



How to explain incurable illness to children

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We welcome your comments on this leaflet and the services we provide. You'll find comment boxes at reception, on the wards, in the Iona Café and in Day Therapies.

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Explaining incurable illness to children

At St Columba's Hospice we're committed to looking after your whole family. We know that coping with an illness and the changes it brings can be a huge challenge for everyone. That's why our Family Support Team offers care, advice and support for children and young people affected by the incurable illness of any adult in their lives.

Explaining the serious illness of a family member to a child can seem daunting and overwhelming, especially when your own feelings can make it difficult to talk openly or to explain things clearly. You may want to protect children from the pain of knowing that someone they care about is very sick and cannot be cured. However even very young children can sense when something is wrong or when others are feeling anxious or sad. Children who are shielded from the truth are likely to worry more and may overhear bits of conversation, or make something up in order to try to make sense of the unusual behaviours they're observing. It is a bit like giving them a jigsaw puzzle with pieces missing – they will try to fill in the gaps themselves, perhaps imagining things which could cause them even more worry, confusion and upset. Children will not be able to start to make sense of what's going on if they don't have the information they need.

Many experts who work with children believe that they are better able to cope with situations if they know what is happening and if they can feel comfortable to ask questions. Telling them about the seriousness of the illness helps them to understand why family members may be unhappy or crying and why some things might have changed – for example, why mummy or daddy is more tired. If you try to hide your feelings, children can learn that this is what they should do too.

If like many of us, you find it difficult to talk about illness, death and dying, you may also find yourself struggling to explain what is happening to children or young people. We're here to help you with that and we can provide you with the information you need to help children and young people to:

- work through their feelings with other family members
- feel included
- feel less isolated
- trust what adults are telling them
- be more prepared for what lies ahead

We can help you to provide children and young people with information that is honest, timely and appropriate for their age and stage of development.

The information in this booklet will provide some general guidance on how to speak to children about incurable illness. If you would like further information or support for yourself or your family, please contact **0131 551 7751** or email access@stcolumbushospice.org.uk and the Access Team will be able to direct you to the most appropriate services for your needs.

We have a dedicated Children and Family Support Worker who can arrange an initial appointment with you. At this meeting, you will have an opportunity to find out a little more about what support might be suitable for your family. The session will last for around an hour and give you information and advice on the services available, it will also give you time to ask any questions you may have. If you don't feel that this is the right time for you or your family then we hope the information in this booklet will be helpful and we want you to know that you can contact us at any time.

CHECKING WHAT THEY KNOW ALREADY

Before you share the details of what's happening with your children, you may want to find out what they already know or believe about the situation.

A starting point can be to check out what they've likely been noticing:

You've probably been noticing that has been more tired lately, and hasn't been able to do as much as s/he used to. I'm wondering if you've been thinking about that, and if you'd like to talk about that...

Remind the child that it is ok to ask any questions, that there is no such thing as a "silly question" and that you will always try to answer honestly. If a child asks a question that you find difficult to answer or that you are unsure how to answer, you can ask them what they think. This can help you understand how much they already know and you can then respond to any gaps or misunderstandings.

You might wonder how much detail to provide about the seriousness of the illness. In general, if a child is asking a question it probably means that they are ready to hear the answer. Don't go into too much detail at first – provide simple, clear information that you can build on at a later time if needed. Remember, no matter how difficult a situation seems, most children are remarkably able to cope and can integrate illness and death into their lives when given accurate appropriate information and support.

Speaking to more than one child
If possible, try to talk to the children together to share the important pieces of information – that way no one was told 'first'. However, there may be times when you want to set aside some time to talk to children individually. If you have children who are particularly sensitive, you may find you have better discussions without their sibling present. You will likely have a sense of what will work best in your situation.

Explaining what is happening and preparing children for what to expect

Knowing what to expect can help to ease the fear of the unknown for children and can help them to prepare for the future. It also helps if they are given some basic information to help them understand any changes they can see in the person due to the illness or treatments.

You might want to share some basic information about:

- changes in the appearance of the person
- symptoms of the illness and any side effects of treatments or medications. If relevant, it can be helpful for the children to know where the person's body is hurting and where they may need to be careful if they touch them (e.g. for getting or giving a cuddle) and to prepare them for the fact that the person might be more breathless, tired or sleepy than usual
- medicines used – for example, explaining that the tubes they can see are giving the person medicine to help them to be more comfortable and/or to breathe.
- where the person will be (at home, in hospital, in the hospice) and why
- what will happen as the person becomes more ill

THE IMPORTANCE OF CHOICE AND INCLUSION

Children can often feel like they have no control over the situation when someone close to them has an incurable illness. Giving them clear information and involving them in some decisions can help them to make choices about how they manage the situation. For example, if the person is in hospital, at a care home or in the hospice you can ask them whether they would like to visit the person and for how long. As the time comes nearer they can be asked how they might like to say goodbye to the person. If children are included in making choices it can help them have a sense of control, to feel included and to manage their distress. This can help with their grief after the person dies.

CHANGES TO THEIR ROUTINE

When children know someone is ill or will die, they can worry about what this will mean for their own life, especially when the person who is ill is a parent. They may be worried about who will look after them when the person gets sick or when they die, where they will live, whether they will still be able to go to nursery/school... If you can, continue to maintain a regular routine, as structure is important for children. If there are going to be any changes, try to give as much preparation as possible, as this will help children to adapt. Explain who will be looking after them, where they will be cared for, and what changes might occur in their day-to-day routines.

CHECK IN OFTEN

Regularly ask children if they have any questions about what is happening or if they want to talk about how they may be feeling. This will let them know that they can talk to you.

Children may have a range of difficult feelings about what is happening, from shock, sadness and worry to anger. Every child is unique and will have their own individual responses. Be prepared to listen and to comfort them. Sometimes children will not have the language they need to describe their emotions and they may instead show their feelings through changes in their behaviour, such as changes to their sleep or eating habits, becoming aggressive or withdrawn, or changes to their participation at school or nursery. It is not unusual for children to pretend that the illness isn't real, that it will go away or that it isn't happening – this is an understandable defence mechanism which helps temporarily protect them from feeling overwhelmed. Your child may need to have information repeated a few times on a number of occasions before they can accept the reality of the illness. Even with good support and preparation things may not always go as you planned and it is important to remember that you are all trying to do the best you can in really difficult circumstances. If you are worried about a child's behaviour please speak to a member of the Family Support Team.

You may also want to discuss how you're feeling with children and that's okay – most children will understand that the situation is sad, and it can be helpful for them to know that adults are experiencing some of the same emotions as themselves.

STARTING THE CONVERSATION ABOUT DEATH AND DYING

At some point it will be important to tell the child that the person is not going to get better and that they will die. This helps the child to be prepared.

Children often become aware of death at a young age – they may see insects, animals or pets die, and they may see death portrayed in books, on television or in movies. You could draw upon these previous life experiences to start a discussion about what's happening. It can be helpful to be clear about the fact that someone they know is expected to die. It's okay to use the words "death" and "dying". Avoiding these words or using vague terms like "passing away" might cause confusion for children, who can be quite literal in their understanding. For a very young child, try to put things in very simple, straightforward language that they can understand.

When speaking with children, it is important to respond in an open and honest way to questions they may have.

If the death is still a few weeks/months away. Telling the story of the illness can be done in stages rather than all at once. Give information gradually so that children are included and prepared but not overwhelmed. Small children can find it difficult to understand long periods of time such as 3 months or 6 months – they might instead be able to think in terms of "how many sleeps". Because they can't think too far into the future it can be better to give them information gradually. To tell them too much too soon could cause them unnecessary worry over a long period of time.

You might start by saying something like:

"..... is ill because of an illness called cancer. You can't catch cancer, it just develops in people's bodies and nobody knows why. Sometimes doctors can make people better with medicine and the cancer goes away but for..... the medicine isn't working so the cancer can't be cured and won't go away. The doctors and nurses are helping to live as well as they can while they can. When anything changes I will let you know."

If someone is expected to die soon. If you have had a chance to prepare the child before then you might explain that you have more information to share. If the person is expected to die soon you could say something like:

"..... is ill because of an illness called cancer. You can't catch cancer, it just develops in people's bodies and no-body knows why. Sometimes doctors can make people better with medicine and the cancer goes away but unfortunately the medicine isn't working for..... Because the medicine isn't working, the cancer is taking away their energy to do things and is making them weaker. That means that one day soon they won't be able to get out of bed anymore. And then their body will be so weak that their heart will stop working and this means they will die."

Families sometimes do not want children to be around someone who is dying. However, this can cause children to have more questions and possibly some fears about illness and the end of life. Making death a natural part of life will help children understand what is happening and can assist them with managing their grief. If the child is coming to the hospice or hospice for the first time, you can show them a photo from the website so they know what the building/rooms looks like. This can help to prepare them. It is helpful to involve children in decisions and give them appropriate options, such as being able to visit the dying person but having the option to leave the room if they want. You may want to consider having a family member or friend available so that there is someone else who can accompany them if the child wants to leave the room and you want or need to stay.

If you would like an opportunity to talk with a member of the Family Support Team before having a conversation with your child, please call **0131 551 7751** and speak to the Access Team, who will be able to put you through to the most appropriate person.

We also have a follow up booklet called "When someone dies" which explains how to share the news that someone has died with a child and has information about children and funerals. If you feel this could be helpful, please ask a member of staff or contact the Family Support Team Worker.

Book Suggestions

The following books can help explain illness and death to small children and support them as they learn new ways to deal with their feelings and worries.

FLAMINGO DREAM

by Donna Jo Napoli

"One day Mamma came early to get me from school. She told me Daddy was in the hospital. I knew that would happen." Indeed, the young narrator and her parents have talked about the fact that Daddy has cancer and is dying. Mamma has explained that as the leaves are changing colour, Daddy is changing inside. And just as the leaves will fall, he will die. The three of them have cried together. But they have also lived and loved together, and they have many rich, funny, wonderful memories.

NO MATTER WHAT

by Debi Gliori

A little fox is in a big bad mood, and is worried that its mother won't love it forever. In this beautiful and lyrical picture book we see a clever and resourceful mother prove to her child that a parent's love is limitless - no matter what! In this reassuring and warm picture book the hugely talented Debi Gliori manages to treat the familiar subject of childhood worries in a very fresh, original and inventive way.

THE HUGE BAG OF WORRIES

by Virginia Ironside

Looks at dealing with worries and anxiety, and can be used as a spring board into important conversations with a child.

FROG'S BREATHTAKING SPEECH

by Michael Chissick

Suitable for children aged 4-11. Can help children learn about coping with difficult emotions and stressful situations. Children learn four yoga breathing techniques in a fun and interactive way. The story increases children's awareness of their breath and shows how breathing can be used to deal with anger, anxiety and tension.

THE INVISIBLE STRING

by Patrice Karst

A story that teaches children about the tie that really binds - mums/dads/family members feel the tug whenever kids give it; and kids feel the tug that comes right back. The Invisible String reaches from heart to heart. Does everybody have an Invisible String? How far does it reach anyway? Whether it's a loved one far away or a parent in the next room this delightful book illustrates a new way to cope with something all children and parents confront sooner or later; a child's fear of loneliness and separation. Here is a warm and delightful lesson teaching young and old that we aren't ever really alone.

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St. Columba's Hospice Care
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