

Factsheet: Supporting children before a death



*The Irish Childhood
Bereavement Network*

Dealing with serious illness when death is expected

When a family member or friend is very unwell and it is known that they will die, it is very upsetting for everyone. This can be a very difficult time for children if they do not fully understand what is happening.

As parents and guardians of children, it is painful to see them upset. You may fear that you will make them more upset by giving them bad news, but children cope better with sad news if they are told the truth. There are some things that can help ease this difficult task just a little:

Who?

- Parents and guardians who care for their children every day are generally the best people to communicate with children. They may need support from a friend or relative to have such difficult conversations.

When?

- If possible, talking to children about illness should be an on-going process, where they are given information gradually. It can be hard for children to take in too much information all in one go, so breaking it down for them can help them to deal with it. Take small steps and add a little to the story each time you talk to the child. This will depend on whether it is a long-term or sudden illness.
- Waiting for the 'right time' for a difficult conversation may delay important information being given to a child.
- Conversations should take place as early as possible in the illness to allow the information to sink in for the child. It can help to allow the child to ask questions later on when they have had time to think. Avoid bed-time conversations.
- Plan to meet in a quiet place where you won't be interrupted.
- Avoid bed-time conversations if you can.

How to communicate:

- Plan ahead what you will say and the words you will use.
- A place to start a conversation may be to let the child know that you want to talk to them about the person who is sick.
- Children often notice a lot of changes in the appearance of the person who is unwell and the daily routine. It can be helpful to check what the child already understands about the person's condition and the conversation can build from here about what they have noticed.
- Tell the child as honestly as you can about what is happening to the person.
- Remember that the amount of information you give and the words that you use will depend on the age of the child and their ability to understand what is said. Children of different ages will need different levels of information.
- It is usually helpful to give them the name of the illness.
- Use simple words that they know and communicate clearly without being rushed.

- Books or drawings of the body may be helpful when trying to explain the person's condition.
- Children will need very clear words for what you are trying to tell them. Although it may be hard to use words like death, these words can help children to understand. They need concrete explanations because children cannot 'read between the lines' as adults can.
- If vague words are used this can confuse children.
- Avoid using the term 'going to sleep' to explain death as this confuses children and often makes them worry about bedtime and sleeping.
- Reassure the child that no one is to blame for the illness.
- When you have broken the news of illness to a child, it can help to ask them what they have understood from what you have said. This will give you an idea of whether they have taken in what you said or not.
- If children are not told the truth about what is happening, then they will make up their own version of the story from things they see and things they overhear. This usually ends up with the child misunderstanding what is going on.

Encouraging questions

- Give the child the chance to ask questions, either at that time or later on. Tell them who they can talk to if they need to ask anything. Children often need to ask the same questions several times before they can understand what they are being told. Repetition is important, especially for younger children.
- Try to answer their questions as honestly as you can and not to give false hope that the person will be ok.
- Be guided by your child and what they want to know. Not all children want to know all the details of an illness.
- Be aware if your child tends to be anxious, to give them information in manageable amounts.

Children's emotions

- Reassure the child about how they might be feeling emotionally and encourage them to be open about their feelings. Sometimes it helps if you can share a little of how you are feeling with a child as it can show them that it is ok to be upset or angry.
- It is very important to listen to children at this time and to observe their emotional reactions and any changes in their behaviour.
- Children react differently to the news that someone is very ill. Sometimes, they may not react at the time and seem to behave as if they have not been told anything or they may be upset or angry. It will be important to re-visit the conversation again.
- If the death is thought to be very close, children should be given the choice about spending some time with the person. This will help them to make sense of what is happening and to feel involved. This will of course depend on the ill person's condition and whether this would be frightening or distressing for the child.
- Letting children know when the person may die can be hard, as it is often difficult to know this yourself but if it is possible it is better to be as clear as we can be with children about time. Flag to the child when the person's illness has got worse. This prepares them for what is coming next and gives them time to do what they need with the person who is dying. For example they may want to tell the person they love them, say goodbye or write them a letter.
- Communicating with children helps them to feel included and an important part of the family.
- Advise children of any changes that might happen, either in the person or the household routine. This is really important if children's normal routine is going to change. Keeping some of their routine, such as still going to school can help some children and it is important to let their teachers know about the illness in the family. It helps to give children some choice about

going to school and that they are not forced at a time when they want to be with the sick person, particularly if time with them is precious.

- If possible, try to keep changes to children's routine for meals and bedtime to a minimum.
- Children may worry that someone else in the family will become sick, so they may need to talk about this and to be reassured that it is hoped that no one else in the family will get sick in the same way, being careful not to promise that no-one will ever get sick again.
- Children's strong emotions may be expressed indirectly, such as by being stubborn arguing a lot or keeping to themselves. This 'acting out' is quite a normal reaction to a situation that is out of their control.
- Children will need a lot of reassurance and love during distressing times of change for the family. They need to know that even though you are very sad yourself, you will still be able to care for them. Child minders, family members and willing friends can often be a great support in providing this care.

Involving children & arranging visits

- Contact between children and the person who is ill, particularly if it is their parent or carer or sibling, is generally to be encouraged when possible.
- Allowing the child time with the person can be important for both of them but ideally visits, especially for younger children should be kept quite short. The child should be told what to expect before they visit, for example what the person will look like and whether they are asleep or awake and any medical equipment they might see.
- If children want to, it can help to involve them in small ways in the care of the person who is ill, such as getting a glass of water for them. This can mean a lot to the child later on but it is important not to burden them too much. Children find tasks like this can give them a sense of control.
- Giving children time with the person can help them to feel they have said goodbye to the ill person. Even if those words are not said, the sense can be felt in a hug or holding the person's hand.

Care for yourself

- Supporting children when someone is seriously ill can be hard, as you may be tired and you are also dealing with your own emotions. Try to avail of any support or help that is available from family or friends. It may help to talk to the team that are caring for the person who is ill, such as nursing team, social workers or doctors.

For further information see: www.childhoodbereavement.ie

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