

When a parent is not expected to live: supporting children

When a parent or prime carer is not expected to live, communicating with the children in the family about this distressing situation is especially difficult and, understandably, is often avoided. Keeping hope alive is so important when someone is seriously ill, and facing this harsh reality is especially painful for everyone involved. The news may not have been expected, or perhaps comes at 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.

For any parent, the thought that your children will grow up without you is devastating. For a child, at whatever age, the awareness that life will be unavoidably changed will bring with it many concerns for the future. The younger the children, the more dependent on their parents they will be. Parents provide stability for children and the child's sense of security will inevitably be more fragile

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; this is never more so than when facing life without a parent. 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

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.

Adolescence, as a period of turbulence and transition in its own right, is a particularly challenging time to deal with the possibility of a parent's death.

Talking with children and young people

Telling a child that their parent is not expected to live is a daunting task. What they are told will depend on how much they already know about the journey their parent has been on through their illness and 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 parent, 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 Daddy has been ill for a long time, and the doctors and nurses have been trying to make him better."

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

"Daddy's 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 him better, and that means Daddy won't live for much longer."

Children need time for information to sink in. Some children may ask directly if their parent 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 parent's illness and that they can't catch an illness like cancer from someone who has it.

Although the death may be inevitable, there is often much uncertainty about when the person 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. Remember, some families will have lived 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 parent 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 will collect me from school?' 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 parent's 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 parent, 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 parent's care - even small things like rubbing in hand cream, 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.

Planning for the future

Children often worry that they will forget their special person and memories of their parent will be greatly valued by children in the years ahead. The ill parent can perhaps be supported to write a letter or leave a memory box with special mementos, photographs and objects for each of the children in the family. This can be especially significant when children are quite young and unlikely to be able to recall lots of memories of their parent. Some parents have written little messages on cards with special memories and thoughts for each child, such as 'You always make me smile when....', 'I love you because.....', 'I was really proud of you when.....' etc. In this way the parent can leave individual memories for each child in the family to treasure and which can help the child maintain a connection with their parent and a sense of their own individual and special relationship with them.

Where a single parent learns that their illness is life threatening, there are many difficult issues to be negotiated such as who will look after the children once their parent has died. It can be especially helpful to have someone there to support the parent when the time comes to talk to the children.

The courage it takes to talk to a child about death cannot be underestimated. Try not to expect too much of yourself and just do what you can when you can. Finding ways to support yourself is really important, whether you are the parent who is dying or the well parent trying to support your partner and your children at the same time as managing all your own feelings about what is going on in your family at this time. However tempting, try not to hide all your feelings from your children; children learn how to express their feelings by watching the adults around them, and hiding your feelings may result in the children thinking it's not OK to feel the way they do about what is happening. If you can show and voice something of how you feel, it will help the children make sense of similar feelings and concerns they may have. And remember, whatever the circumstances, children are children first and foremost; they need to be given permission to have fun and to enjoy themselves at times, despite the distressing situation they find themselves in.

Resources and further support

Child Bereavement UK Support and Information Line 0800 02 888 40

You are welcome to call this number for confidential support, information and guidance. The professionally trained bereavement support workers are available to take calls 9am-5pm Monday-Friday.

Child Bereavement UK has a range of suggested reading and resources at www.childbereavementuk.org which children and families may find helpful. This includes:

Remembering

“Remembering” is a beautifully illustrated memory/keepsake book for children. It’s part book, part scrapbook and has been created to help keep a child’s memories alive and to give children a place to return to whenever they wish to talk about and remember their special person. Only available from Child Bereavement UK.

Price: £5.00 www.shop.childbereavementuk.org/remembering-123-p.asp

Someone I know has died

This is an innovative activity book with many unusual and 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. Although designed with pre-school and early years age groups in mind, some older children may also enjoy this book. Only available from Child Bereavement UK.

Price: £9.99 www.shop.childbereavementuk.org/someone-i-know-has-died-125-p.asp

Support Organisations

Sometimes families feel that they require support from an outside agency either while a parent is terminally ill or following the death of a parent: organisations which provide this type of support in the area in which you live can found via the support organisation section of our website.

www.childbereavementuk.org/Support/SupportOrganisationsDirectory