in the care of their child before and after death is good practice, and offering choices is vitally important.

The way parents perceive that care varies and depends on how the professionals have provided information at this crucial time, particularly regarding post mortem examinations, organ donation and helping bereaved siblings. Many doctors and nurses feel untrained and unprepared to support these grieving families."

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working to help bereaved families



There is little anyone can say or do to help ease the pain of losing a child. It is a time no parent ever forgets, a time of unbearable anguish and sorrow. And yet, experience has shown that what happens in the hospital and the community when a child has died can have lifelong repercussions. It can affect the severity and duration of parental grieving as well as the ability of parents to resume a normal life.

The following suggestions have been compiled by parents whose child died. They contain their reflections on what was and was not helpful to them in their interactions with professionals.

what you can do for parents when their child is not expected to live

Make every effort to arrange for parents to be with their child, both before, at the moment of death, and afterwards, if they wish to be there. Please don't 'protect' parents from this opportunity. Help parents to 'parent'. They may be afraid to get involved and need your help with information to make important choices. They may not have thought about the value of including brothers and sisters, or know how to prepare siblings.

Treat parents equally in giving information and breaking news. Mothers need information and fathers need support too. Prepare parents and siblings for what they will see before they see it. Explain the machines, tubes, needles and other equipment. Try to avoid complicated terminology without 'talking down' to families. Explain what you mean if you use words that are unfamiliar in everyday conversation.

When a baby or child is not expected to live, make sure the parents understand that nothing more can be done for their child and help them to participate in the decision to withdraw treatment. Offer families the use of a bereavement room to give them privacy in the hours leading up to the change from intensive to palliative care, with the use of a bed so they can lie down with their child after death. Parents appreciate knowing what the choices are and that a child could possibly be taken home to die. Explain carefully the arrangements for pain relief, feeding, hydration and facial oxygen, if appropriate.

If parents want to be at the bedside during the removal of life saving equipment, enable them to see what you are doing with their child and let them help you, if they want to. Any involvement will reinforce the reality of what is happening and that their child is dying or has died. At the time of telling parents that their child has died, explain what steps will be taken next. Parents in shock can feel confused, and need your direction and guidance. No matter how planned or discussed beforehand, death causes shock and an element of disbelief.

helping parents after their child's death

Parents need to be given the choice to participate in the care of their child as much as they wish after the death. A clear, unhurried time needs to be available for them to be with their child before he or she is transferred to the mortuary.

Fathers and mothers may not know how to be with their dead child. Watching you, observing your tenderness and interactions

with their child can guide them. Help them to talk about how they feel, to cry, to speak to their child, to express their emotions, if they are able.

Explain to parents that a photograph is normally taken at this time and kept in the notes and can be obtained at any time in the future. This is particularly important when a baby dies. Ask parents if they'd like you to cut a lock of their child's hair – never do anything without the permission that you would afford parents of a live child. Enquire if parents would like to wash their child and if they'd like to choose clothes for their child to wear. Suggest siblings may like to be included in this choice of clothes.

honesty and preparation

Always tell the truth. Honesty is a vital ingredient and establishes trust in you, as a member of the professional team. Tell parents everything you know about their child's death. Be honest about what you don't know. Suggest you can seek the information and make arrangements for relevant colleagues to speak to parents.

sudden, unexpected death

If your only contact with parents is in an emergency, be sure to give them time to absorb what has happened and remember the other children in the family who may need support. When parents are unable to be with their child, most fathers and mothers want detailed information about what happened and the circumstances surrounding the death. Was she in pain? Who was with him? Did she open her eyes? Reassure families that everything possible was done. They won't automatically know or assume that.

Tell parents who was there, let them know your name and how to contact you later, preferably also in writing. Parents have said that being present when the life saving team were trying to save their child was a comfort as they saw that everything possible was done – despite the distress it caused them to observe the procedure.

Be available to answer questions and let parents know they can phone you if more questions surface later. Tell them you will telephone or write to them in 3-4 weeks. Be sure to keep to this arrangement. Setting a time aside to meet with parents later for a specific follow-up bereavement appointment can be useful to them. They can share again what happened at their baby's or child's death, or maybe have explained anything they did not understand. This is especially helpful if you were there. This time can be a valuable opportunity to find out what support the parents or siblings have or may need.

cultures and beliefs

Each and every one of us comes from a culture – what is minority in one setting is majority in another. Not only do we come from a national culture and a religious culture, but a family culture as well.

The bereaved family may be agnostic or atheist, Catholic or Church of England, Muslim or Jewish, Hindu or Sikh. Each person's belief is personal and we all have our own traditions that need to be respected and honoured. Your own cultural traditions may be quite different from those of the parents and it is best to assume nothing and when in doubt, ask the father and mother.

Enquire about the parents' beliefs, what they need and what may be available. Parents who never go to church may be comforted by seeing the Chaplain who can offer a blessing. Others who have a faith may choose to have nothing to do with a God who they feel has not heard their prayers. Resist any need to talk about your own beliefs.

When caring for families from different ethnic backgrounds, be aware of their particular needs. Families who do not communicate well in English may need an interpreter and written information in their own language or audio tapes. It is not appropriate to use children as interpreters.

Be aware that the standard Caucasian response to bereavement may not be appropriate – for example Muslims believe that a child's death is Allah's will and that prolonged grief is disrespectful. Also it is important to know about the restrictions of different religions regarding who can touch the dead body and how it should be handled. For Muslims, Hindus and Sikhs, it is very important that the whole body is prepared for the funeral – nothing should be retained.

Always treat parents as individuals and enable them to grieve in their own way.

expressing emotions

Give parents permission to talk about their feelings. As a professional, showing your emotions if you are truly sad is something parents appreciate. Don't hide your feelings to protect them. You are in a position of authority and your humanity gives their feelings validity. Some parents are unable to accept the sad news and may cope by denying it.

DO be patient with parents as denial is a form of emotional protection which will disappear when an individual is ready.

Everyone is on a different timetable, remember there is no right way to grieve. Very often parents' initial feelings

of shock stop the expression of feelings. Withdrawing and being angry are also natural ways of expressing grief. However parents react, it is a normal reaction to an abnormal event.

sensitivity to parents' needs

Refer to the child by name – this is just as important after death. Recognise that sometimes there is a need to repeat the same explanation or information several different times. Parents under stress may only absorb a little of what you have explained. Allow enough time for parents to ask questions. Ask them to tell you what they have understood from you. In this way, you can take responsibility for communication and be sure that what the parents heard and understood was correct. This is your responsibility as a professional, not the parents' responsibility.

show parents you care

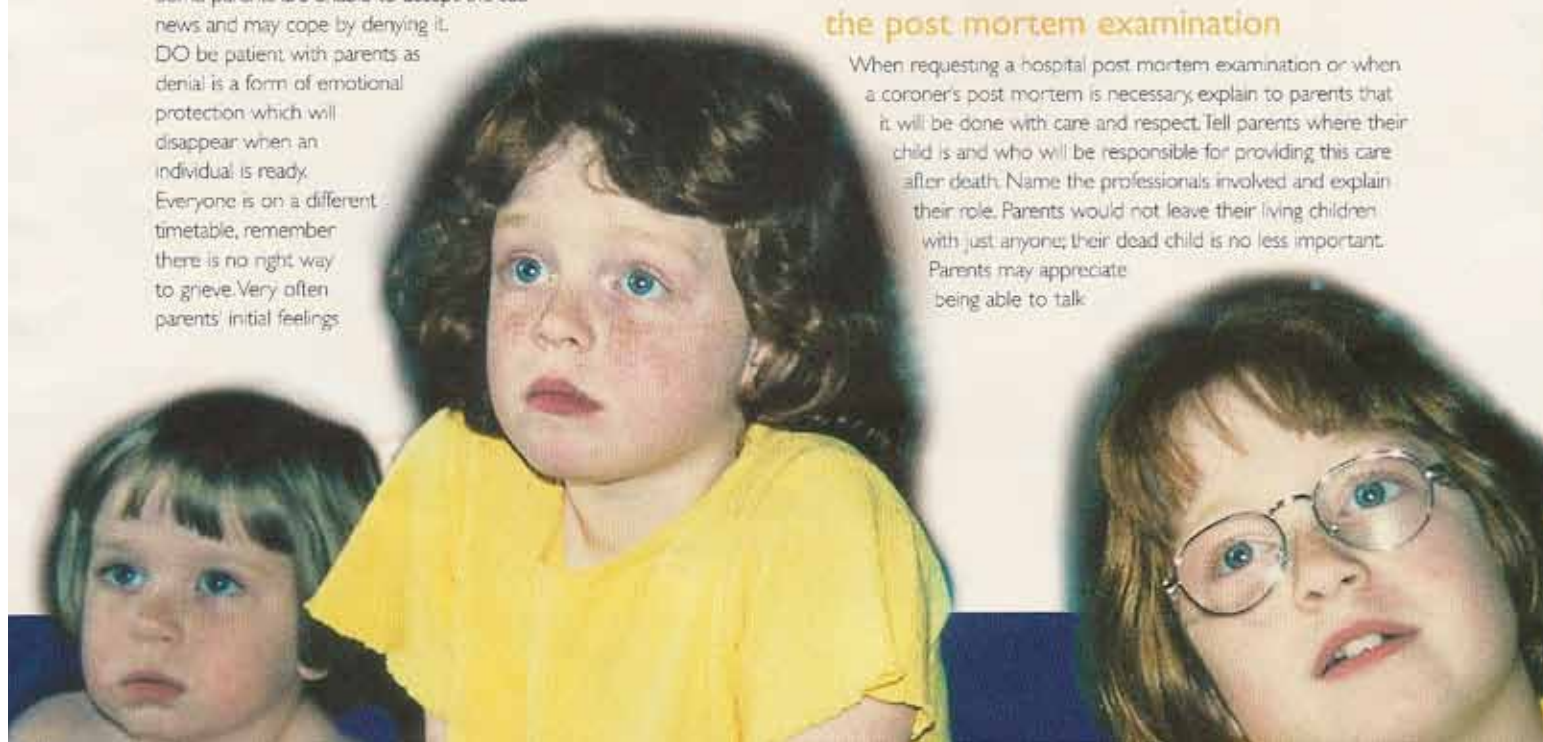
Touching is our most basic form of comfort and communication. Don't hold back if you want to put your hand on a parent's arm or your arm around a parent's shoulder, or if you want to say, "I'm sorry". Saying sorry does not mean you have done anything wrong. Be sensitive to where the need to touch may be yours and not what the parents want or need. The more self-aware we are as individuals, the more likely we are to provide parents with the care appropriate to their need, recognising culturally what might be important to families. Don't 'hit and run'; if you break bad news, do not rush away. Let parents know when and where they will see you again and be specific regarding the place and time agreed.

the process of consent

When a child dies parents will remember the professionals who have cared for their child, and how they were asked to make difficult decisions. Obtaining post mortem consent should be the responsibility of a senior member of the team. However, all members of the team should be able to assist parents in understanding the consent process, be able to answer their questions and be familiar with the Code of Practice from the Department of Health.

the post mortem examination

When requesting a hospital post mortem examination or when a coroner's post mortem is necessary, explain to parents that it will be done with care and respect. Tell parents where their child is and who will be responsible for providing this care after death. Name the professionals involved and explain their role. Parents would not leave their living children with just anyone; their dead child is no less important. Parents may appreciate being able to talk



about the post mortem with the pathologist or a professional who has attended such an examination. Parents need to know it will not affect their child's face, hands or feet and that they can see their child afterwards.

Parents will need to know that their baby's or child's body is fully repaired following the post mortem and that nothing is removed from the body permanently without consent.

coroner's post mortem examination

In a sudden unexpected death or where the cause of death is uncertain, a coroner's post mortem is legally required and it is important to discuss this with parents and how the findings may provide understanding about their child's death. Having information explained and written in easy to grasp language is important and can often be more easily absorbed.

When the coroner needs to retain organs or tissue, parents must be informed and told why this is necessary. For families the length of time an organ will be retained is important. When it is likely to be a short time, discuss with the parents the arrangements for returning the organ to the body prior to the burial or cremation. Parents have a right to know when organs are retained and when respectful disposal could occur at some point in the future. Tissue samples taken at post mortem are kept as blocks and slides as part of the medical records.

gift of donation

Families will need to have information with regard to possibly donating their child's organs and tissues after post mortem. Parents who carry a donor card may not automatically think of organ donation when their child dies. Choice is vital and sometimes parents who are not asked wonder why and feel resentful later. When parents request information about donation, explain that the professional retrieval team will discuss all the implications and procedures clearly with them. They will need reassurance that their baby's or child's body will be treated with dignity. Additionally information about heart valve and cornea donation which is possible for up to 48 hours after death needs to be made available to parents. Parents also need to understand that in the case of heart valve donation (often referred to as tissue donation) a large part of their child's heart may be retained, not just a small piece of tissue. Consideration as to how this organ is later respectfully disposed of is vitally important and something all parents have the right to make a decision about.

aiding medical research

Tissue and organs may be given as a gift with fully informed consent for medical research or for education and training.

communicating with children

The decision is not whether to talk to children or not, but who will do the talking, when and how, as it is impossible for parents not to communicate with their children. Children read body language, overhear conversations and notice changes in routine. Momentous situations in a family cause changes and children quickly sense when something serious is happening. They require clear, simple, truthful, often brief explanations about what has happened, and what may happen next.

Children do not need protecting from their feelings, but support in them. Young siblings are not likely to grieve in the same way as older children – children often express themselves through play, drawing or with friends.

Professionals may guide parents in how to create an appropriate environment for children to express themselves. In hospital, a suitable child friendly place needs to be available, with appropriate toys and furniture.

children's reactions and understanding

Children generally have a shorter concentration span and do not tolerate intense emotions for long. They may switch abruptly from crying to playing, which can be upsetting for adults as they appear casual and not to care. This does not mean that children are unaffected. Their vulnerability may make them suppress feelings which are then manifested through behaviour such as sleep disturbance, clinging, insecurity or bed wetting.

Few children under the age of five will understand the permanence of death. They think in literal concrete terms and therefore metaphors or euphemisms such as 'lost' or 'gone away' are confusing. By five or six years of age most children begin to understand that death is permanent and it can happen to them.

preparation before the death of a sibling

Even before death, it is helpful if parents prepare children when a baby or child is not expected to live, giving honest information appropriate to their children's age. They need to understand that the babies and children on the hospital unit are all needing nursing care and that most get better, but sadly some children die. It is important not to overwhelm children with information but to be guided by them and to answer their questions honestly.

preparation after the death of a sibling

Most children who have been included and see their dead brother or sister are not afraid and have a better understanding of what has happened. What they don't know or aren't told about children often make up and their fantasies can be worse than the reality. Children need to be reassured that their sibling's death is nothing to do with their thoughts or actions and that their parents love them and life will not always be so sad.

The environment in which families and children see their dead child, brother or sister is important as it will become part of their memories at that time. The viewing room needs to be conducive to grieving parents and siblings. It should be sensitively furnished with comfortable seating, a bed low enough to view easily for children and in case families want to lie down with their baby or child and have washing facilities close at hand. This room may be a Chapel of Rest or a bereavement room near the ward, however, careful planning is needed to ensure that there are appropriate resources, meeting the needs of families at this sad time. For children a toy box is important, as is to include air-conditioning (as in many hospices) which allows the family more time with their dead child, especially in the warm weather. Privacy can be ensured after discussion with the family and a sign placed on the entrance.

Parents may be concerned that seeing a dead sibling will be too upsetting – this is unlikely to be the case, especially if the children have been prepared for what to expect. Factual explanations of death are helpful.

When people die it means their body doesn't work any more and although they will look as if they are asleep, they are not sleeping, they are dead, because when you are just asleep your body works very well.' It is useful to explain that the baby or child may feel cold to touch and their skin colour can be different.

When deciding how to involve children, explain about the funeral. Parents need to be aware that children like adults are often helped by ritual and that they may like to be directly involved by choosing a song for the service that they sing at nursery or school, or by putting a toy or a drawing in the coffin.

how professionals can help children

It is important to make a direct offer of help and ensure there is time to discuss parents' worries and anxieties. Remember that parents are individuals and not all of them will feel able to involve their children directly or tell them about the death immediately. Never lose sight of the fact that different cultures will have different ways of dealing with death, so be sensitive and offer parents choices. Explain to parents that they may meet resistance from grand-parents and others, who did not receive the same care years ago. Advise them that we now recognise children need:

information

offer help with words, which should be clear, simple, truthful and repeated. Avoid confusing explanations of death, linking explanations to things children have noticed already

reassurance

concerning practical anxieties, illness of themselves or others they love also dying

extra stability, routine and physical affection

parents to share their feelings

children learn to grieve by observing others.

They need explanations about different adult reactions.

It is not always possible for staff to give parents as much time as they need both at the time of their child's death and if they return. The bereavement counsellor can have a valuable role in training staff in this difficult work and also provide ongoing support for parents in the many months ahead.

bereavement advisor

Remember your boundaries as a professional caregiver. What you can offer is professional bereavement advice and support. Always keep in mind that parents have experienced the most painful ending when their child dies. All hospital meetings they experience with professionals need to be managed with sensitivity and clear expectations. The environment is crucially important and privacy and comfort are as important after death. Offering parents a specific time for a follow-up bereavement appointment with the midwife or nurse who knew their baby or child, can be useful to them. Some units offer the loan of a resource about grief such as a book or a video.

liaison between hospital and community

When bereaved parents leave the hospital, walk with them to their car. Tell them you will be letting the community professional know about their child's death and that they will be contacted by their doctor or health visitor. Speak directly to a member of the primary healthcare team as soon as possible and inform them of the circumstances surrounding the death – this all helps with the continuity of care.

Information about the bereavement counselling available is valued by parents who may request this in the months or years after their child's death.

key factors when interacting with bereaved parents

RESPECT

- ➔ The bond between the parents and their child will not be diminished because the child has died. Their child should be shown the same degree of respect when dead as when living.
- ➔ Parents' beliefs and wishes should always be respected.

TIME

- ➔ Spending time with parents will assist in developing a relationship and establishing trust. This will be the foundation for all future discussions.
- ➔ Ensuring parents have information to make informed choices takes time. Lack of information may result in subsequent regrets. When a child has died there is a window of opportunity in which to do things. When this time has passed it is impossible to change what is done.
- ➔ If time is short let parents know what the limitations are.

COMMUNICATION as a vehicle to UNDERSTANDING requires

Listening

- families in distress may find it difficult to listen
- do not assume that because information has been given that it has been understood as intended
- establish the family's understanding by listening to them and reflecting back what you have heard

Information

- should be honest and clear
- use simple explanations where possible
- consider the environment in which information is being given and who should provide it
- if there are options discuss them
- do not make assumptions about what parents might know or want to do
- be prepared for families to require very detailed information about what will happen to their child after death and to return to issues covered previously
- provide written information for families

Questions

- some questions will be extremely difficult for parents to ask, particularly if they think it is an unusual request. However these questions may be important not only to inform and empower parents, but to allay their fears.
- lines of communication should remain open as questions do not always occur immediately.

ACCESS

- ➔ Knowing the name of someone to contact is as important after the child has died as before. It is easy for parents to feel abandoned.
- ➔ Clear access to written information is very helpful.

