

The Helping Relationship with Parents of Babies who have Limited or Uncertain Life Expectancy

Jenni Thomas



Jenni Thomas OBE founded The Child Bereavement Trust in 1994. She is President of the charity and also worked as Maternity and Paediatric Bereavement Facilitator for the Buckinghamshire Hospitals NHS Trust. In 2000, Jenni was joint winner of the inaugural Nye Bevan Lifetime Achievement

Award in recognition of her services to the NHS and in January 2002 received the OBE for her work with The Child Bereavement Trust.

Summary

There is nothing more difficult for parents to face than a loss in relation to their child, whatever that loss may encompass. Health care professionals are all taught to help their patients and to try to take pain away but it can be difficult for professionals to come close to these families and witness their pain. In this article Jenni Thomas, who founded the Child Bereavement Trust, discusses some of the key issues when professionals support bereaved parents and siblings.

*A simple child
That lightly draws its breath
And feels its life in every limb
What should it know of death?*

(William Wordsworth 'We Are Seven' 1798)

One hundred years ago it was not unusual for a family to experience the death of a child. Babies were born at home, many with conditions or abnormalities that led to their death. These babies would have been cared for by family members for whom the death of a baby was not something unusual or unexpected. Today, in the twenty-first century, the majority of babies are born in hospital. Those with complications and conditions that could lead to their death are cared for in a hospital environment. Their care is provided by nurses and doctors who are seen as the 'experts' and this can lead to parents feeling alienated and disempowered. More premature babies survive today because of advances in technology. These babies are born at an increasingly early gestation and may at birth (or later) have multiple disabilities and complex needs. For some families, this results in their baby having an uncertain or short life expectancy. The enormity of managing these situations puts the whole family under considerable emotional stress. However, in contrast to families of the past, bereaved parents today often cannot readily access available support either within the family unit or from the communities in which they live. As a result, our role today as professionals has taken on a very different dimension. In our working relationships we must provide not only clinical care but also the psychological care and support that is so vital. We are increasingly learning that it is impossible to separate medical and emotional care, as both are concerned with our basic needs as human beings.

As we in the NHS give more time and space to medical technology, it is crucial that we also invest in constantly assessing, and providing for the emotional needs of parents and children. We need to continually review

how we meet the emotional needs of families and respond in line with what they tell us they want. It is only through being open and willing to listen to, and learn from, families that we can really provide that care.

That is how my learning began. In the 1960s, at the beginning of my career, I worked as a nursery nurse in a hospital where colleagues in paediatrics had the vision to see the value of listening to families and children. I worked with enlightened professionals at Amersham Hospital and learned about the needs of families where babies and children had an uncertain or limited life expectancy. One of our consultant paediatricians, Dermot McCarthy, highlighted the importance of child and family-centred care: that is, care that puts the baby or child at the centre, care that involves the whole family. Until then, this had not been a generally recognised way of working. In most hospitals at that time parents were excluded from their baby's care on a Special Care Unit or Children's Ward. Another pioneer for change was John Bowlby,¹ the British psychoanalyst and child psychiatrist who wrote about the importance of affectional bonds. He recognised the greatly increased emotional problems parents faced when they were not allowed to participate in the care of a sick infant or allowed to be with their dying child.

Dermot McCarthy encouraged staff to listen to the parents and to provide accommodation for them wherever possible to enable them to stay close to their child. The team was led by Jean Macdonald MBE, who brought together all key professionals involved in the care of each child to discuss what was best for that particular family. She was equally committed to listening to her staff. This changed the culture on our Special Care Baby Unit from a hierarchical structure to one that gave equal value to each individual staff member regardless of discipline. I was enabled to develop a wider role providing psychological support for families which, to this day, is included in my work in co-ordinating bereavement services, in providing individual or group support to grieving families and in staff training. In the mid 1970s, the philosophy begun at Amersham continued and developed as we were moved to a new a Special Care Baby Unit specifically built with space for parents to stay and be together with their baby. This Unit at Wycombe General Hospital provided physical space to enable families to be involved and to do all they could in helping with their baby's care and, importantly, emotional space to enable grieving families to express their feelings. Having these parents on the Unit further changed the way we worked when a baby died. This has since been recognised as best practice. Previously, when a baby was dying we, as professionals, tended to put the screens around the child and 'take over' in order to protect the parents from what we assumed they would not be able to bear. We quickly learned that most parents

wanted to be involved in the care process even when their baby was dying. We realised that it was up to us as staff to learn how best to support and include these families who needed a great deal of sensitive support and communication in order to feel cared for at this difficult time.

It was paramount that we acknowledged that there was nothing more difficult for parents to face than a loss in relation to their child, whatever that loss may encompass. We, as staff, also recognised that it was difficult for us to come close to these families and witness their pain. As healthcare professionals we are taught to help patients and to try to take pain away, to 'make things better'. When we are confronted with our own inability to remedy painful situations we can feel that we have failed in our duty of care, despite the fact that the death may not be due to any lack of skill or care on our part. What we have learned from talking to families is that they need us to be honest with them at all times, to recognise how devastating the situation is and not to endeavour to 'make it better'. We also recognised that staff who worked with grieving parents needed the communication skills and sensitivity to be able to provide the emotional care these families needed. As staff, we needed to be trained to develop self-awareness, to look at our own feelings about death and to explore our own experiences of loss and bereavement. In our lives we had all had times that were emotionally demanding. We found that in order to provide the best standard of care, it was necessary for us to recognise and acknowledge these. My training as a counsellor gave me the essential understanding of the importance of boundaries and self-awareness in this work.

To help make our discussions with parents more effective, we needed to recognise that whenever we are with people we are communicating. Families are likely to notice our reactions far more than we realise. When we are working in a caring capacity we may experience strong emotions which can lead us to react with assumptions and judgements that will not always be helpful. These may well derive from an experience in our past. Our losses may not only be associated with death but could include a situation of loss such as lack of parenting, family break-up, separation and divorce. An opportunity to look at ourselves and develop self-awareness can enable us to care for families in a more helpful way.² We were fortunate to have a manager who understood this philosophy. Unfortunately, within healthcare today, many professionals have been trained to suppress human emotion and feel unable to ask for emotional support. The level of emotional care that we need when facing loss and grief is frequently undervalued. Our greatest asset as people is our humanity. We need to be in contact with this part of ourselves and to be able to tune into it in our response to parents. To support a grieving

family we need to understand that there is no right way to grieve and that parents only express how they feel when they are able to. We know that this is much more likely to happen when the family feels safe and accepted by a helper who recognises the significance of their loss and the depth of their painful feelings.

Parents and children explained to us that listening is one of the most caring things we can do. Our listening empowers them to say what is important to them and gives them a chance to express themselves. Listening is not easy and can be especially difficult if we ourselves are lacking in confidence or finding the situation challenging. The Chinese pictogram for listening is a useful example of the complex process involved when we truly listen. The way the different characters are interpreted means we listen with our ears, our eyes, our heart, our undivided attention and with respect. We listen as if we were listening to a king. This is an essential skill in communicating with families and is invaluable in conveying information that is difficult for parents to come to terms with.



Chinese pictogram for listening

We must never lose sight of the significance of the way in which families are initially told sad and difficult news. How this is done will influence their ability to manage, both at the time and in the years ahead. Parents will have to share this news with their family and friends and the way we have helped them can provide a helpful example of how they themselves speak about their child's condition. When parents learn that their child has an uncertain life expectancy, they appreciate us treating their concerns seriously and responding sensitively. They need to be with a member of staff they know and in an environment that is private where they can comfortably express their feelings.

If there are two parents, both parents should be spoken to together in a language and at a pace that they can manage to understand and with many opportunities for them to ask questions. The importance of available and honest information in language they both can understand cannot be overstated. This is paramount in enabling parents to comprehend the

seriousness of what they are being told and allows them to feel involved in the crucial decisions they will need to make with the doctors about their baby's future treatment.

Case Study: Amy

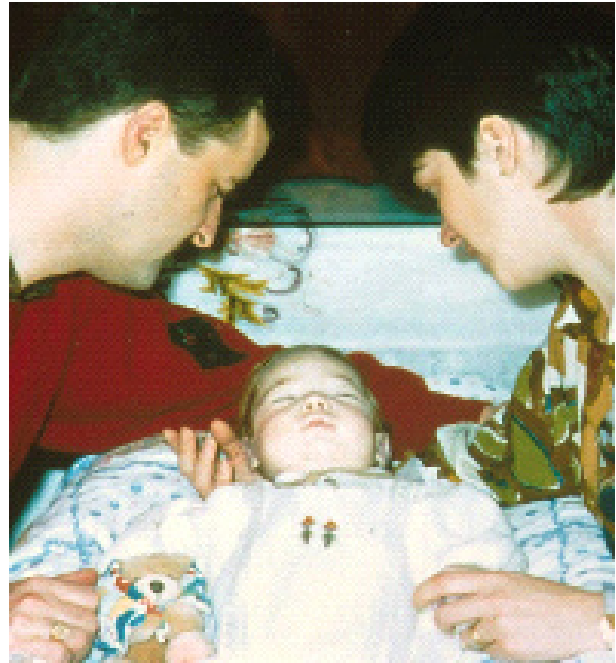
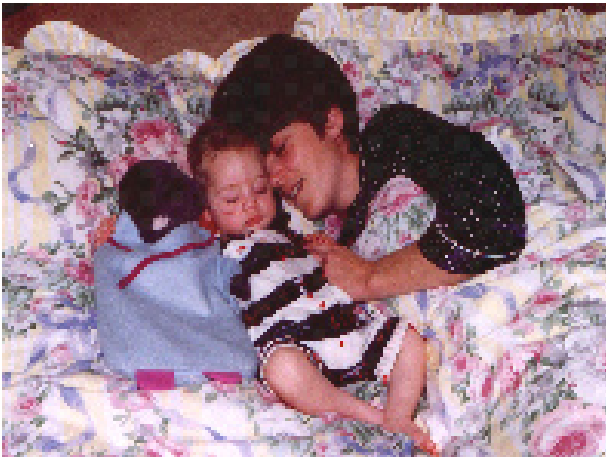
Amy was born prematurely at 28 weeks gestation and was ventilated for many weeks on the Special Care Baby Unit. Her twin brother died at birth. The first time Amy's parents were able to hold her, the doctor needed to explain to them that she had recently had a serious bleed in her brain. The way the doctor broke this devastating news to her parents, who were sitting together and holding Amy, had a significant impact on their ability to respond in a way they have never regretted.³ The fact that Amy's mother was holding her close to her breast meant that she could instinctively cuddle her closer when she heard that Amy had serious problems. Her mother later explained that, had she been apart from Amy when this news was broken, she may well have responded very differently — as she had always felt that she would be unable to cope with a brain-damaged child. The physical closeness to their baby helped her respond protectively and this has enabled her to bond, despite the many problems they have faced with their little girl.

To make informed choices, parents need to be informed. As the choices are inevitably emotional in nature, staff need a high level of emotional competence in order to be able to communicate effectively with parents. Parents' reactions naturally vary enormously and can never be predicted. We must respect their individual reactions and attempt to respond appropriately and supportively in meeting their needs. Only parents who are facing loss can know the true grief that loss creates and the length of time it takes to accept the reality of the situation. The support families need when facing the huge responsibility of taking home a child with a life-limiting condition can never be over-estimated. Close liaison between hospital and community staff, keeping the child at the centre of our practice, is crucial. Working together for the family across disciplines and agencies means sharing information and learning about each other's roles so that we can enhance the care we provide.

Case Study: Ben

When Ben was born he suffered severe birth asphyxia and spent many weeks in the neonatal unit before being taken home to be cared for by his parents, Rachel and Simon. During the year that he lived, Ben needed to come back to hospital on many occasions to see the doctor as he was on medication for the control of his fitting. Whenever his mother Rachel returned to the neonatal unit or the paediatric ward with Ben, the staff always greeted her warmly and spoke about how

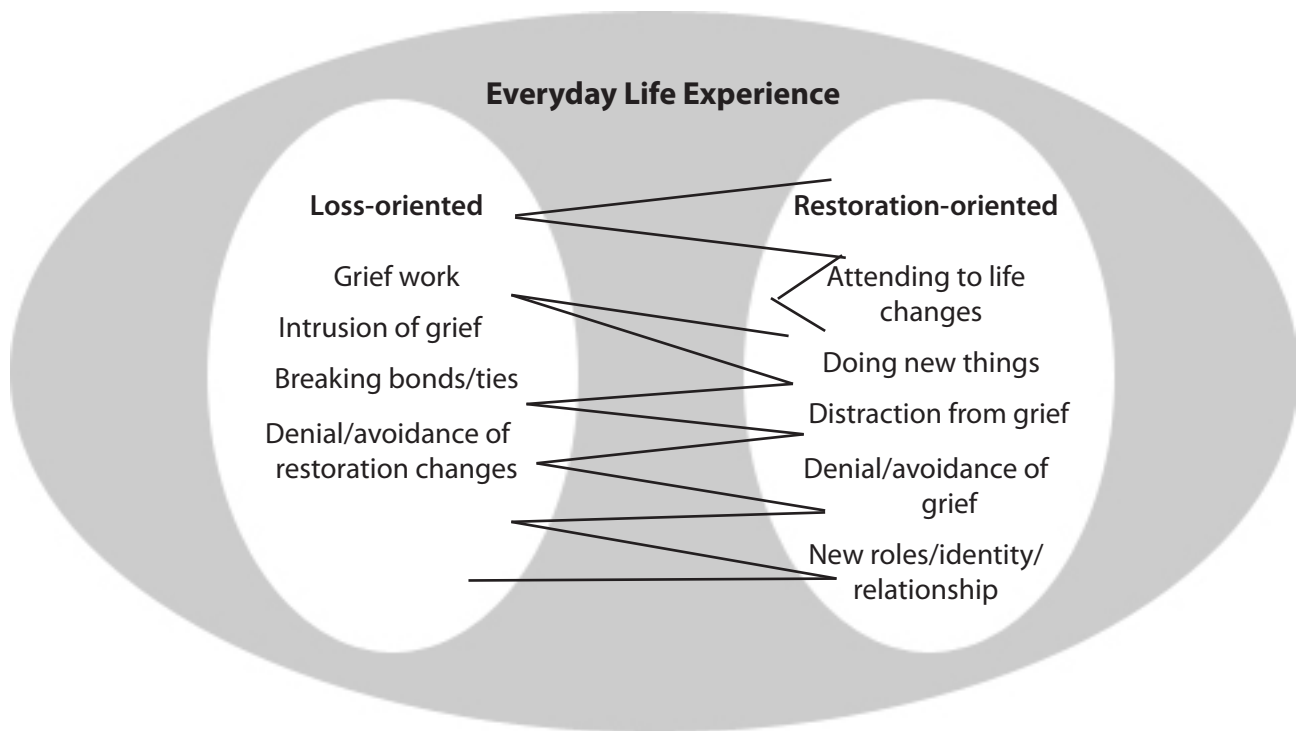
well she was managing Ben and how lovely he looked. After he died she told us that what she longed for during these visits was for someone at the hospital to ask her how she was coping emotionally in such a difficult situation. She realised the staff found it hard to broach the subject of her emotions and this left her feeling isolated during the months she cared for Ben.



Searching for my happy face

After Ben died, his parents said they felt comforted to know from staff where his little body would be taken. They have never forgotten the words of the mortuary technician who acknowledged that leaving Ben behind in the hospital would be an extremely painful thing for them to do. She said she would take care of Ben's body and asked them to think of her as Ben's baby-sitter. The support they received then and later was instrumental in helping them face a future in which they hoped to have another child. Rachel recognised that her confidence in her ability to parent effectively in the future had been helped by her involvement with Ben and by grieving for him. She needed to understand her grief and to let people know that Ben would always be an important part of their life. Initially, when the news of Ben's severe brain damage was confirmed, his father Simon grieved very deeply for the son that he had expected, whereas Rachel responded very differently, with her real grief beginning only after Ben's death.

Rachel was a nurse and despite this, she was anxious about Ben dying at home. She wanted to be able to bring Ben back into hospital where people knew him and could support her. It meant a great deal to Rachel and Simon that, at this time, they would be with staff who knew Ben. They felt secure in the knowledge that the staff would have the skills to help them do all they could as parents in the time leading up to Ben's death and afterwards.⁴



A Dual Process Model of Coping with Bereavement*

The way men and women experience loss and bereavement has been recognised in the research done by Stroebe and Schut.⁵ Their findings are both interesting and helpful in deepening our understanding of the diverse ways in which men and women behave in grief. Bereaved parents have explained that grief is solitary. Even when they are grieving the same loss they are ultimately alone and normal patterns in their relationship can be disrupted. Grieving couples often have an inability to communicate adequately with one another and to express the awfulness of their feelings. The mother's response to the loss of a child is frequently different to that of the father. Margaret Stroebe and her colleagues identified a model of coping with bereavement in which there is a need to engage in both loss-oriented and restoration-oriented behaviour. Women naturally tend to be loss-oriented and are very much concerned with their feelings. They focus on their loss and the emotions they are experiencing. They need memories and to constantly recall and be reminded of the child who has died. In contrast, men are more restoration-oriented and want things to return to normal as soon as possible. Traditionally, men have not been encouraged to show their feelings and so they instinctively try to suppress them. They often try to be strong, as society demands, and function as if nothing had happened. This very differ-

ent response can be misinterpreted by their partner as not caring about their child.

These different ways of dealing with grief can put a significant strain on the parents' relationship. It is helpful for each of them to understand that their partner's response to grief is natural and to find ways of sharing their feelings and reaching out to one another. We have learned on the Special Care Baby Unit that parents often grieve differently and that it is not helpful to see the mother as the chief mourner, but rather to help and include both parents around the death of their baby. When people engage in either type of mourning to the exclusion of the other it can cause added difficulties. Women need help to develop some form of restorative response to enable them to move on from the intensity of the pain and men need to be helped to allow themselves to confront and explore their painful feelings.

What is life, what is death, and why do young children have to die?

We have learned that an important, though often neglected, aspect of care is that of involving siblings. As staff, we have a role in helping parents to explain death to their children. We may well need to help

*Diagram has been redrawn for this TAC article

parents to prepare their children to come and see their dead brother or sister. Children have told us that knowing what to expect is helpful. When they are visiting after a death and they first come into the hospital room, it is important that they are told what their brother or sister will look and feel like, for example, the tubes, the monitors, how cold he or she might be. We realised that it was equally important that we used language that the children understood, remembering to keep it appropriate for the age of the child while still being real and honest about what has happened. Using honest words and phrases such as, 'When you die, your body doesn't work any more. It's not like sleeping because when you sleep your body works really well.' keeps it simple and clear for children. Most parents will never have thought about how they might talk to their children about death and will rely on the staff to help them. It is important to let parents know, while acknowledging their natural desire to protect their children from painful experiences, that children themselves have said they wanted to be included, to be told honestly what was happening and to be involved around their brother or sister's death.⁶

Case Study: Evie Rose

Evie Rose was born following a normal, healthy pregnancy. She was a third, much-wanted baby girl and there were no signs that anything could be wrong. At her birth it was immediately clear that her condition meant that she would not live very long. The paediatrician sensitively explained this to Evie's parents, Dave and Jane, and told them that, with the help of a ventilator, she could be kept alive for only a few hours. This information gave her parents the chance to make the best use of the time they had to say hello before they had to say goodbye. Jane treasures a photograph of her with her baby daughter taken by the staff on the Special Care Baby Unit. She said later that it mattered so much that Evie knew she had a Mummy.

Dave and Jane were grateful for the help they were given to be a family, to have a family room on the Unit and to have staff who were trained in understanding loss and grief. Evie's sisters, Seline and Katie, were asked if they would like to come in and see their baby sister and were given this opportunity to see and hold Evie Rose after she died.

Whenever we work in situations that are emotionally demanding, we can feel overwhelmed by helplessness and our incapacity to 'make things better'. Those of us who work in situations of loss and grief need to be able to recognise when we need help, and then ask for support from our colleagues or request professional supervision that enables us to continue to provide the care families deserve.



References

- ¹ Bowlby, J. (1981) *Attachment and Loss Volume 3: Loss, Sadness and Depression*. Penguin.
- ² Burnard, P. (1997) *Know Yourself! Self Awareness Activities for Nurses and other Health Professionals*. Whurr
- ³ McHaffie, H. E. (2001) *Crucial decisions at the Beginning of Life*. Radcliffe Medical Press
- ⁴ Department of Health (2003) *Getting the right start: National Service Framework for Children, Young People and Maternity Services – Emerging Findings*
- ⁵ Stroebe & Schut. (1999) A Dual Process Model of Coping with Bereavement. *Death Studies*, 23, 3, i97–224
- ⁶ The Child Bereavement Trust Information Sheet. Understanding Bereaved Children and Young People

Contact

The Child Bereavement Trust is now the Child Bereavement Charity:

<http://www.childbereavement.org.uk/>

Jenni's website: www.jennithomas.com