

Explaining Life Limiting Illness to Children

The impact of a life limiting illness on a family is enormous whether it is a child or an adult who is ill. Somebody may become seriously ill as the result of an accident; they may have a long term disability or have been diagnosed with an illness such as cancer. Adults may strive to protect their children by withholding information from them in the hope that it will spare them from emotional pain and worry. Parents may be faced with very difficult decisions about how much information to give a child. The diagnosis can throw the whole family into turmoil and children may become scared and confused. The following information may help you deal with some of the questions facing you.

Should I tell my child/children that someone close to them is going to die?

- Most children usually know when something serious is happening in their family even if they are very young, they may notice changes in routine and that the adults close to them seem worried or unhappy.
- Children are often more able to deal with the truth and painful information than adults think.
- Whether the death of someone special is sudden or expected we cannot say that one is better or worse than the other, both can be devastating. However, knowing someone is going to die allows you the opportunity to prepare the children and allow them to say goodbye. Children who are not told the truth may feel resentful especially if they feel other people knew the person was going to die and they didn't.



Explaining Life Limiting Illness to Children ...continued

How do I tell my child/children that someone close to them is going to die?

- It is important to try and give yourself some time to understand what you have been told by the medical profession. You may want to seek their advice or speak to one of the Family Workers at Daisy's Dream about what to say to the children.
- If possible discuss within the family how and what you will tell the children. It is not unusual for family members to have different views about what children should be told.
- Consider what will be the best time and place to tell the children.
- Try to think beforehand about what information you want to give the children.
- Consider the ages of the children and whether you will tell siblings together or separately.
- Be as open and honest as you can. Some children may ask very direct questions, others may not want to talk about it.
- Try to use words that cannot be misunderstood. Telling a child that "Mummy is going to go to sleep" may sound like a more gentle way to explain that their parent is going to die, but may cause confusion and anxiety for the child about sleep and bedtime.
- It is usually better to give children small pieces of information at any one time as they may not be able to absorb it all in one go.
- It is understandable that you and the children may become upset when you talk but it is also not unusual for children to react in other ways such as asking "What's for tea?" or running off to play.
- Let the children know they can talk to you again if they need to or have any questions they would like to ask.



Explaining Life Limiting Illness to Children ...continued

What questions might my children ask?

The sorts of questions children may ask will vary according to their age and understanding. The following are examples of some of the things parents have told us their children have asked them-

What happens when you die?

Why can't the Doctor make them better?

Why does it have to be my Mummy/Daddy/Sibling?

Will I see them again?

Are they asleep?

Are you going to die too?

Will I get ill and die?

Can I catch cancer?

Is it my fault they got ill?

Who will look after me?

Sometimes we have to say to children that we don't know the answers to some questions but we can acknowledge the feelings that go with them for example, "I know it seems unfair that your Mummy is going to die and that you feel very sad". Some families will have cultural and religious beliefs that give them the answers to some of the questions children may ask. If you find it difficult to deal with your children's questions at a particular time, it is okay to acknowledge the question and say that you will come back to them about it at a later time.

Who else needs to know about the situation?

It is advisable to inform your child's nursery / school / college / child-minder about what is happening so that they are aware of the difficulties your child is facing and be prepared for any questions they may be asked.

What support can Daisy's Dream offer?

The Family Workers can provide:

- information & advice on ways you can prepare your child for a bereavement
- pre-bereavement support for your child, either at home or at school
- ongoing support once the person has died



Families facing Life-Limiting Illness - Useful Organisations

Macmillan Cancer Support

Provides practical, medical, emotional & financial support.

Helpline: 0808 808 2020, Monday – Friday 9am-10pm

E-mail: cancerline@macmillan.org.uk

www.macmillan.org.uk

Macmillan Youthline

A free & confidential service for young people between 12-21 to ask questions and discuss concerns about cancer.

Helpline: 0808 808 0800, Monday – Friday 9am-9pm

E-mail: youthline@macmillan.org.uk

Cancerbackup

Offers up to date information about cancer and support for cancer patients, their families & carers.

Helpline: 0808 800 1234, Monday-Friday 9am-8pm

E-mail: info@cancerbackup.org

www.cancerbackup.org.uk

There are a range of other organisations that can provide support and information on a range of life-limiting illnesses. We suggest you contact your GP Practice for further information.

Parentline Plus

Provides telephone support and resources on a range of parenting issues.

Helpline: 0808 800 2222 – Monday – Sunday, 24 hrs

www.parentlineplus.org.uk



Families facing Life-Limiting Illness - Book List



When Someone Has A Very Serious Illness by *Marge Heegaard*

ISBN: 0962050245

This workbook can help families communicate and teach children about illness and coping skills.

As Big As It Gets: by *Julie Stokes & Diana Crossley* supporting a child when someone in their family is seriously ill

ISBN 0953912329

This booklet provides a range of ideas for parents and carers to help them talk to their children about the serious illness of a parent or child and offers ways they can support children to cope with the stress and uncertainty of life-threatening illness.

Talking to Children about Cancer

Available from cancerbacup (see useful organisations)

This guide for parents and carers discusses how to talk about cancer with children aged from two to sixteen. It outlines the steps you can take to help your children understand what is happening to you at this difficult time in family life.

The Secret C by *Julie Stokes*

ISBN: 0 9539123 0 2

This book can help adults and children to talk openly about the difficult issues and feelings involved, when someone they know has cancer.

When Your Mum or Dad has Cancer by *Ann Couldrick* (available from **The Child Bereavement Charity 0845 3571000**)

This booklet helps to answer some of the questions children may have when a parent has cancer.

Flamingo Dream by *Donna Jo Napoli*

ISBN: 0-688-17863-4

This beautifully illustrated book tells the story of a young child whose father is seriously ill with cancer. Before he dies they go on a trip to Florida to see the place where he grew up. The book goes on to describe how the father becomes weaker and then goes into hospital, where he dies. It describes some of the child's emotions and emphasises the importance of having memories of his father.

Two Weeks with the Queen by *Morris Gleitzman*

ISBN: 9 780141 303000

This book tells of the adventures of a 12-year-old boy called Colin, who is determined to find a way to cure his younger brother, who is ill with cancer. The author writes about a serious subject in a way that is easy for children to read.