

## When a child dies: a loss like no other

*"It does not appear to make a difference whether one's child is three, thirteen or thirty if he dies. The emotion in each of us is the same. How could it be that a parent outlives a child?"*

Harriet Schiff, *The Bereaved Parent*

No-one expects their child to die before them. It is out of the natural order of things and something that should never happen. For some the tragedy feels too overwhelming. They go through the motions, unable to rebuild their lives around their grief. At Child Bereavement UK, we believe that with the right help and support, lives can slowly be rebuilt. This information sheet includes quotes from bereaved parents who attend our child loss groups. It contains information on ways that might help you start to make small steps towards learning to live a new life, one that will continue to have a place for your child, but a different place.

*"I know that we cannot see our child by our side, we cannot hold them, but the love we felt for each other is imbedded in our soul, runs through our veins and inhabits every breath we take."*

### Age makes no difference

When a child of any age dies, parents and carers lose much more than a precious son or daughter. Life as they knew it has been irreversibly changed. They lose a future which included a child they nurtured, cared for, loved and who has now been taken away from them. With younger children the milestones are different from those of a teenager, or a young adult, but the pain surrounding shattered dreams is the same whatever the age.

### How you might be feeling

Everyone is different and grieves the death of a child in their own way. What you feel is what you feel. That doesn't make your response right or wrong, it is just how you are. Grief is made up of a surprising number of responses of varying intensity. It is normal to shed a few tears, sob uncontrollably or do neither. There is no set formula and no predictable timescale.

The families we support at Child Bereavement UK talk about some common responses. These include:

- complete exhaustion, particularly in the early days;
- physical aches including a tightness in the throat or chest;
- being unable to concentrate on anything else, making the simplest task a challenge;
- a sense of "what's the point?" to life: a feeling of complete helplessness;
- a great void or emptiness that will never be filled; and
- feeling that life will never again hold any pleasure or happiness.

Emotions might include complete disbelief but mixed in with flashes of a reality too awful to think about. You may have feelings of guilt, feeling that your child was your responsibility to keep safe, that there should have been something you could have done to prevent their death. Some people need to blame someone else, or something else. For others this is not an issue. Even if these feelings are not rational, they can be strong and can replay over and over again as you try to make sense of what has happened.

*"I think my body has let me down, I think I have let my husband down."*

Grief can be all-consuming and all-powerful. It has a habit of catching you unawares. Familiar routines may trigger unwanted, painful memories.

*"I avoid people in supermarkets... hide up another aisle... I don't want to talk to anybody."*

Sudden waves of emotion overwhelm you when you are desperately trying to keep them under control. This is common. It might help to protect yourself a little by doing things such as the shopping in a different supermarket until you feel a bit stronger and a bit more in control. Grief does not go away but it may become less sharp, and you become aware that the days where you can cope better are increasing in number. Eventually, a more manageable grief becomes a part of your life, a part of who you are, and a part of your continued connection with your child. Some describe it as a new way of being.

### **Grief and relationships**

Parents may change so much after the death of their child that to each other they become unrecognisable as the people who met and began a family life years before. They will need to discover who they are all over again and both partners will need space and time as they grieve for their child in their own way and on different timescales.

*"My partner cannot talk about our child or look at photos, I want to and need to."*

Marriages and partnerships may shake or crumble under the heavy weight of grief and loss but in time many will find a path forward. They can become stronger and life can mean something again. Some adults find their loss too painful to think about and cope by "switching off". It can be hard if your partner appears unaffected or is behaving in what might seem an insensitive or inappropriate way. It might help to remember they are still grieving, just doing it differently. For more information, see our information sheet *Women, men and grief*.

### **Other people**

Some families tell us that only other parents who have experienced the death of their child can truly appreciate the depth of pain and distress. They explain that this is why they feel so isolated. They do find comfort from support and concern offered by family and friends, but what is lacking is a real and deep understanding of what it is like to lose a child and how life changes as a result.

*"People think I am OK because I am dressed and out, they don't know how I feel inside."*

Some people will struggle with what to say to you and therefore say nothing. Others will unintentionally say something hurtful or insensitive. It takes energy you might not have, but if you start to talk about your child, people will probably follow your lead. Sometimes, however, it is a conversation stopper which you feel you have to manage. Others may have expectations of how they think you should be feeling and what you should be doing. Try to remind yourself that this is your grief, for your child, and you know better than anyone what is going to get you through.

### **What might help**

Families tell us they would say "don't expect anything of yourself and take each day as it comes". There is no timescale, and it will probably take longer than you would want before you start to get some sense of life being manageable.

Many people find it makes a great difference to be supported by people who are prepared to listen to them going over the death time and time again. Some will find these people amongst their own families and friends, others will prefer to seek help from professionals while many use both. It may help to be open to more than one type of support if these are offered.

Professional bereavement support or counselling offers time with someone whose job it is to listen and who has the training and experience to understand. You can say exactly what you think or feel and know that you are not upsetting them in the same way as family and friends. Some families tell us that professional support provides the only time in which they feel safe enough to honestly talk to one another about thoughts and feelings.

Child Bereavement UK offers face to face support in our centres across the UK as well as booked telephone support for bereaved parents and carers, or those supporting bereaved children and young people. Our helpline on 0800 02 888 40 can help you to find bereavement support services in your local area. There is also a directory of support services around the UK on our website, under the link Find support near you.

You can share experiences by going to a group to meet other families whose child has died. Child Bereavement UK runs groups in our services around the country. You can also contact The Compassionate Friends to find groups throughout the UK (see Resources section).

*"Meeting other parents who are also going through the devastating loss of a child has shown us that some of the difficult emotions that we feel are 'normal' and it has helped enormously to know we are not alone."*

It might help to share experiences over the phone with others who have 'been there' by calling the free Child Death Helpline on 0800 282 986 (see Resources section). This helpline is available for anyone affected by the death of a child. It is staffed by volunteers, all of whom are bereaved parents.

### **Looking after yourself physically**

Grief can be exhausting, and you may feel helpless and overwhelmed at times. It may not feel important to look after yourself physically, but this can help in managing the impact of grief. Emotional pain shows in physical ways, such as sleep and appetite problems, or physical aches and pains. Having a routine, getting social support from other people, exercise, and managing sleep and diet are all ways to maintain your physical wellbeing. These can help to reduce stress, anxiety and isolation, and give you more energy to be able to focus on what is most important to you.

### **Going back to work**

Returning to work can be a daunting prospect. The amount of leave people are able to take after a bereavement varies enormously. However much time you have had, you will still be grieving for your child and the decision to go back to work can be a difficult one. For others, returning to work is a positive step, providing some routine to the day.

Try to meet with your manager to discuss how you would like your return handled and how best to let everyone know what has happened. It might help if you arrange to go in for a short time before your actual start day to meet colleagues. This is a way to help overcome the hurdle of seeing everyone on your first day back, some of whom may struggle with what to say to you. Your employer only needs to have as much information as you want to give them, but it is important that they are aware. You may be anxious about becoming tearful or emotional. This may well happen but if people know the reason why, it will help them to understand your distress.

### **Be kind to yourself**

Try not to ask too much of yourself. Be realistic about what works for you, at home, in your relationships, at work and in any support other people can offer you. If possible, find time for grieving as well as time for activities in everyday life that you feel you can manage and that are helpful for you.

## **Resources and further reading**

All available from Child Bereavement UK unless otherwise stated.

### **Child Bereavement UK information sheets**

*How we grieve*

*Looking after yourself*

*Returning to work after the death of your baby or child: guidance for employees*

*When your baby dies: a particular kind of grief*

*Women, men and grief*

### **Farewell My Child**

Book of stories from families with a wide range of experiences from those whose babies have died to those who have lost adult children.

### **When your baby dies: a particular kind of grief**

Booklet version of our information sheet. Practical and emotional guidance for parents at the time of their baby's death, and afterwards.

Further resource references are available from Child Bereavement UK.

## Organisations offering support

### **Child Bereavement UK**

[www.childbereavementuk.org](http://www.childbereavementuk.org)

0800 02 888 40

Offers face to face support for bereaved parents or families when a child dies or is dying, or when a child or young person up to the age of 25 faces bereavement.

### **Sands: the stillbirth and neonatal death charity**

[www.uk-sands.org](http://www.uk-sands.org)

Helpline 0808 164 3332

Runs groups across the UK for anyone when a baby dies during pregnancy or shortly after birth.

### **The Compassionate Friends**

[www.tcf.org.uk](http://www.tcf.org.uk)

Helpline 0345 123 2304

Northern Ireland helpline 0288 77 88 016

Charity dedicated to the support and care of other bereaved parents, siblings, and grandparents who have experienced the death of a child or children.

### **The Child Death Helpline**

[www.childdeathhelpline.org.uk](http://www.childdeathhelpline.org.uk)

0800 282 986 or 0808 800 6019

Helpline for anyone affected by the death of a child of any age, from pre-birth to adult, under any circumstances, however recently or long ago.