

When a sibling is not expected to live: supporting children

When a sibling is not expected to live, communicating with the children in the family about this distressing situation is especially difficult and, understandably, is often avoided. Facing this harsh reality is especially painful for everyone involved. The news may not have been expected, or may be the end of a long period of illness and uncertainty. Whatever the circumstances, there is likely to be a wide spectrum of emotions ranging from shock, anxiety, fear, anger and guilt, and perhaps even relief that finally some questions have been answered.

At such a difficult time, talking to the children in the family may feel overwhelming and just too difficult and painful to contemplate. As parents, our natural instinct is to protect our children, but when something significant is happening in the family children have often said they experience that protection as exclusion. Adults in the family may feel they need time to adjust to the news themselves, but keeping the information from children for a prolonged period of time can place a significant added burden on parents and other family members, and leave children feeling bewildered. Children watch adults closely and overhear adult conversations; they are usually aware that there is something seriously wrong, even when adults think they have successfully hidden the signs. They often sense when things are being kept from them and this can lead to anxiety and confusion, and sometimes even to a sense that they have done something wrong or are in some way to blame. They need overt reassurance that this is not the case.

Children's security is based on trusting the people who care for them. It is particularly important in these circumstances that children feel they can trust their parents and be included. Children need clear and honest information and explanations, using language appropriate to their age and level of understanding. They need to be reassured that they will be looked after, to have their grief acknowledged, and to have their experience and feelings validated by adults they trust.

Children's understanding of death and dying

The way in which children react and understand will be influenced by their age, their life experience, their emotional maturity and their family's culture and beliefs. Even very young children are likely to be aware of, and be affected by, the sadness and other feelings of those around them. Young children will not understand the permanence of death, and will take everything that is said in a very literal way. They will be likely to ask lots of questions and need facts repeated frequently. Older children will begin to understand that death is final, permanent and an inevitable part of life for all, including themselves.

Talking with children and young people

Telling a child that their sibling is not going to live is a daunting task. What they are told will depend on how much they already know about the journey their brother or sister has been on through their illness and any treatment. For example, letting children know what the illness is called - they will hear the words used by the adults around them - and explaining as simply as possible what this means is important in lessening their confusion.

Accurate information is best as children do tend to fantasise about things they are not told about or don't understand. They need to make sense of what is happening - when the jigsaw puzzle is incomplete, if we fail to give them the information they need to complete the picture then children will fill the gaps themselves.

Talking to them in words they can understand and being truthful is what will help them make sense of what is happening. It is helpful not to say too much and overwhelm children with information all in one go, but to be led by them and to tell them in 'bite-size chunks', a little at a time. This can give them the opportunity to say what they think and ask questions as they try to take in what they have been told. Young children often ask the same questions over and over again as they try to make sense of what is happening; this can be especially hard for the adults around them. It is also helpful when giving children information to check what they have understood.

They are likely to have noticed changes in their ill sibling, not only any obvious physical changes but also changes in their mood and energy levels - being grumpy when they're noisy, being tired and unable to play with them as much as they used to etc. . It is useful to establish exactly what children have noticed and to relate what you tell them to what they already know:

"You know that (name) has been ill for a long time, and the doctors and nurses have been trying to make her better."

It can be helpful at this point to ask a child what they have noticed about their brother or sister and what they think about their illness. Then to follow on with something like:

"Your sister's (name) illness has got a lot worse and the doctors and nurses have tried everything they can. There isn't anything more they can do now to make her better, and that means she won't live for much longer."

Children need time for information to sink in. Some children may ask directly if their sibling is going to die; however tempting it may be to offer false reassurance, it is best to support children in the reality of what is going to happen rather than try to protect them from it.

So often we, as adults, may be reluctant to raise a subject with children for fear of the questions they may ask. It can be particularly hard when children voice the very questions we as adults dread or can't bear to even contemplate, but it is vital that we do our best to respond to children in their timescales and don't put them off, as opportunities may then be lost. Answer any questions as honestly and simply as you can. Adults should never be afraid to say '*I don't know*' as an honest response to a child's question and to reassure them that they will be told as soon as you have the information.

Just as important as establishing what children already know is giving them the opportunity to express their concerns and how they feel about what is happening in their family. It is also important to reassure children that there is nothing that they did to cause their sibling's illness.

Although the death may be inevitable, there is often much uncertainty about when someone is likely to actually die. Some people die much sooner than expected and others live longer than anyone thought they would, surviving treatment after treatment. Young children often only understand things in very concrete terms, and being unable to provide them with a definite answer can be hard. Equally hard is living with the emotional rollercoaster of uncertainty. You may have had to live with uncertainty for many months - even years - and may have prepared for the worst several times. In such circumstances it can be hard to believe the death will actually happen, and so children may just not be willing to take on board what is now being said to them.

When a child asks a question such as '*What happens when people die?*' it can be useful to gently acknowledge that this is a difficult question and ask the child what they think. This gives the opportunity to gauge the child's level of understanding and correct any misconceptions they may have. A simple explanation that being dead means your heart and breathing stop and your body doesn't work any more can be understood by most children. This can also be an opportunity to share thoughts according to family culture and beliefs.

Just as adults seek to protect children, so children may tend to protect the adults around them by not showing their feelings. Adults can misinterpret this as a sign that a child is largely unaffected by what is happening, but children do switch in and out of feelings, often not staying with particularly difficult feelings for long.

Everyday life

Each child within the family is an individual and is likely to react in a different way. Their individual personality, age, level of understanding and the nature of the relationship they have with the sibling who is dying will all have a bearing. Young children's thinking is often very self-focused, and it is not unusual for practical questions like 'Can I still go to football practice?' or 'Who's going to have his bike?' to be uppermost in their minds. Familiar routines can be helpful in fostering feelings of security and comfort at a time of inevitable disruption in family life. Being honest with children about what will continue and what may not be possible for a time will help address some of their concerns. Older children and teenagers are likely to want more detailed information and to ask more searching questions. They are able to think more deeply about the impact of a death, and they too need opportunities to discuss things with someone they trust, especially when they have had some time for the news to sink in. Keeping your child's teachers aware of what is happening at home can help them support your child while they are in school.

Continuing with a normal level of discipline can help a child feel safe within known boundaries. Children's feelings are often shown through their behaviour and their play; they may exhibit naughty behaviour and be more disruptive than usual with angry outbursts, or alternatively may become quieter and more helpful than usual. These are normal reactions to an event in their life that feels anything but 'normal', but it is important to look for out-of-character behaviour that continues over a prolonged period of time, such as no longer playing with friends, not being able to sleep, and reverting to much more babyish behaviour.

Children's self esteem can be helped greatly by being involved and doing practical things for their ill sibling, such as fixing their pillows to help make them comfortable or making a card for them. It is important that we ask children what they think or what they would like to do wherever possible, and provide them with the information they might need to make that choice. Giving children a choice and being involved in their sibling's care - even small things massaging their feet or reading to them - can help children feel included and boost their self esteem. Anything that gives the children in the family some control in a world where so much feels out of control will be helpful to them.

Support for you

This is an enormously difficult time for the whole family and meeting the needs of your other children when you have such a huge load to carry yourself can seem impossible. Use whatever support is available to you, practically and emotionally, and don't expect too much of yourself. You can call the Child Bereavement UK Support and Information Line on 0800 02 888 40 for further help and guidance.

Resources

My Brother and Me

Simple story deals with the issues surrounding a sibling's serious illness, stays in hospital, and how his brother copes with different emotions and feelings. For children ages 4-10. Only available from Child Bereavement UK.

Cost £5.99 www.shop.childbereavementuk.org/my-brother-and-me-124-p.asp

As big as it gets

A short and practical booklet by Winston's Wish which aims to help families cope with the serious illness of a parent or child. It includes a range of ideas to help you explain to a sibling what is happening and suggestions of what to say. Available from Amazon.

Cost £5.99