



Children's
Cancer and
Leukaemia
Group

Bereavement

Sources of help and support

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





Children's
Cancer and
Leukaemia
Group

Working together to
beat childhood cancer

This booklet was written by the CCLG Publications Committee, comprising multiprofessional experts in the field of children's cancer.

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ChildrensCLG



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Introduction

The loss of a child is a devastating experience for anyone who loved the child. When a child dies, it simply does not make any logical sense. It is not the normal way of things. Suddenly, all the promise of that young life has gone.

This booklet contains suggestions of sources of support for families who have lost a child from cancer. It may be helpful to bereaved parents, grandparents and other family members, as well as to those such as teachers, health professionals and friends who are offering support to the bereaved family.

The information in this booklet is taken from the CCLG booklet 'Facing the death of your child', which contains practical information and suggestions for helping families to cope with the death of a child, as well as ideas that other families have found useful. 'Facing the death of your child' is available to order or download for free from our website.

How family members grieve

Grief is a natural process after someone important has died. The death of a child or young person is particularly hard to accept and cope with. Parents who have lost a child grieve over a long period of time, usually for many years. Bereaved parents often experience strong emotions and often a need to be with their child. They may find that this grief takes up all of the 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, that has died.

Children need to 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.

Whatever your relationship with the child who has died, there are professionals who can offer help, free booklets and websites as well as books that can be bought or loaned that give guidance.

How friends can help the bereaved parents

Parents have told us they would like information to give to friends. The following suggestions may help you understand what you can do to help after your friend's child has died.

How can I help my friend whose child has died?

Your friend whose child has died may not feel that you really understand their total devastation. Clearly, it is impossible to understand completely how anyone else feels as you are not in the same position. However, you can help them in many different ways.

The following suggestions may help you feel you are doing something useful:

- Offering to do practical things like cooking, shopping, washing, ironing. The list is endless. This can take away the burden of having to even think about doing these things.
- Sometimes taking care of their other children, so that your friends can have some time for themselves, either alone or as a couple.
- Driving 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 ring 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 it must be for you".

It is also clearly devastating to hear that a close friend's child 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 their 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 worrying about those closest to them, however when a tragedy like the death of a child occurs, this is natural.

How can I talk to my friend whose child has died?

The following suggestions may help:

- Try not to just 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.
- Try to sit and listen for as long as it takes, accepting what is said rather than giving reassurance or advice. It is exhausting listening to anger, sadness, accusations and guilt. Listening to the same story repeatedly can become difficult but it will help. Telling their story is the main way that people start to grieve. Try to understand that there will be times when your friend does not want to talk and wishes to be on their own.
- Never 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 say so, because at least you are acknowledging the person’s sadness. 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 change the subject when a pupil mentions their loss.
- 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 to help both before and after the child has died. They have also suggested it may help to have some guidance for schools about how to talk to the rest of their child's class, and if brothers or sisters of the child who has died are still attending the school.

It is crucial for schools to remain in contact with any child who is receiving treatment for cancer, as school can be such a normal and important part of a child's life. If the child becomes very unwell, then we would always recommend that contact is kept with the family. This will ensure clear communication and the school can act with the family's and child's wishes in mind. To the child, however, any kind of normality can be a great distraction and help them to cope.

We recognise that having a child who is terminally ill in the school will have a huge impact both on the staff and on other pupils. Staff will need to be able to reflect on their own feelings and experiences before being able to help the dying child or other pupils.

What can we as a school do to help when one of our pupils is likely to die?

- Having a liaison person at the school is essential to maintain contact with the family. This will stop the family having to explain the whole situation again to someone new. The family can trust the liaison person to give out information in the way the pupil and family feel is appropriate.
- The pupil may feel that they would appreciate some contact with the outside world, but can't manage a whole day in school. It may be possible to do a half day or even just a lesson or break time, with a member of staff designated to take responsibility. Schools need to be flexible with these kinds of arrangements.
- If the child is too unwell to manage school at all, perhaps a short visit from a few classmates might be welcome. Consider using social media, video messaging or Skype, although bear in mind that the ill child may not want to be seen on screen themselves if they are self-conscious about any change in their appearance. This could be monitored and organised by the teacher responsible. The chances are that teachers and classmates will have followed the child's illness from the start. This may make them feel involved and want to help in some small way to make the last days special.
- Emphasise that, even if pupils feel uneasy about seeing someone very ill, they can still remain in contact by telephone, email, videos, texting, social media, or letters.
- Home tutors can be especially useful as they often have a special empathy for very seriously ill children and their families.
- Always talk with all staff involved before talking to pupils, as staff members may have strong feelings. They have to feel able to manage these feelings and then manage pupils' reactions. Keep those who need to know informed. Try and think about the need for support both for pupils and staff.

- Discuss how to let pupils know what is happening. Think carefully how to talk in classes where there may be a brother or sister. Give siblings a chance to choose whether or not they are present or absent when a class discussion takes place.
- Discuss who is available to support staff and pupils. Think about their availability.

What do schools need to consider after a child dies?

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 policy of the school on staff and pupils attending funerals.
- 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.

Helpful organisations

A Child of Mine

www.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.

The British Humanist Association

www.humanism.org.uk

Represents the interests of ethically concerned but non-religious people. Their celebrants provide non-religious funeral ceremonies.

Child Bereavement UK

www.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

www.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

www.childfuneralcharity.org.uk

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

Childhood Bereavement Network

www.childhoodbereavementnetwork.org.uk

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

ChildLine

www.childline.org.uk

Tel 0800 1111

A free, confidential, 24-hour support line for children and young people.

Children of Jannah

www.childrenofjannah.com

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

CLIC Sargent

www.clicsargent.org.uk

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

The Compassionate Friends

www.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

www.cruse.org.uk

Cruse Bereavement offers counselling and support for all bereaved people.

Gingerbread

www.gingerbread.org.uk

Provides advice and support to single parents.

Rainbow Trust Children's Charity

www.rainbowtrust.org.uk

Provides practical and emotional support to families who have a child with a life threatening or terminal illness. They can provide respite care/ short holidays.

Samaritans

www.samaritans.org.uk

Tel 08457 90 90 90

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

Winston's Wish

www.winstonswish.org.uk

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

Social media

Some families have joined or started Facebook pages or other online forums, which can be an open and frank way of expressing and sharing feelings, and sharing memories of the child who has died.

While some families find that social media can help them to cope with what is happening, other families have not always found this is the case. Sometimes online forums can be negative and a place to air complaints rather than offer mutual support. Sadly, sometimes these pages can also be a target for 'trolls'.

Always use the internet with caution and ensure that you have appropriate privacy settings for your social media accounts.

Helpful books

For young children

Always and Forever

Durant, A
ISBN 0552548774
A story which reinforces the power and importance of remembering.

Am I Still a Sister?

Sims, A
ISBN 0961899506
A lovely book for siblings, helping them to feel valued.

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.

Fred

Simmons, P
ISBN 1783440295
A story book about a cat who has died. Useful for starting conversations about death.

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: Your activity book to help when someone has died

Crossley, D
ISBN 1869890582
An activity book offering 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.

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.

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 Has a Very Serious Illness: Children Can Learn to Cope with Loss and Change

Heegaard, M
ISBN 0962050245
Activity booklet to be completed by children, with or without parents. Introduces ideas of change, loss, and support, great to start conversations and to get children drawing out their feelings.

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

Heegaard, M
ISBN 0962050202
Carries on the work started above, but can be read on its own. This is an activity book to be drawn in and completed by children. Great place to start talking about feelings, and death and support.

When Something Terrible Happens: Children Can Learn to Cope with Grief

Heegaard, M
ISBN 0962050237
A workbook to help children work out their feelings about a difficult event, helping the child to express their feelings.

For older children and teenagers

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.

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.

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.

Helpful local sources of support

Staff at the hospital where the child was treated

Staff at the child's hospital, 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)

Your 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.

School

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.

For parents and other adults

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

Grollman, E

ISBN 0807023078

For adults supporting children and young people.

The Bereaved Parents' Survival Guide

Cassuto Rothman, J

ISBN 0826410138

Addresses the issues bereaved parents are likely to face, handling the grief and guilt of siblings, dealing with well-meaning friends and relatives, to how to deal with the lost child's room and belongings.

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.

Just My Reflection

Sister Frances Dominica

ISBN 0232522111

Helping Parents to do things their way when their child dies. With suggestions for funeral arrangements and services.

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.

Sad Book

Rosen, M

ISBN 0744598982

Honest book for children or adults about what makes us sad, but for the author what makes him most sad is thinking about his son who died.



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Children's Cancer and Leukaemia Group is a leading children's cancer charity and the UK and Ireland's professional association for those involved in the treatment and care of children with cancer. Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Two out of ten children will not survive their disease.

We bring together childhood cancer professionals to ensure all children receive the best possible treatment and care. We fund and support research into childhood cancers, and we help young patients and their families with our expert, high quality and award-winning information resources.

If you have any comments on this booklet please contact us at the address below

CCLG publications on a variety of topics related to children's cancer are available to order or download free of charge from our website

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