



NEW WRITING

The Child Bereavement Charity: Supporting families and educating professionals when a child dies or a child is bereaved

Ann Rowland

Ann Rowland joined Child Bereavement Charity on 1st May 2009 as Director of Bereavement Services. She is a Chartered Clinical Psychologist and has extensive experience of working with children, young people and families in a wide range of community and health service settings. For the previous 15 years, Ann was Head of an NHS Child and Adolescent Psychology Service. She has experience in working with families facing a wide range of difficulties, including loss and bereavement, and is particularly interested in supporting children with learning difficulties and Autism. She has provided training on loss and bereavement to the statutory and voluntary sectors both in the UK and overseas. In addition, Ann's previous roles have included service development, supervision, consultation, audit and research. She has a number of publications in a range of professional journals and books.

Summary

This article outlines the work of the Child Bereavement Charity in educating professionals and supporting families. The focus in this article is on situations where a child with special needs or disabilities dies or is bereaved.

Background

The Child Bereavement Charity (CBC) supports families and educates professionals when a child, of any age dies, and when a child grieves. The Charity's vision is for all bereaved children and grieving families to have access to relevant support and information from appropriately trained professionals. Everything the Charity does is based on what we have learned from bereaved families and children, and the professionals who work with them.

When a child dies

For parents and families, the death of a child has been described as the ultimate tragedy with on-going grief for unfulfilled future hopes and dreams (Thomas & Chalmers, 2009). 'I am learning that for me grief will be something I live with for the rest of my life.' (Parent quoted in Chalmers, 2008.) Each year, almost 3,000 children and young people between the ages of 1 and 19 die as a result of illness or accident. Every year one baby in a hundred dies before, at, or soon after birth and a further 1,200 babies die before reaching their first birthday.

For professionals, working with families where a child is dying or has died is challenging and emotionally demanding. CBC trains and supports professionals whose work brings them into contact with grieving families, in order to enhance the quality of care and support they are providing. Professionals can access CBC's wide range of workshops at the national base and training can also be provided to organisations in their own locations across the country. Courses of particular relevance include:

- When a child dies: supporting parents and family members
- Communicating with families when children have a life-limiting condition and complex needs

CBC's interactive website provides a wide range of information to support professionals in their work with bereaved families. It offers free downloadable articles, resources and professionals and teachers' forums to provide a space for professionals working in the field to raise questions or seek peer support. CBC's national telephone and email support line offers information to professionals and schools and can signpost to resources, other appropriate national organisations or local bereavement support available in different areas of the UK. In working with families facing or experiencing loss, it is important that professionals take into account their own reactions and needs. Professionals need to be self-aware and open to reflect on the impact of the work on them at a personal level, and to have in place mechanisms for their own personal support. CBC's support line can offer an opportunity for professionals to reflect on their experience.

The following, hypothetical scenario of a health visitor calling the support line is typical of the calls we receive. She has heard that a boy she has been supporting, who was aged 4 with special needs, has died. The family also has a 6-year-old daughter. The health visitor wants to know what information could be helpful to the parents, how she can help the parents support the sibling and how she should answer the parents' questions about whether the sibling should see her brother before the burial. A member of the support and information team guides the caller through the CBC website, highlighting the information and resources that may be helpful to the family and signposts to bereavement support agencies in the family's locality. The team member also thinks through with the health visitor the discussions that she may have with the family about their daughter seeing her brother, and the ways young children can be prepared, if the family decide to take her to see her brother. The support and information team also discuss with the caller her own sense of loss, having supported the family since their son's birth. They suggest a number of CBC resources that may be helpful for the sibling:

1. ***My Brother and Me***. The simple story deals with the issues surrounding a child's serious illness and stays in hospital, and how his brother copes with different emotions and feelings.

2. ***I Miss my Sister.*** The words and illustrations in this book help to guide a child through the different emotions they may encounter following the death of a sibling.
3. ***Remembering.*** Part book, part scrapbook, this was created to help keep a child's memories alive after the loss of someone special and to give children a place to return to whenever they wish.
4. ***Someone I Know has Died.*** An activity book with interactive features, written for bereaved children to help them understand what it means when someone dies, and to explore their thoughts and feelings with an adult. This book is designed for children in early years' settings although it has also been found useful by older children.

CBC also offers direct support to families where a child is facing a terminal or life-limiting illness, and/or following the child's death. The national telephone support line provides confidential listening to parents and other family members, and can, as with professionals, signpost to information, helpful resources, other national organisations and local support agencies near where the family lives. A frequently used resource is CBC's online Families' Forum, where families gain peer support from other parents who have experienced the death of a child. This is most frequently used very late in the evening or in the early hours of the morning – when parents are unable to sleep. Parents know that going online they will be able to read, post and share experiences with others.

The following example typifies calls to the line. A mother, whose only child died three months ago, calls the line. Her son was aged 14 and had a life-limiting condition. She is finding it very difficult to cope. Her husband returned to work just a few days after their son's death. She feels her whole role and sense of purpose has disappeared and she finds it hard to face each day. A member of the support and information team listens to the mother, guides her to sources of peer support that may help her feel less alone, discusses with her how men and women may grieve differently and signposts her to bereavement support organisations in her locality. They also suggest she may find it helpful to look at one of CBC resources for families:

Farewell My Child. This is a range of families' stories, from those whose baby died at birth to those who have experienced the death of adult children, and from those where the death was sudden to those where the death was anticipated.

When a child grieves

It has been suggested that we have inherited a legacy of thinking that people with learning disabilities are incapable of feeling loss (Read, 1996), yet we know that children with learning disabilities have the same need for understanding, love and support at a time of crisis as any other child (Sanderson, 1998) and that, in fact, children with physical or learning disabilities are more vulnerable to family and emotional stresses of everyday life (DOH, 2001).

Around 53 children and young people are bereaved of a mother or father every day. Studies suggest that by the age of 16, 78 % of children have experienced the death of a close relative or friend. At CBC we have become increasingly aware, from the calls to the support and information line, of the need to support professionals who are working with children with learning disabilities following a bereavement. We have therefore developed a new course

which is held at our Buckinghamshire base but can also be provided to organisations at their own locations across the country – ‘Children and young people with special educational needs including Autistic Spectrum Disorders: supporting them through grief.’

There are many situations in which a whole school is affected by a death. The way in which children are communicated with and involved at the time of a significant death will affect how they are able to grieve at the time and how they manage loss in the future. This will, in turn, impact on their ability to learn and to achieve. The way a school responds is very important to children and young people. CBC’s ‘schools section’ of the website and *Schools Information Pack* can support schools dealing with these situations. They have articles and resources specifically targeted to the needs of children with special needs.

Professionals and parents can access our national support and information line to seek information in relation to supporting children with special needs. A typical call to the line may be from a head teacher of a school for young people with special needs, who calls on a Monday morning, having just heard of the death of a pupil over the weekend. She is seeking advice on how to support the staff and pupils, how to inform parents and how to mark the child’s life – taking into account the family’s cultural and religious background. A member of the support and information team listens to the head teacher’s distress, thinks with her about ways to support the staff team, guides her to information about breaking bad news and shares information about cultural beliefs around death.

Conclusion

The Child Bereavement Charity believes that bereaved parents can be helped with sensitive and informed care when a child dies and that children have the right to information and support when someone important in their life dies. This article has outlined the work of the Charity in educating professionals and supporting families, particularly in situations where a child with special needs or disabilities dies or is bereaved.

References:

- Chalmers, A. (Ed) (2008) *Farewell my child: stories told and memories cherished, shared experiences of child bereavement*. Child Bereavement Charity.
- Department of Health (2001) *Valuing people: a new strategy for learning disability for the 21st century*. London: Department of Health.
- Read, S. (1996) Helping People with Learning Disabilities to Grieve. *British Journal of Learning Disability Nursing*, **5(2)**, p. 91-95
- Sanderson, J. (1998) Helping families and professionals to work with children who have learning difficulties. In Smith, S. & Pennells, M., *Interventions with bereaved children*. London: Jessica Kingsley
- Thomas, J. & Chalmers, A. (2009) Bereavement Care. In Price, J. & McNeilly, P. (Eds) *Palliative Care for Children and Families: An Interdisciplinary Approach*. Basingstoke: Palgrave MacMillan

Contact:

Child Bereavement Charity
The Saunderton Estate
Wycombe Road
Saunderton
Bucks
HP14 4BDF
Tel: 01494 568900
E-mail: support@childbereavement.org.uk
Visit: www.childbereavement.org.uk