



Choices

When it seems there are none

Suggestions for parents when curative treatment for their child is no longer an option



ACKNOWLEDGEMENTS

This booklet was written by Dr Jan Kohler, Consultant in Paediatric Oncology, Susan Hartley, Sargent Social Worker and Vivienne Oram, Macmillan Nurse, all at the Department of Child Health, Southampton General Hospital, with contributions from many parents who have faced the death of their child. The latest edition (October 2007) includes suggestions made by the CCLG Publications Committee.

First published (1995)

Republished 2001 with minor revisions by:

Leukaemia Research, 43 Great Ormond Street, London WC1N 3JJ

Tel: 020 7405 0101 Fax: 020 7405 3139

Charity Registration No. 216032

and

Cancer Research UK, PO Box 123, Lincoln's Inn Fields, London

WC2A 3PX Tel: 020 7242 0200 Fax: 020 7269 3100

Charity Registration No. 1089464

Leukaemia Research and Cancer Research UK collaborating in the fight against cancer throughout the UK.

Production of this booklet was made possible by a donation from Leukaemia Research and Cancer Research UK.

© CCLG, Leukaemia Research and Cancer Research UK 2007

All rights reserved. No part of this publication may be reproduced or transmitted, in any form or by any means, electronic or mechanical, including photocopying, recording or any information storage and retrieval system, without permission in writing from Leukaemia Research, Cancer Research UK or Children's Cancer and Leukaemia Group.

Designed and Published by the CCLG October 2007

CANCER RESEARCH UK



Children's Cancer and Leukaemia Group

3rd Floor, Hearts of Oak House
9 Princess Road West
Leicester LE1 6TH

Tel: 0116 249 4460

Fax: 0116 254 9504

Email: info@cclg.org.uk

Website: www.cclg.org.uk

Registered Charity No: 286669

INTRODUCTION

The loss of a child is a rare event nowadays, and is one of the most devastating things that can happen to a family.

The purpose of this booklet is to provide information which may help you to have some control over the end of your child's life and the dark days which follow. Although you may not be able to change the final outcome, there are still many areas in which you do have a choice. Knowing the options may help you to choose what is right for you and your family.

This booklet includes thoughts and suggestions from many parents who have faced the same situation as you. Every family is different, however, so do talk to the staff at your own hospital who care about you, and who also know what support is available locally. Although there seem to be a lot of decisions to make, you can often change your mind as time goes by and the right choice becomes clearer.

For simplicity we have referred to the child as 'he' and health care worker as 'she' throughout the booklet.



PREPARATIONS

When you are told that your child cannot be cured, all sorts of questions may come to mind, some of which may seem too terrible to ask. In order to make appropriate plans for your family, however, you need to have some answers. Your own hospital team is in the best position to give you accurate information, but the following may be a general guide.

Where should my child die?

Most children are happiest at home, and all through treatment great efforts are made to keep them there as much as possible. It usually seems to be the natural place for them to die too. When it is practical, this enables the whole family to be together, supporting each other and sharing the ups and downs.

There may be times when the child needs to go temporarily back into hospital, perhaps to get a particular symptom under control. If you do not have the support you need at home or if you or your child would prefer to be in hospital, you can always, at any stage, be readmitted. Occasionally a children's hospice may be the right place and visits can easily be arranged so you can see the hospice well in advance. Parents and siblings often cope better with bereavement if they have been actively involved in the child's palliative care. Whether this is at home, in hospital or in a hospice, it's your choice.

How long will it be?

Most children with terminal leukaemia die within a small number of weeks – sometimes only one or two. Children with localised solid tumours, such as brain tumours, may live for a few months. It is always impossible to predict exactly what will happen but your doctor will be able to give the best estimate for your child. You need to have some idea of the time-scale so that you can make appropriate plans.

How will my child die?

It is almost always possible to ensure that your child does not suffer pain. Pain-killers can be given via a number of routes and in increasing doses and are very effective. These medicines may eventually contribute to the child's sleepiness, and most children die in their sleep.



Other symptoms depend on the site of the cancer, but most children gradually become weaker and eventually die peacefully. Your own doctor will be able to give you specific advice related to your child. Vomiting sometimes occurs with brain tumours, for example, whereas bruising and bleeding may occur with leukaemia. There are usually ways of combating these symptoms with medicines or transfusions and the aim of all treatment offered at this stage will be to ensure a pain-free and dignified death for your child. The doctors and nurses will do their best to achieve this aim.

As the disease progresses, it usually becomes clear when the end is near. Parents seem to sense that their child is about to die and can make arrangements to be with them. Sometimes this is not possible.

What shall I tell my child?

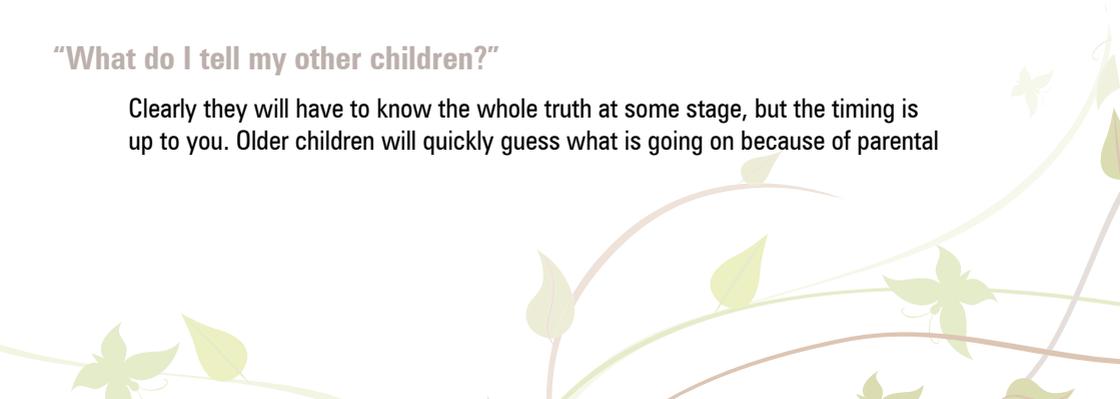
A child's understanding of death depends on spiritual beliefs, age and experience. Many children, however, seem to know deep down when they are going to die: the problem is being able to talk about it. You know your child best, and the questions he or she is likely to ask, or not ask. Try to respond to each question as it arises and at the level at which it is asked, since often only a simple answer is required. Try always to tell the truth, even if it is to say that nothing can separate him from your love.

Older children, like adults, may need the chance to put their lives in order and say goodbye. They often accept a shortened life-span with amazing courage, and make the most of every day of life. There may be certain people they want to see, or places they wish to visit, but be a little wary of well-meaning friends who want to send you abroad on holiday; if the timing is not right, the trip may be a nightmare.

Some children are well enough and want to go to school for a while, or to have friends in to play. Trips to favourite parks or picnic spots can be very special. Each day with your child is so precious and it's your choice where to go, who to see and what to discuss.

“What do I tell my other children?”

Clearly they will have to know the whole truth at some stage, but the timing is up to you. Older children will quickly guess what is going on because of parental



attitudes and changes in treatment, and they need a chance to talk and be involved. With younger children, it may be appropriate to wait until the last few days when the dying child is clearly deteriorating. Don't be upset if they don't appear to be too sad. Having a sick brother or sister has already turned their lives upside down and they have suffered all sorts of conflicting emotions.

Try to encourage each child to do small tasks for the sick child, to talk about the situation if they want to, and reassure them that they are not about to die. Remember to tell their teachers what is happening so that any unusual behaviour is understood. Children feel more secure if life is as routine as possible and going to school helps them to escape for a while from their confused feelings. They also need opportunities for fun and times for privacy if they wish. Although most of your energy is taken up by the sick child, try to spend a little time with each of your other children each day. They need your love more than ever, and you have need of theirs.

“Should I try alternative therapies?”

When a child's cancer returns despite the most powerful treatments available, most parents reluctantly accept that cure is impossible. If it helps you to consider other options, however, discuss it with your doctor. The important thing is not to mar the last weeks with your child in any way, and building up false hopes is not usually helpful.

Who will help me to care for my child?

The aim of palliative care is to give your child the best quality of life possible in the time that is left. You may take on as much or as little of this care as you feel able. The arrangement should always be a flexible one allowing you to take on more, or relinquish some of your child's care, as you wish.

If you have a specialist community nurse looking after your child, she will probably be the key person in co-ordinating everyone who may be involved during palliative care. She will arrange a meeting with your G.P., Health Visitor or District Nurse in order to make arrangements which meet your needs. If there is no specialist or Macmillan nurse, the hospital will liaise directly with the health care team at your local surgery.



Friends may be anxious to help too. If you are able to accept offers of practical assistance such as baby-sitting or shopping for example, this may help you to pace yourself and preserve your energy. You might consider electing a relative or friend as a 'family spokesperson' to deal with some of the repeated enquiries about how things are going, to save you endless emotionally draining telephone calls. Do not feel, however, that you are obliged to accept all offers of help or invitations to visit you at home. Some visitors may be more helpful than others. Don't worry about giving offence, good friends will understand. These are your decisions - your choice.

How will this affect my family?

Individual members of the family may have different ways of responding and behaving during this very difficult period. Some members may resort to frantic activities which distract them from the progress of the child's illness. Some may become reflective, isolating themselves in private thought, and this may lead to misunderstandings and hurt feelings. It is important to remember that individuals need to be accepted even when their way of coping is not understood clearly by the rest of the family. Mothers and fathers may have very different coping strategies, and time spent with each other - especially doing something pleasurable to both - is vital to safeguard this relationship. Palliative care may last some time, and not every moment needs to be spent with the sick child. Opportunities for discussion are vital, but these should not be forced or contrived as this may lead to a sense of being further out of control. Some people find comfort in sharing feelings and fears with a trusted person. Others may be afraid of being overwhelmed by their feelings if they give them expression. Both approaches need to be respected and protected by gentle responses.

Each member of your family is different and has a right to an individual choice.



WHEN DEATH COMES

Do we need to call someone?

If you think your child is about to die and you want someone to be with you, there should be a named person available (a doctor or nurse) on a 24 hour basis for you to call.

Afterwards it is not necessary to call your G.P. or the funeral directors straight away if you want some time alone together. It is best to discuss this in advance with your doctor or nurse to ensure that they are aware of your wishes.

What about organ donation or post mortems?

Organ donation is not really practical for most children dying from cancer. It is very rare for such children to require a post mortem examination since the cause of death is known.

How do we register the death?

All deaths must be registered within five days in the registration sub-district in which the death occurred. The parent registering the death does not usually need to make an appointment. If a person other than the parent is to register the death it may be better to phone first. The registrar will require the death certificate, which will either be given to you by the hospital or hospice doctor or can be obtained from your general practitioner if your child died at home. In addition he will need to know the full name of the deceased, full address, sex of the person, date and place of birth and will also need to know the full names and occupations of the child's parents. If possible, take with you the NHS Medical Card, and any benefit or allowance books in case this information is required.

You will receive in return a document confirming the registration of the death. It is advisable to make a note of the number of the entry in the register, the date and registration district since you may need more copies of the entry later.

You will also receive a certificate for burial or cremation, whichever you have decided on. Once you have obtained the necessary certificate, give it to the undertaker since the funeral cannot take place without it. Sometimes financial assistance is available through your social worker or community nurse to help with expenses.



“How do we arrange the funeral?”

Many of us nowadays have very little experience of death and funerals and so when faced with it, there may be a tendency to get caught up in all the organisation of an event which later may seem irrelevant and not what was really wanted. We have included this section in the hope that it will assist you to make your child's funeral a memorable and appropriately personal occasion, enabling you to say what you want about your child and ultimately helping you to mourn his loss.

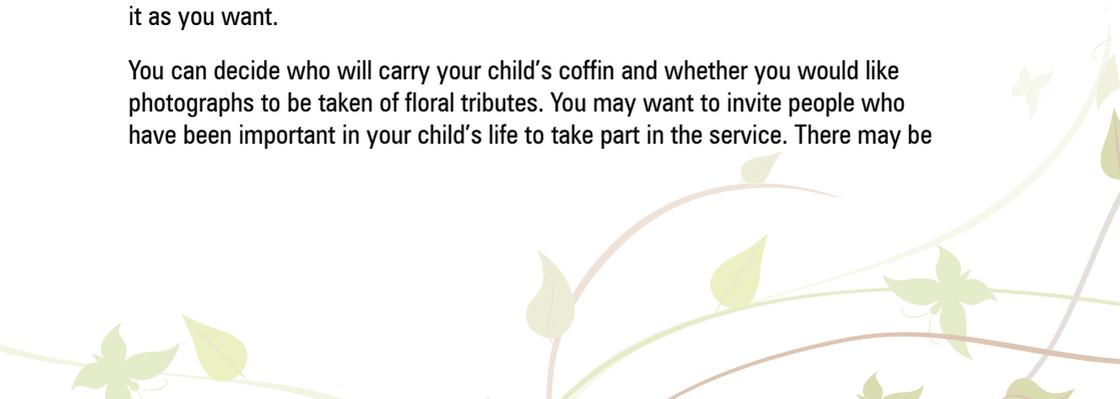
Your child can stay at home with you if you wish for some or all of the time before the funeral. It is advisable to discuss this at an early stage with the funeral directors since not all of them provide the necessary arrangements. Children's hospices have a special room where families can visit the child who has died. This can usually be offered even if the child did not actually die in the hospice, and some parents may prefer to see their child in those surroundings. Seeing your child's body can be very distressing but many parents, relatives, friends, brothers and sisters have found it helpful in beginning to come to terms with the reality of their loss.

You may want to choose what your child is going to wear and whether you want to dress him yourself or would prefer someone else to do this for you. A lock of hair, handprints or footprints and photographs can be taken if you wish. You may also want to place a favourite toy or possession in the coffin.

You will need to decide whether your child will be buried or cremated, and sometimes older children may have made this decision for themselves. If you choose cremation, you do not need to make an immediate decision about disposal of the ashes. Bear in mind that with a small child there will be very few ashes. You can also choose to have a memorial service sometime in the future.

The funeral does not have to take place within a certain time period so you can take as long as you need to decide what you would like. You may wish to discuss your thoughts with the rest of the family, close friends or a minister of religion. There is no requirement for a religious service as such, so you can plan and shape it as you want.

You can decide who will carry your child's coffin and whether you would like photographs to be taken of floral tributes. You may want to invite people who have been important in your child's life to take part in the service. There may be



particular readings, poems or pieces of music that have a significant link with your child which you wish to use. Some parents like to include a photograph of their child in the order of service, or display a photograph in the church.

If you have other children it is important to include them in the discussions and arrangements. They have their own contributions to make, and their own feelings of grief to cope with. They may want to see their brother or sister, place a toy in the coffin or choose some music for the service. Listen to what they say and respect their choices. It is surprising how often children are thought of as too young to understand what is happening and so not given the chance to participate. This can lead to major regrets at a later stage.

Some parents say that they have very little recollection of their child's funeral. Since memories and being in control of situations are so important later, you may want to tape-record the service or ask those who spoke to give you a written copy of what they said. You may wish to ask people who attend to sign a book. Offers of medication or alcohol to 'help you get through the day' need to be considered with care and caution.

Traditionally relatives and friends will send flowers, but you can choose to collect donations to send to a charity, or to buy a piece of equipment for the hospital or school in memory of your child.

Discussing the alternatives and making the choices can help to reduce the feelings of helplessness and encourages you to regain control. Your involvement in these decisions will ultimately help you to grieve for your child.



AFTER THE FUNERAL

How will we cope?

The sadness experienced by families when a child dies is immense and far-reaching. The time between the death and the funeral may be one of frantic activity and this may carry you through this period. Then life for everyone else seems to return to 'normal', and you have time to think.

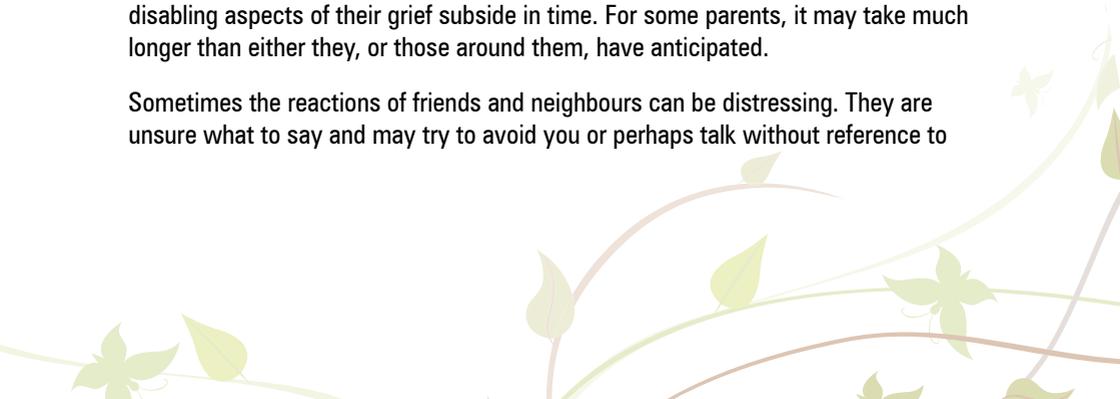
Sometimes parents feel a sense of relief after their child actually dies and feel confused and guilty about this. But being relieved that the struggle is over is not the same as being glad that someone has died. Other children in the family may be secretly relieved that it is all over and that the family is free to focus on other matters. They also may feel that these thoughts are unworthy ones and be confused by them.

Children, especially younger ones, are not able to sustain great sadness indefinitely so they may appear to 'bounce back' very quickly. However, the loss of a sibling in childhood can have very far-reaching implications so you may need to be especially watchful of your surviving children. If in doubt about children's reactions, do discuss this with a healthcare professional.

Parents have described feeling as if they might go mad following their child's death. Failure to think clearly, lack of concentration, memory loss and being prone to accidents are common, and not permanent. Exhaustion is perhaps the most common feeling since the experience of such grief is physically and emotionally draining. Be gentle with yourselves and take whatever time you need to care for yourselves. Other parents have found that talking with someone, especially another similarly bereaved parent, can bring some comfort and reassurance. Individual support or meeting with other parents in a group setting can be made available to you, and your palliative care team will be able to advise you about this.

As your child will never return, it may be impossible to imagine that the distress you feel now will ever ease. Other parents have discovered that, while the sadness will always be there and their child's memory remains as precious as ever, the disabling aspects of their grief subside in time. For some parents, it may take much longer than either they, or those around them, have anticipated.

Sometimes the reactions of friends and neighbours can be distressing. They are unsure what to say and may try to avoid you or perhaps talk without reference to



your child. You may have to start the conversation yourself, giving them permission in a way to talk about your child.

If your child is at school, the other children may want to commemorate his life in some way; perhaps by planting a tree or raising money for the hospital ward. This can be a very positive experience for the school and also important for you to know that your child's death has been acknowledged and he will live in the memories of other people.

Old photographs will also bring back happy memories so keep them around you. There is no rush to sort out all your child's possessions, so wait until the moment feels right for you. Some families do this quickly, and others wait many years. In the meantime it is not disloyal to allow the other children to enjoy his toys and clothes.

You may feel pressured by the expectations of both yourself and others to 'return to normal' and plan for the future, but again you must decide for yourself and choose what is helpful to you. Although the loss of a child is a very personal experience which may isolate you from the rest of your world, you do not need to manage on your own. Do tell someone whom you trust how you are feeling and perhaps then you need not feel quite so alone.



SOME BOOKS WHICH YOU MAY FIND USEFUL

Water Bugs and Dragonflies

Author: Doris Stickney

Ages: 3 – 8 years

ISBN: 0264669045 (Available from Christian Bookshops)

Uses the analogy of a water bug's short life under water for man's short time on earth, and its emergence as a dragonfly as man's life after death.

Easily interpreted by children to understand the idea of leaving the old body behind - of never coming back.

I'll Always Love You

Ages: 3-7 years.

ISBN: 0340401532

A gentle introduction to the idea of death through the death of a dog.

Badger's Parting Gifts

Ages: 4-8 years.

ISBN: 0006643175

All the animals are very sad when Badger dies, but they comfort themselves by remembering all the good things he had done to help them. A very good book to help children understand how they are feeling.

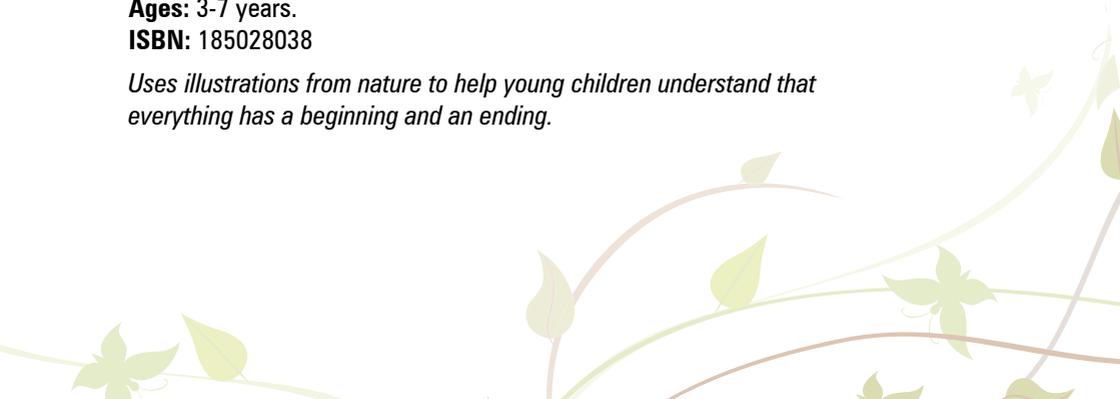
Beginnings and Endings with Lifetimes in Between

Authors: Bryan Mellonie and Robert Ingpen

Ages: 3-7 years.

ISBN: 185028038

Uses illustrations from nature to help young children understand that everything has a beginning and an ending.



Someone Special Has Died

St. Christopher's Hospice.

A booklet for children up to 12 years explaining emotions of bereavement.

A Summer to Die

Author: Lois Lowry

Age: Older teenagers.

ISBN: 0385734204

A very good account of how teenagers feel and how to come to terms with feelings.

Facing the Death of Your Child

Authors: Lesley Edwards and Jacquie Palmer

ISBN: 0949015571

A booklet exploring a wide range of issues both before and after your child's death.

Bereavement: Where to go for help

Children's Cancer and Leukaemia Group

A guide for families and professionals when a child or young person has died from cancer



USEFUL CONTACT ADDRESSES:

Cancer Research UK

PO Box 123
Lincoln's Inn Fields
London NWC2A 3PX

Tel: 020 7242 0200

Fax: 020 7269 3100

Children's Cancer and Leukaemia Group (CCLG)

3rd Floor, Hearts of Oak House
9 Princess Road West
Leicester. LE1 6TH

Tel: 0116 2494460

Email: info@cclg.org.uk

Website: www.cclg.org.uk

CCLG booklets are available to download from www.childcancer.org.uk

Leukaemia Research

43 Great Ormond Street
London WC1N 3JJ

Tel: 020 7269 9060

Fax: 020 7405 3139

Email: info@lrf.org.uk

Website: www.lrf.org.uk





supported by

CANCER RESEARCH UK



Children's Cancer and Leukaemia Group

3rd Floor, Hearts of Oak House
9 Princess Road West
Leicester LE1 6TH

Tel: 0116 249 4460

Fax: 0116 254 9504

Email: info@cclg.org.uk

Website: www.cclg.org.uk

Registered Charity No: 286669

CCLG leaflets are available to download from www.childcancer.org.uk.