



Children's
Cancer and
Leukaemia
Group

the EXPERTS
in CHILDHOOD
CANCER

Bereavement

Sources of help and support

A guide for families, friends and schools when a child or young person has died from cancer



www.cclg.org.uk



This booklet was written by the CCLG Information Advisory Group comprising multi-professional experts in the field of children's cancer.

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Adapted from the CCLG resource entitled: '**Facing the death of your child**', which contains essential information for helping parents to cope with the death of their child. It is free of charge to order or download from the CCLG website www.cclg.org.uk/publications

The death of a child is a devastating experience for everyone who knew and loved the child. Suddenly, the promise of a young life with a future of hopes and dreams is gone. This simply does not make sense and goes against how we expect normal life to be. The loss of a child is intense and profound.

This resource contains suggestions of how others such as friends, neighbours and schools can help bereaved families whose child has died from cancer.

Coping with grief and loss

Grief is a natural response after someone you love has died. The death of a child or young person is particularly hard to accept and cope with, and parents will grieve for their child over a long period of time.

Bereaved parents will experience painful and strong emotions. They may find that their grief is overwhelming and takes up all of their energy, making it hard to cope with any other demands on them. As a result, parents will often not be able to ask for, or find, the support that might help them at this time.

Grandparents too may find that they are overwhelmed by grief, often feeling that it should have been them, not their grandchild, who has died.

Children grieve too. Some children are able to talk openly about their feelings which may help them to cope well with the death of their brother, sister, friend or cousin. Other children find it harder

to say how they feel and may need help to communicate in other ways.

Bereaved children are very sensitive to the emotions of their parents and may not want to discuss their thoughts and fears with them, feeling that their worries may worsen their parents' sadness. Bereaved parents may themselves feel that the strength of their own grief means that they do not have the capacity to fully support their other children.

There is no right or wrong way to grieve and it can't be forced or hurried. It just takes time. There is plenty of help and support available to help understand and process grief.

Whatever your relationship with the child who has died, there is plenty of help and support available to help understand and process grief.

How to help the bereaved family

Parents have told us they would like information to give to others. The following suggestions may help you understand what you can do to help them when their child has died.

How can you help?

Parents may not feel that you really understand their feelings of total devastation. They may find it difficult to ask for help and may withdraw from others. However, you can help them in many different ways.

The following suggestions can help you to feel that you are doing something useful for them at this difficult time:

- ▶ Offer to do practical things like cooking, shopping, washing, ironing. The list is endless. This can take away the burden of having to think about doing these things.
- ▶ Take care of their other children, so your friends can have some time for themselves, either alone or as a couple.
- ▶ Drive them, for example, to the shops, when they feel they cannot face the traffic.
- ▶ Some friends can listen but others find it too upsetting. If you find you can't listen, it doesn't mean you don't care. Offering to do things instead can help your friend to feel you are trying to support them.
- ▶ Your friend is likely to need more support as the weeks go by, when

they begin to feel everyone has forgotten them. People tend to phone and offer support in the beginning. The longer you remain in contact, the more you will be able to help your friend. Frequent but short contacts are really appreciated.

- ▶ Your friend may have difficulty in accepting your healthy family. Try not to feel guilty or upset about this. At this time, it is really difficult for them to think about anyone else's point of view.
- ▶ Your friend will appreciate honesty and if you want to tell them how difficult it is for you to understand, you can say "I just cannot begin to understand how terrible this must be for you".

It is also devastating for you to hear that a child you know has died. While you were probably told it may happen, no one believes it really will happen, and the news often comes as an enormous shock.

Everyone hopes that the poorly child will escape, and be the one who is cured against all the odds. This may make you worry about your own family as well as feeling desperately sorry for your friend and their family.

Some people feel guilty about this, however, when a tragedy like this happens, it is natural to feel this way

What can you say to them?

The following suggestions may help:

- ▶ Try not to say "How are you?" Although very well intentioned, your friend will probably feel the need to say "Fine". Sometimes, comfort can come from simply putting an arm around your friend and saying very little. Or, if you are ready to hear the answer, you can say "How are you really feeling?"
- ▶ Try not to say "The good die young" or "God needed him" or "She was too special". The list of these could be endless and, while there may be truth in some of them, your friend is unlikely to find them helpful.
- ▶ Euphemisms such as 'fallen asleep' are not helpful. It can be difficult to use the word died, but it is the truth. To say to your friend they have 'lost' their child makes them sound careless. The best words are often the ones your friend uses. You will soon pick up how they refer to their child who has died.
- ▶ It is almost never helpful to say to someone "You can always have more children". This may or may not be true. The child who has died can never be replaced. He or she was absolutely unique and individual.
- ▶ Listen to your friend talk, accepting what is said rather than giving reassurance and advice. It is hard to listen to anger, sadness, accusations and dark thoughts, and listening to the same things can be difficult but it will help your friend to process their grief. Try to understand that there will be times when your friend does not want to talk and wishes to be on their own.
- ▶ Don't cross the road to avoid speaking to your friend, even if you feel you want to. This can feel very hurtful. If you do not know what to say, then be honest and say so because you can still acknowledge your friend's sadness even if you are unable to say anything. They had no choice that their child died, but you do have a choice in how to be a real friend.



- ▶ Look after your friend's physical needs. For example, encourage them to eat and get enough rest. You may be able to help them resume activities they had previously enjoyed.
- ▶ Talk about your friend's child in everyday conversation. There may be some bereaved parents who do not want their child's name mentioned but most do. You will not be reminding them about their sadness, because it is there all the time. Parents will probably welcome the chance to talk about their child for the rest of their lives.

How to help someone who is going through loss and bereavement

- ▶ Let your genuine concern and caring show.
- ▶ Be available or arrange for someone to be available for them.
- ▶ Allow them to talk about their feelings, both positive and negative.
- ▶ Remember, there is no right or wrong way to feel after a loss. Everyone will find their own way of dealing with it.
- ▶ Don't let your own feelings of helplessness keep you from offering support.
- ▶ Don't avoid grieving brothers or sisters because you feel uncomfortable.
- ▶ Don't say you know how they feel, unless you have had the same loss. Never tell them what they should feel.
- ▶ Don't try to find something positive to say about their loss. This can trivialise it in their eyes.



How schools can help

Parents have told us that it would be helpful to have some information to give to their child's school. This is to help schools understand what they can do after a pupil has died.

Parents usually contact the school after their child has died. Schools often want to have a special assembly or service. Check that it is not too soon, or at a time that is too difficult for the family. This is particularly important for schools where there may be a brother or sister as no-one wants to make the situation more difficult than it is already.

- ▶ Make sure that all staff are aware and that there is one key person to remain in contact with the family. Talking to many different members of staff may become too difficult for the family. Make sure, too, that all staff are telling the same story.
 - ▶ It is important for the school community to acknowledge the death of a pupil. This needs to be done in a way that will convey the importance of each individual in the community, and respects the child and his or her family.
 - ▶ Think about the impact on staff. They should only be asked to speak to classes if they feel able to deal with pupils' reactions and questions.
 - ▶ Consider telling pupils in small groups if possible. This will allow for questions and expression of feelings.
 - ▶ Consider how the family would feel about staff or pupils attending the funeral.
- ▶ Consider the school's policy regarding its staff and pupils attending funerals of former pupils.
 - ▶ Arrange for support to be available for both pupils and staff.
 - ▶ Think very carefully if there is a surviving brother or sister and how you will include them in any memorials. Talking with them and their family will ensure the best level of support is available. Make sure you treat the surviving brother or sister in a way that is acceptable to both the child and the family.
 - ▶ The school may also feel they would like to make a more permanent memorial to the child in the following months, such as a bench or seat with a plaque, or special tree planted.
 - ▶ Listen to pupils if they want to talk and don't change the subject when they mention their friend and how they are feeling.

Resources for schools:

Cruse Bereavement Care:
www.cruse.org.uk/get-help/for-schools

Child Bereavement UK:
www.childbereavement.org/for-schools

Childhood Bereavement Network:
www.childhoodbereavementnetwork.org.uk/schools

Grief Encounter:
www.griefencounter.org.uk/professionals-schools

Helpful organisations

A Child of Mine

achildofmine.org.uk

A charity led by bereaved parents offering practical information, guidance and support from people who really do understand. The website also lists local support groups around the UK.

Care for the Family

careforthefamily.org.uk/family-life/bereavement-support

Christian faith-based charity that supports families.

Child Bereavement UK

childbereavementuk.org

Child Bereavement UK supports families and educates professionals when a baby or child of any age dies or is dying, or when a child is facing bereavement.

Child Death Helpline

childdeathhelpline.org.uk
Tel: 0800 282 986

A helpline staffed by trained volunteer parents who have suffered a loss of their child. The Helpline is available every evening 7pm to 10pm and Monday to Friday mornings 10am to 1pm and Wednesday afternoons 1pm to 4pm.

Child Funeral Charity

childfuneralcharity.org.uk

Offers financial support with the costs of a funeral for families.

Childhood Bereavement Network

childhoodbereavementnetwork.org.uk

An organisation for those working with bereaved children, young people and their families across the UK.

Children of Jannah

childrenofjannah.com

A charity that supports grieving Muslim parents and families following the death of a child or baby.

CLIC Sargent

clicsargent.org.uk

Provides information and support for children and young people with cancer and their families.

The Compassionate Friends

tcf.org.uk

TCF is a charitable organisation of bereaved parents, siblings and grandparents dedicated to the support and care of other bereaved parents, siblings, and grandparents who have suffered the death of a child/children.

Cruse Bereavement Care

cruse.org.uk

Cruse Bereavement offers counselling and support for all bereaved people.

Grief Encounter

griefencounter.org.uk

Supports bereaved children and teenagers.

Samaritans

samaritans.org.uk

Tel: 116 123

The Samaritans support anyone in distress and offer a 24-hour helpline.

Winston's Wish

winstonswish.org

Offers practical support and guidance to bereaved children, their families and professionals.

Social media: There are many social media groups on Facebook dedicated to those coping with bereavement and loss. These can offer a safe supportive space to be open and honest about how you feel with others who understand. This can be very helpful but it can also mean that you are exposed to other people's grief at a vulnerable time for you which can be even more overwhelming. As with all social media, trying to keep a balance and to step back if needed is the best thing.

Helpful books: For young children

Always and Forever

Durant, A. ISBN 0552548774

A animal storybook about remembering for 3-5 years old.

Badger's Parting Gifts

Varley, S. ISBN 1849395144

The animals of the forest are heartbroken when Badger dies, but gradually find ways to remember him for 3-5 years old.

Fred

Simmons, P. ISBN 1783440295

A story book about a cat who has died. Useful for starting conversations about death.

Goodbye Mog

Kerr, J. ISBN 0007149698

The final book for children of the popular cat series.

I'll Always Love You

Wilhelm, H. ISBN 0780788710

A short introduction and conversation starter.

The Lonely Tree

Halliday, N. ISBN 0953945987

A story using the simple metaphor of trees to explain the cycle of life.

The Mountains of Tibet. A Child's Journey Through Living and Dying

Gernstein, M. ISBN 1898000549

Based on the Tibetan teachings of Life and Death.

Muddles, Puddles and Sunshine: Our Activity Book to Help When Someone Has Died

Crossley, D. ISBN 1869890582

Practical activities and conversation starters for bereaved children.

On The Wings of a Butterfly: A Story About Life and Death

Maple, M. ISBN 0943990688

A gentle way to try to explain to children what happens when someone dies and is a true story about a little girl who has cancer.

Overcoming loss

Sorensen, J. ISBN 1843106463

Activities and stories for children.

Remembering My Brother

Perkins, G. ISBN 0713645415

Story with photos showing a family of children who have lost a brother. Will help 4-10 year olds understand grief.

Sad Isn't Bad: A Good-Grief Guidebook for Kids Dealing with Loss

Mundy, M. ISBN 0870293214

A book exploring grief for children aged 4 and over. Sensitive to different religious beliefs.

The Coat I Wear

Maxwell, M. ISBN 0993117902

A story which follows the grief of a child after their sibling dies.

Up in Heaven

Chichester Clark, E. ISBN 1842703331

A story about a little boy's dog that may help children to discuss their views and ideas about heaven.

Water Bugs and Dragonflies: Explaining Death to Young Children

Stickney, D. ISBN 0829816240

A short story using the analogy of waterbugs developing into dragonflies for death. Beautiful and easy to understand.

When Someone Very Special Dies: Children Can Learn to Cope with Grief

Heegaard, M. ISBN 0962050202

An activity book for children to start talking about feelings, and death and support.

For older children and teenagers

A Young Person's Guide to Dealing With The Loss of a Brother or Sister

CLIC Sargent

www.clicsargent.org.uk

Charlotte's Web

White, E. ISBN 0141354828

Beautiful story introducing death, in a novel. Ideal to be read over a period of time as a story, or read independently.

Facing Death and Talking About It

CLIC Sargent

Written to help young people who are not going to recover from cancer talk to their family, partner and friends.

The Harry Potter Series

Rowling, JK

This series has deeply entrenched themes of death, loss and bereavement throughout, and may help children to understand their feelings.

Hope Again

www.hopeagain.org.uk

A safe place where young people can share experiences and learn how to deal with grief.

Michael Rosen's Sad Book

Rosen, M. ISBN 1406317845

A moving picture book which considers the effect that sadness can have. May help to reassure children that it is ok to be sad sometimes.

Straight Talk About Death for Teenagers: How to Cope with Losing Someone You Love

Grollman, E. ISBN 0807025011

Suggests how to deal with grief and other emotions.

A Teenager's Guide to Getting On With Life After Death

Grief Encounter

www.griefencounter.org.uk

What on Earth Do You Do When Someone Dies?

Romain, T. ISBN 1575420554

A guide for older children written in a straightforward way, with practical tips and advice.

When a Friend Dies

Gootman, M. ISBN 1575421704

A book for teenagers about grieving and healing.

For adults

A Child's Grief: Supporting a Child When Someone in their Family Has Died

Stubbs, D. et al.

Useful and informative introduction for any adult who is supporting a child through bereavement.

Bereaved Children and Teens: A Support Guide for Parents and Professionals

Grollman, E. ISBN 0807023078

For adults supporting children and young people.

Talking About Death: A Dialogue Between Parent and Child

Grollman, E. ISBN 0807023639

Straightforward book, a guide to talking about death.

Grief and Bereavement, Understanding Children

Couldrick, A. ISBN 0951753711

Very short booklet, explaining how children respond to grief.

The Grieving Child

Fitzgerald, H. ISBN 0671767623

For adults supporting children and young people.

Helping Children Cope with Grief: Facing a Death in the Family (Overcoming Common Problems)

Wells, R. ISBN 085969559X

For adults supporting children.

Helping Teens Work Through Grief

Perschy, M. ISBN 0415946964

Useful hints for professionals working with bereaved teenagers.

Losing a Child

Hurcombe, L. ISBN 0859698866

Gives an understanding of how grieving for a child can affect every member of the family, and the relationships between the surviving members.

One Day at a Time Series (Booklets and DVD)

CLIC Sargent

Compiled using the real experiences of bereaved parents to support parents and carers when their child dies of cancer.

What Does Dead Mean? A Book for Young Children to Help Explain Death and Dying

Jay, C. and Thomas, J.

This book guides children through questions they often ask about death and dying. For children aged four and above.

You Just Don't Understand: Supporting Bereaved Teenagers

MacKinnon, H.

Practical guidance on supporting a teenager who is bereaved.

Helpful local sources of support:

- **Staff at the hospital where the child was treated**, including the CLIC Sargent Social Work team, can provide advice to the child's family about the services available locally that may be able to help and support them.
- **Your general practitioner (GP)** will be able to provide advice about the services available locally. This may include information about local bereavement services, support groups, and organisations that offer other support, including practical, emotional and financial help.
- **Schools** may also be able to provide information about local services, and offer advice and sometimes access to counselling services for the siblings of the child who has died.
- **Religious organisations:** The chaplain at the hospital, or your local religious leader can offer support and advice.
- **Your local hospice:** Hospices are specialists in looking after patients with terminal illnesses and their families. They usually offer information, advice, emotional support and bereavement care services to everyone in the local community.



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Children's Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.

Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

If you have any comments on this booklet, please contact us. CCLG publications on a variety of topics related to children's cancer are available to order or download free of charge from our website.

Our work is funded by donations. If you would like to help, text '**CCLG**' to **70300** to donate **£3**. This costs £3 plus a standard rate message.



Patient Information Forum

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