

## The Child Death Helpline

As bereaved parents we know that to lose a child is the most devastating experience any parent has to face. In the UK thousands of children under 19 die every year. Grief is no less intense for those affected by the death of an adult child.\*

The Child Death Helpline provides a supportive listening service to anyone affected by the death of a child of any age, from pre-birth to adult; however long ago, and whatever the circumstances (stillbirth, illness, accident, murder, suicide...). For parents, their son or daughter will always be their child, irrespective of age. We receive calls from parents who have lost children during pregnancy and from those whose child was 30, 40 years old or more when he or she died. We listen to people affected by the death of a child in the last few days and to those who lost children 20, 30 or more years ago. On average, we answer over 2,500 calls a year from a wide range of people affected by the death of children, including parents, grandparents, family friends and professionals.

The national Child Death Helpline was formed in 1995 by bringing together the experience of those working on two helplines which were already operating, at Alder Hey Hospital in Liverpool and Great Ormond Street Hospital in London. Bereaved parents and relatives often say that they find that the most valuable support is provided from others who have experienced the death of a child. With this in mind all the volunteers who staff the helpline are bereaved mothers and fathers. In 2008, the Helpline received the prestigious Queen's Award for Voluntary Service, the highest award given to voluntary groups in the UK.

The Child Death Helpline is open 7 nights a week from 19.00 to 22.00  
Monday, Thursday and Friday mornings 10.00 to 13.00  
Tuesday and Wednesday 10.00 to 16.00

The number is Freephone **0800 282986**  
To ensure your call is free if you are using a mobile phone ring  
**08 08 800 6091**

We can take calls from people who wish to speak in languages other than English by using the Language Line telephone interpreting service.

Our website address is [www.childdeathhelpline.org.uk](http://www.childdeathhelpline.org.uk)

- For up to date figures see [www.Statistics.gov.uk](http://www.Statistics.gov.uk)

## The death of a child

As bereaved parents we know that to lose a child is the most devastating experience any parent has to face. The death of a child is a particularly difficult kind of grief. No one expects their child to die before them; it is out of the natural order of things. It feels like something that should never have happened.

The information below is provided by parents who have themselves been bereaved. Although we know that consolation is impossible, we offer you our experience at this terrible time.

## How you might feel

There is no right or wrong way to feel after the death of a child. Most people experience a whole range of different emotions; initial feelings may include disbelief, numbness, anger, sadness, guilt, emptiness, maybe even, in some instances, a sense of relief. These feelings may be mixed up together, so that you wonder if you are going mad. It is very likely that if you have other children they will also have equally strong feelings, and may need a trusted person or friend to confide in.

Some parents will need to talk about the child's death over again for many months. Some parents will not want to talk about it at all, and will wish to try and "divert" their feelings, some of the time, into work and hobbies, sometimes to an obsessive extent. The greatest difficulty may be experienced where one parent needs to talk, and the other cannot listen or express their own feelings.

It is very common for partners only to have energy for their own grief and be temporarily unable to help each other. You may have to acknowledge together that you are expressing your grief differently, and respect each other's need to find support in your individual ways. Having someone listen to the way you feel is almost always helpful. Try not to be afraid to ask for help, outside the family if necessary, especially if you feel that your need to talk is a further "burden" on relatives and friends.

Talking to someone you met perhaps at the hospital may be helpful, or you may find support through the hospital Social Work Department, your GP or Health Visitor, or child's teacher. There are also specialist voluntary groups and organisations for families whose child has died in particular circumstances. There may also be groups of parents in your area, who meet through such organisations to share experience and mutual support.

## As months and years go on

Most bereaved parents feel that they will never 'get over' the death of their child. Instead they find ways to accommodate the loss and build their life around it. The numbness you felt initially will pass in time, but feelings of occasional disbelief, terrible sadness, anger, guilt and emptiness may remain very powerful for a long time after the death. Many bereaved parents mention similar experiences, such as:

- The feeling of being on an emotional roller-coaster
- . The need to talk about the child constantly.
- Trying to put on a brave face for others.
- Wondering whether they will ever feel better.
- The feeling that there is no point in getting up to start the day.
- The feeling that no future can be envisaged – sometimes leading to thoughts of suicide.
- The feeling of constant struggle to live hour by hour and day by day.

Do not be afraid to ask for help; talk to someone you trust about the way you feel.

## Anniversaries and special days

The anticipation of anniversaries and other significant days such as birthdays may be especially difficult, and unexpected and poignant feelings and reactions may take you by surprise. Some people plan events or family gatherings to mark these days while others try to treat them just like any other day. There is no right or wrong way to manage these situations. Try not to feel pressured into doing things on these days because you feel you ought to, or because it's what other people want.

## Other people's reactions

Some people, while meaning well, may say very clumsy things. They do not mean to hurt you further, but they can have no idea of the depth of your grief.

- Some may not know what to say, and say nothing at all.
- Some may feel they cannot face you. They may avoid you.
- Some may feel they should not mention your child, for fear of upsetting you.
- Some may be frightened of the reality that they or their own children could also die, because this has happened to you.
- Most will not know how to react.
- Some people will think you should be "over it" in a matter of months.
- Some people may, very tactlessly, try to find something "positive" to advise, such as focusing attention on other children you may have, or by using unhelpful clichés.

Tell them how you want them to react. If you want them to talk about your child, and to use his or her name, tell them.

It is not uncommon for friendships, or for your circle of friends, to change in these circumstances

### Other children

Even if you have included siblings as openly as you can, their needs to talk about their brother or sister, and what happened, will change as they mature. You may find that much basic information is required, perhaps over and over again. Children will take in the information as they are ready and increase their understanding as they develop. When parents are grieving, the needs of a surviving child or children can be overlooked. Even very young children can sense loss in the family. Older children may exhibit behaviour problems as an expression of their grief, especially if they have no opportunity to talk honestly about their feelings. It is important that the parents, grandparents and friends remember that the surviving child also had a close relationship with the dead sibling. It is not uncommon for children to feel guilty for their sibling's death. The child may blame himself for the death, thinking the death is a result of "being mean" to their brother or sister, or a punishment for some other action or behaviour.

Relatives are often reluctant to show emotion in front of a child. This form of silence can be very difficult and puzzling for children to cope with: they may think that you don't care about the child who has died. It is alright to cry in front of the child.

Any child born into your family in the future should know about his or her brother or sister, and be given the opportunity to ask and talk about him or her.

If your only child has died you may feel a desperate and bitter sadness, that your parenthood is no longer visible to others. Whether you have other children or not, if you long for another baby, but pregnancy is not possible, or does not occur, this can be an added grief.

If you are already expecting a baby, or become pregnant again soon after your bereavement, you may feel very frightened about your ability to love and care for this new baby. Alternatively, you may worry that focusing on the new baby will prevent you "remembering" and grieving for your child who has died. You may also sometimes find yourself becoming particularly anxious about the well being of this baby – or of other children you may have.

All of these feelings are normal, and you may be helped by talking about the way you feel to someone you trust.

## The future

The death of your child is the most devastating thing that can happen to you. Surviving it may seem impossible for a very long time. Your life will, of course, never be the same again, but a life worth living is possible.

As you go through the rest of your life, memories and thoughts of your child will always be with you. Grieving means slowly accepting the reality of what has happened and learning to live with the change that has taken place in your life. Grieving isn't about forgetting the person who has died. It is about finding a permanent place for that person in your life, where it does not cause you so much pain. Nearly everyone needs help in some way, so do not be afraid to ask, no matter how long it is since the death.

## Comments from callers to the Child Death Helpline

*"She listened and listened, and I talked and cried and talked, and I listened, and I talked and talked and talked and she listened again, poor lady. But she helped, she helped more than anyone before...and I woke up in the morning feeling better than I have felt for a long time since my baby died"*

*"The Child Death Helpline offered a pocket of time and a climate of safety that was entirely for me. It was my opportunity to talk openly about my son's life and death. I needed to continue to talk about my son's life and death and to express the raw powerful emotions that would overwhelm me unexpectedly. I felt weighted down. How was I going to cope? During Child Death Helpline conversations I did not feel that I had to edit my conversation or worry what the person listening may be thinking. Being able to identify with someone who recognised, accepted and reassured me that what I was going through was normal, gave me hope that I would myself one day gradually move away from the raw emotions and feelings of despair that I was experiencing. I cannot imagine sharing my experience or feeling so accepted by a non bereaved parent."*

*"Your charity is a Godsend. Simply knowing that the Child Death Helpline is there waiting for your call is usually enough to stem the panic attacks and soothe the pain, a little. At least enough to get on with living. I know you guys are there if needed. Thanks for your help so far and keep up the good work."*

## A Volunteer's View

What does a Child Death Helpline volunteer do? First and foremost we listen. In the weeks and months following a child's or young adult's death, those affected may feel they cannot continue to burden friends and family with their grief. They may find it helpful to talk to someone who is impartial, and has some understanding of their day to day struggle. As bereaved mothers and fathers ourselves we recognise the need to re-tell the story of our child's death even though others may often expect us to "get over it" and return to normal. We understand that 'normality' is very different after the death of a child.

Anger, guilt, anxiety, hopelessness, and having no idea how to cope are commonly experienced feelings. Many bereaved parents temporarily think they are going mad. Some of us have felt "heavy with grief", describing how grief can have physical effects as well as emotional ones. Grief affects people in different ways. Relationships between partners and within the family may become strained, and misunderstandings can develop.

Every story is unique. Whatever the situation, the common link between volunteer and caller is the death of a child. We know we cannot take away the pain of grief and we do not try to tell people what to do or to offer solutions. What we are able to do is be alongside our callers, lessening their sense of isolation and encouraging them to talk about things other people may not want to hear. A different life can emerge after the death of a child. However there are still times, even many years on from a child's death, when those affected need a listening ear. People can contact our Helpline whenever they need to talk, over the course of a lifetime.

During a helpline call we enter someone else's world. What we have learnt, and what we continue to learn, helps us continue to offer support to all those affected by the death of a child. By being there for others who are going through what we have experienced, we may bring a glimmer of hope and a realisation that life can go on.



The Helpline is supported by charitable funding from the Alder Hey Children's Hospital: charity number 1049275 and Great Ormond Street Children's Charity number 235825

## Opportunities to volunteer

We are always interested to hear from bereaved parents who may feel able to offer telephone support to others who have been affected by the death of a child. Potential volunteers must be bereaved parents whose child died at least three years ago. Training and ongoing support will be provided.

Potential volunteers should be prepared to an initial training course of 30 hours and then undertake at least two Helpline duties per month; each duty lasts for three hours.

- Volunteers are needed in **London** on  
Tuesday, Wednesday or Thursday mornings 10.00 – 13.00  
Tuesday or Wednesday afternoons 13.00 – 16.00  
Monday, Thursday or Saturday evenings 19.00 p.m. – 22.00 p.m.
- Volunteers are needed in **Liverpool** on  
Monday or Friday mornings 10.00 – 13.00  
Tuesday, Wednesday, Friday or Sunday evenings 19.00 – 22.00

**For further information please contact:**

- London – 020 7813 8550 / 020 7813 8551 / 020 7813 8416
- Liverpool – 0151 252 5391

e-mail: [contact@childdeathhelpline.org](mailto:contact@childdeathhelpline.org)

## Friends of the CDH

Those who would like to offer their support but are unable to volunteer can become a Friend of the Child Death Helpline. Friends can help by publicising the Helpline or fundraising in their local area, for example. You do not need to be a bereaved parent to become a Friend of the CDH.

For more information visit our website: [www.childdeathhelpline.org.uk](http://www.childdeathhelpline.org.uk)

If you would like further supplies of packs, cards or leaflets please contact us via the website address or at any of the numbers above or you can write to us at our administration address (see front page).