

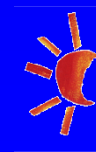
From end-of-life care to bereavement support: providing joined-up services

Ann Rowland
Director of Bereavement Services



‘The family, including children, close friends and informal carers of people approaching the end of life, have a vital role in the provision of care. **They need to be closely involved in decision making, with the recognition that they also have their own needs.** For many this will have been the first time they have cared for someone who is dying. **They need information about the likely progress of the person’s condition** and information about services which are available. They may well also need practical and emotional support both during the person’s life and after bereavement.’

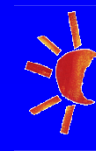
End of Life Care Strategy 2008



Child Bereavement Charity

One of the fundamental problems is that services are not always joined up and, as a result, communication between staff and agencies can break down

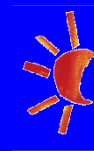
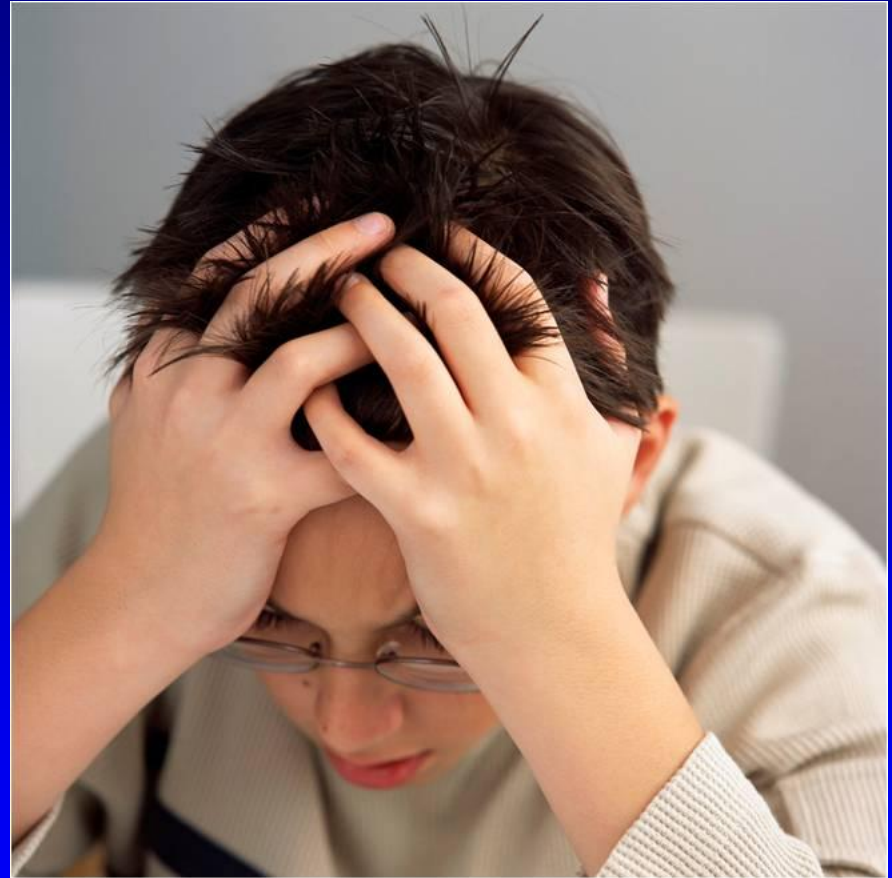
Alan Johnston : End of Life Care Strategy 2008



Child Bereavement Charity

Around 1 in 29 children and young people have experienced the death of a parent or sibling

Fauth, Thompson, & Penny (2009)



Child Bereavement Charity

Children can only cope
with what they know

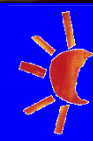
Wolfelt, 1996



© Child Bereavement Charity



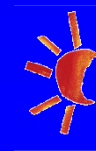
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Blocks to parents talking to their children

- Concerned they will hurt their children
- Concerned they will not manage the emotions
- Believe they should protect their child from distress
- Believe talking about dying will hasten the end
- Unable to comprehend not being there for their child



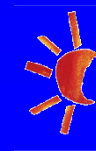
Talking to children



Honesty is the best policy

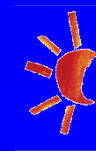
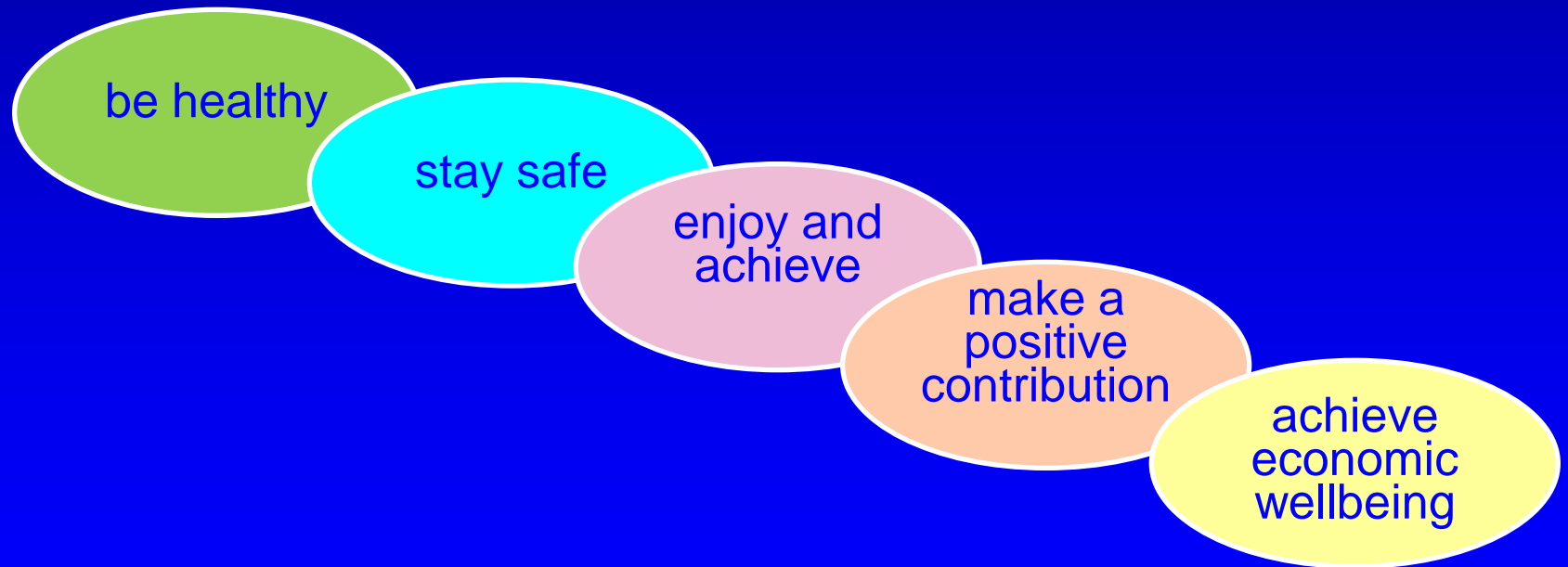
Talk to the child about what they have experienced or noticed

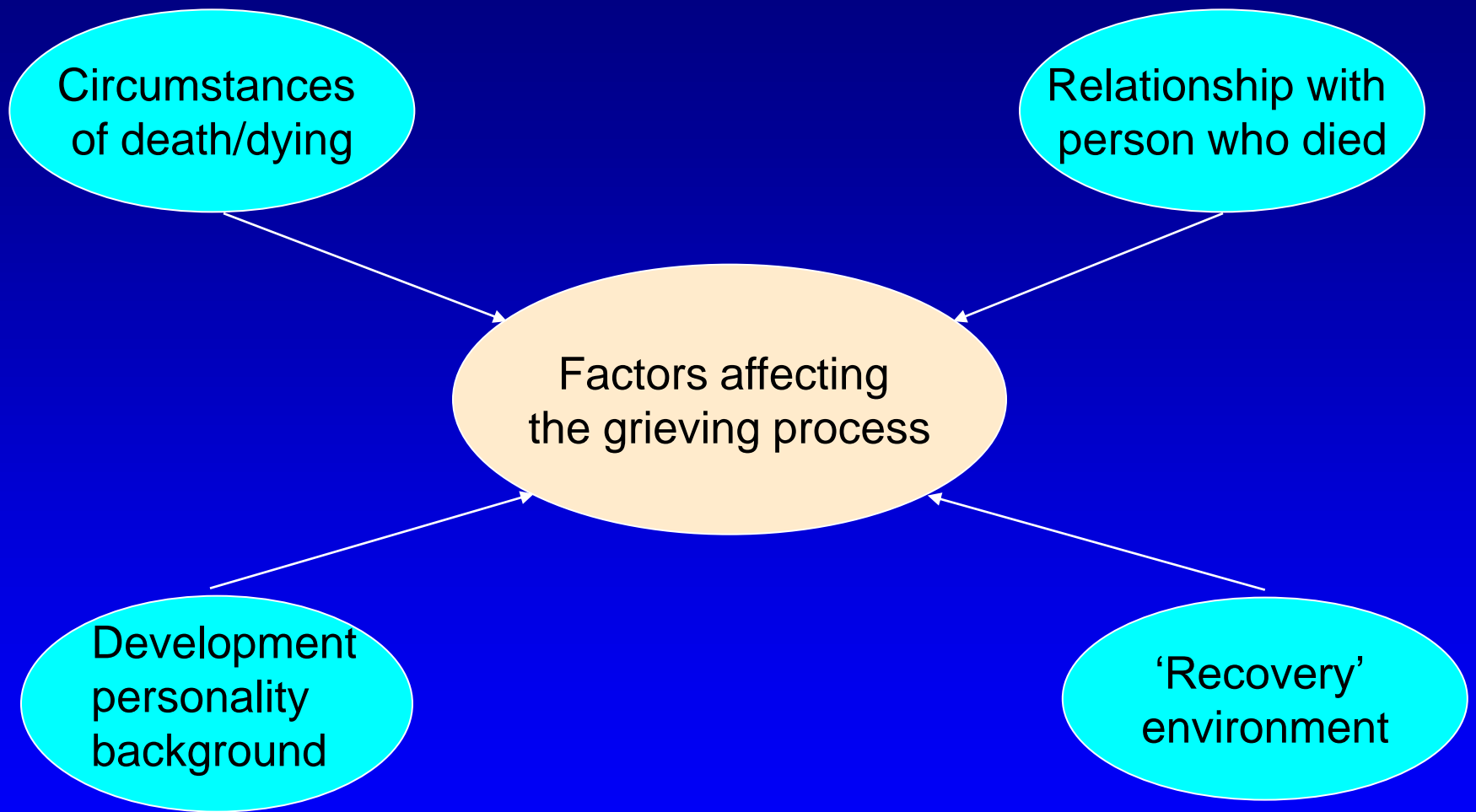
Give enough accurate information in an understandable manner, so that the child can answer 'how' and 'why' in a way that makes sense



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Bereavement increases the risk of poor outcomes for children and young people – particularly those already in disadvantaged circumstances - and these outcomes can be costly to individuals, families and society:





Resilience

Resilience in children is seen as a relying on a triad of factors:

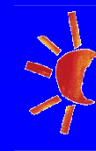
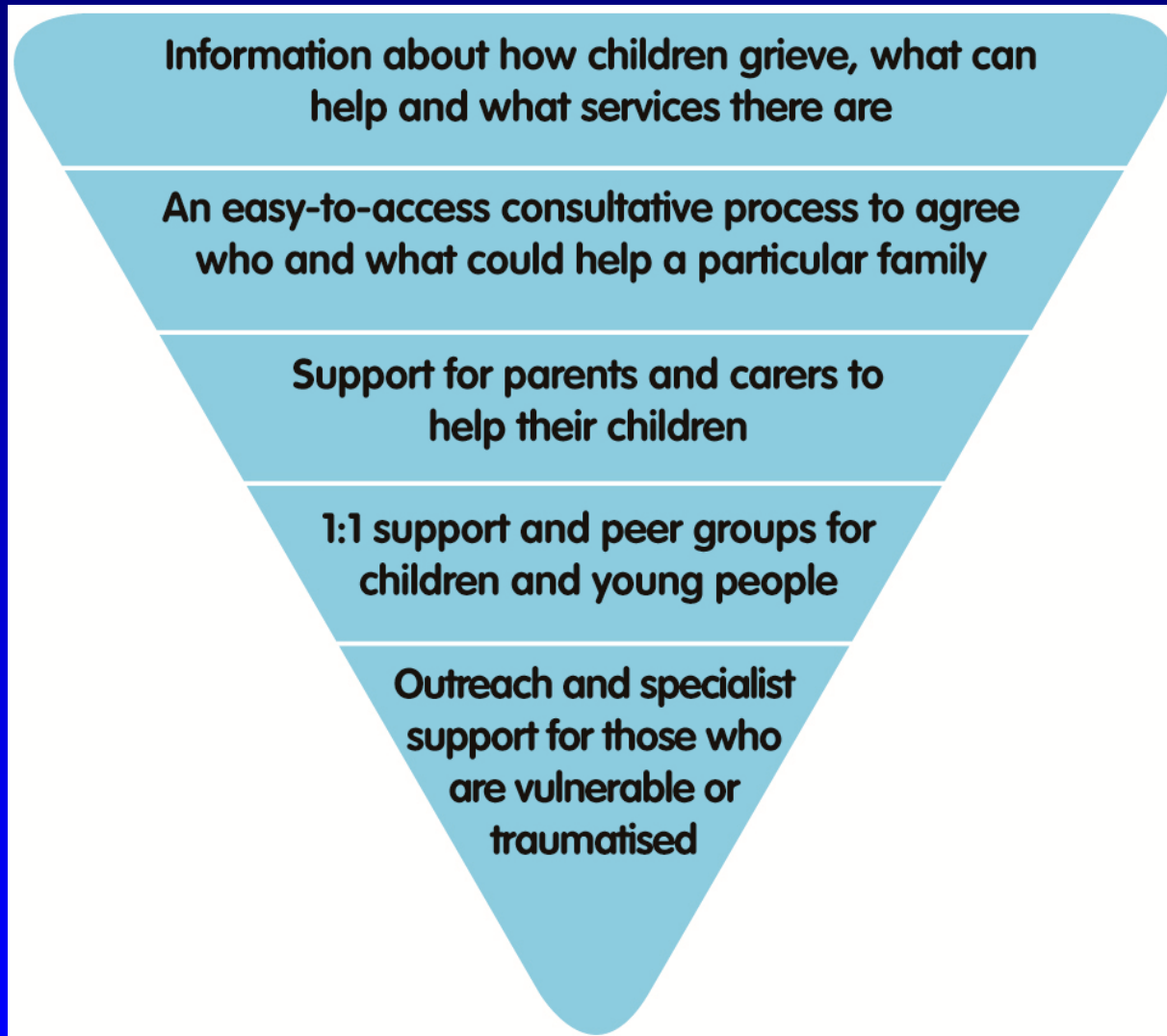
- the individual's genetic make-up
- close bonds to at least one family member
- the availability to parents and children of outside support systems

Garmezy 1985



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What good provision for bereaved children looks like:



Children and young people's views on support following the death of a sibling in hospice care



Children's Hospices across London (CHaL)

Project aim :

to identify the bereavement support needs of families receiving services from Children's Hospices across London

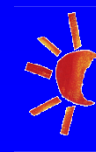
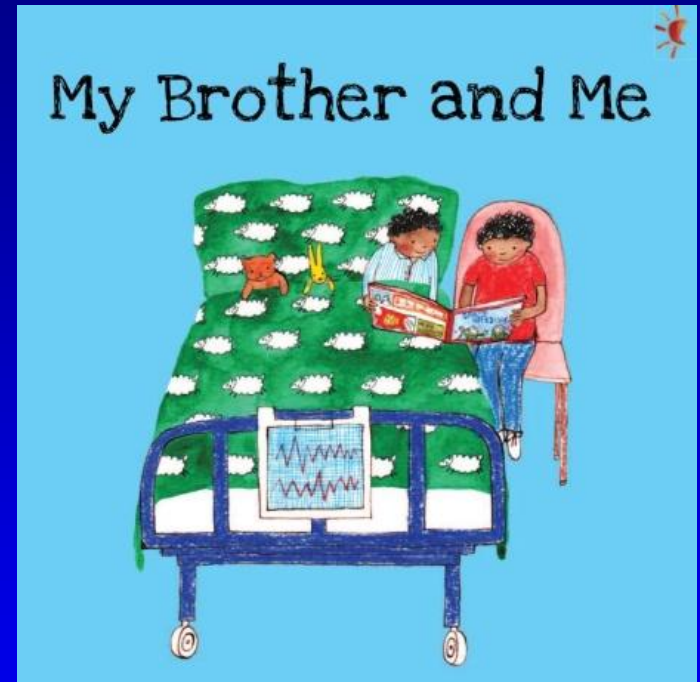


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The child who has died

Siblings appreciate support that recognises that:

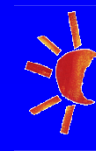
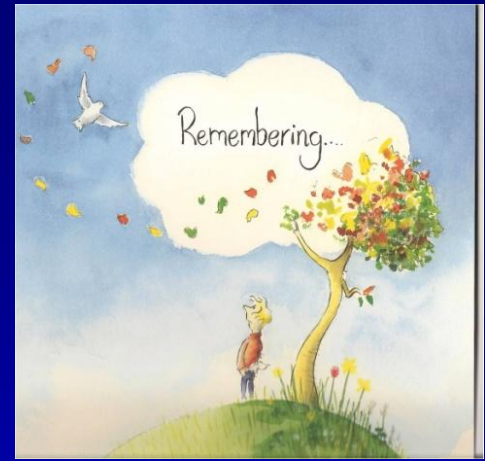
- their sibling was unique
- their sibling's life had meaning
- their sibling will be remembered
- their sibling's life had an impact on other people



Their response

Siblings appreciate:

- support that recognises them as individuals
- information and explanations of what was happening
- being involved
- open family communication
- opportunities to express feelings and thoughts of grief
- help to remember the person who has died; their life - not simply their death
- memorials and 'rituals'

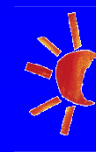


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Their parents

Siblings spoke passionately about wanting their parents to have the right support. They appreciate:

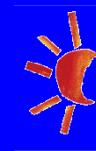
- support being offered to their parents from the hospice
- support being offered to their parents from the community
- feeling that someone else is watching out for signs when more professional help might be necessary



Continuing links with the hospice

Many siblings really appreciate a link with those who had known them and their sibling before the death:

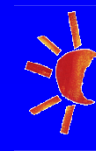
- continuing to attend the same group of siblings they had been part of before their brother or sister died
- some would prefer attending a group of bereaved siblings linked to the hospice
- emotional support from the people they already knew – key staff and volunteers
- counselling, if appropriate, from trained and experienced staff linked to the hospice



Support from other sources

Some siblings appreciated a break from the hospice where their sibling had died:

- preferring to break the link from a place of sadness
- preferring not to see others whose siblings were still alive
- appreciating creative and/or physical activities alongside grief support
- welcoming information on how to access support-at-a-distance (helplines, websites, books etc.)

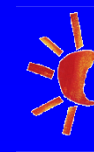


Meeting Others



Siblings were prepared to:

- meet other bereaved siblings of similar ages, whatever the cause of death
- attend groups with both bereaved and non-bereaved siblings and didn't like changing groups
- meet other bereaved children and young people of similar ages, whatever the relationship with the person who has died
- attend groups of bereaved children and young people organised by the community



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The role of schools



- primary schools were reported to be better at offering appropriate support than secondary schools
- a hospice key worker can play an extremely valuable role in helping a school provide appropriate support
- when moving to a new school siblings would like the new place to know that they had experienced the death of someone important
- if the young person is not involved in decisions, they can become disassociated from their own lives



Considerations for joined-up services

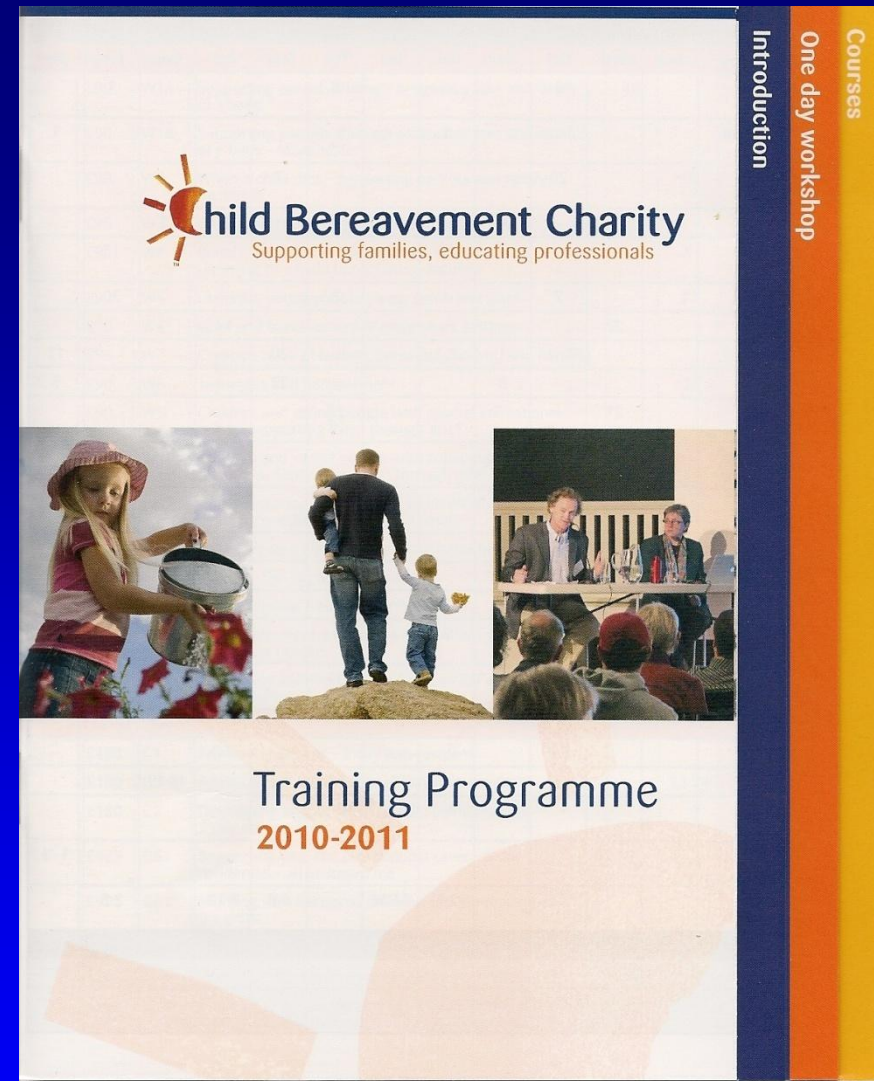
- Children need involvement and clear communication on an ongoing basis, from the point of diagnosis.
- Children need to know their parents are supported: a network of linked family services.
- Children need a choice of support either from the hospice or community service: a network of services.
- Children need to feel they are not alone: peer support.
- Children need joined-up holistic support to involve schools.



Website
www.childbereavement.org.uk
Families Discussion Forum

Support and Information Line
01494 568900

Email
enquiries@childbereavement.org.uk



Child Bereavement Charity