



A nationwide organisation of bereaved parents and their families offering support after a child dies.

## Living with grief

A child of any age dying before their parents is devastating. This bereavement is like no other and changes us forever. At first, we are in a state of shock, numbness, denial and disbelief that can cushion us temporarily from the full impact of what has happened. Gradually this protection against the cruel reality begins to wear off and we are overtaken by the pain of grief.

Our preoccupation with thoughts of our child can make us fear that we are going mad. Sometimes we engage in restless overactivity and suffer from exhaustion. Sleep and appetite routines are disturbed. We may feel helpless, anxious, depressed, confused, angry, out of control or in despair. The ordinary activities of life have little meaning for us. We may find ourselves unable to concentrate on anything. These are natural responses and quite normal. Every bereaved parent goes through some or even all of these at different times. Certain feelings may be more troubling than others.

#### The pain of grief

In the words of Colin Murray Parkes, a British psychiatrist and author on bereavement: "Grief is the price we pay for love." This quotation may be appropriate when we face the loss of an elderly relative or friend, but it brings little comfort when our child has died. The death of a child goes against the natural order. Not only the present, but the future shifts and alters in myriad ways, particularly if this loss has left us childless. It is not surprising that the devastating reality hits us over and over again. If we have surviving children, we may also grieve deeply for the loss they have suffered.

Individuals grieve differently; there is no timetable for grief. Initially, survival might seem impossible or perhaps even undesirable. Grief is not orderly or progressive. It pours in with great turmoil, and is

unpredictable in its timing and intensity. It comes in waves and often feels overwhelming. Gradually the interval between the waves extends, and the initial rawness of our grief begins to abate. In time, we will adjust to the thought of life without our child. However, even when we have reached a plateau of relative acceptance of this "new normal", we may be surprised – even many years down the line – to be suddenly overwhelmed by sorrow once again. This is all natural.

Facing the pain of grief takes courage. We need to talk about our child's life and the circumstances of their death. There are good memories to be shared, although at first the pain of their passing, along with the devastation of unfulfilled dreams and shattered hopes, dominate our thoughts. We need to find ways of expressing emotions and coping with them. This may seem easier said than done; grief can often feel unmanageable. Allowing ourselves – and others – to cry can be better than bottling up our feelings. None of us expects that our child will die before us. The worst thing that any parent can imagine has happened, and grief is our right as well as our burden. Some of us need solitude and will want to process our grief alone, yet we may also find that talking freely to a sympathetic friend or another trusted person can bring comfort and reassurance.

We may find ourselves turning to telephone helplines, such as those operated by The Compassionate Friends (TCF), or other national or local bereavement services. Support groups, whether in person or virtual, can help us feel less alone, particularly when we are able to connect with other parents who have been bereaved in similar ways. The TCF online forum, support groups and private Facebook pages are safe places to express our feelings and listen to the experiences of others. (See back page for details.)

### Coping with the intensity of our feelings

We may be shocked by the intensity of our feelings in comparison with earlier bereavements, such as the loss of elderly relatives. In our worst moments, we may find ourselves depressed or even suicidal. We may want to seek professional counselling. Some of us may find we need medical support to help us cope, even temporarily.

Our priority now is our own survival. We should not feel obliged to measure up to somebody else's expectations. We are each unique. Even though it may seem that we are in similar circumstances, we each have to find our own way through.

The trauma of our child's death may create tensions within our marriage or relationship. We may feel too drained to support each other as we would wish. We all grieve in our own way and at our own pace, and we may not understand each other's pattern of grief. Our partner needs to their own space to grieve, just as we do.

Almost every parent feels a sense of guilt when their child dies, over things they have done or not done, said or not said to their child. We may feel that we should not be alive when our child is not. However far-fetched, we tend to blame ourselves over the cause of death – for example, allowing our child to have a car, go backpacking or swimming, and so on. Whether the death occurred suddenly or after a long illness, we torture ourselves with thoughts that we should have taken better care of our child, so that their suffering might have been reduced or death averted. No matter how irrational our reasoning, we are plagued by "what ifs".

So often we demand more of ourselves than we expect of others. We would not reproach others with the judgement we cast upon ourselves. Most parents try to do the best they can in a situation where there are no rehearsals or second chances. Later we may think that we should have done something differently, but that is with the benefit of hindsight.

Anger is another common feature of grief. We may feel angry over the circumstances of our child's death, or with the people involved, whether or not they were really to blame. We may resent relatives, friends or colleagues for the things they say, or omit to say. We sense that they are uncomfortable in our company. Perhaps they avoid mentioning our child's name "for fear of reminding us," or they expect us to function normally within a short time. We may blame God or bewail the unfairness of life, asking, "Why did this happen to my child?"

If our child contributed towards their early death, such as through reckless behaviour or self-harm, we may experience conflicting emotions. We might feel angry as well as upset when we consider the impact of their actions on the rest of the family. We may also feel guilty, wondering whether we did enough to keep them safe.

These feelings are natural. The reversal of our expectations is shattering.

#### Living with grief

We will experience intense sadness immediately after the death of our child. We find ourselves reliving those days, constantly replaying the events in our minds. For a long time, our child is always in the forefront of our thoughts. There are reminders in all we see, hear and touch. We might think that we hear our child's voice or see their familiar figure in the street. We still sometimes expect them to walk through the door; when the phone rings, we think it might be them. Then comes the yearning and the realisation of what "never again" means in our mourning.

Some of us feel a suffocating weight in the chest, or a grey fog, an absence of colour in everyday things. We are lethargic or agitated, or swinging from one state to the other, losing interest in everyday tasks and finding it almost impossible to complete them. We may weep constantly, or be unable to cry. We seek refuge or oblivion in sleep, only to lie awake hour after hour. Our rest might sometimes be disturbed by vivid dreams about our child and we wake up unrefreshed. All of these experiences are normal responses to the loss of our precious child.

Yet, slowly, almost imperceptibly, changes begin to take place.

There are brief moments of enjoyment, even if these are followed by guilt. We should not feel disloyal to our child when we begin to laugh again. Living with grief involves discovering how to handle and channel our constantly changing emotions into activities which release the tension they create. Some of us may find we need outside help, such as professional counselling, if our grief remains very intense as time goes by. If this is the case, we may wish to seek advice from our GP.

#### Helping ourselves

What can we do to help ourselves and live with the "new normal" of grief?

Many of us benefit from a mixture of both new and familiar activities. Trying something new demands a level of concentration that can divert us momentarily from the intensity of our grief. Meanwhile, more familiar activities can bring a comforting sense of continuity.

Physical activities are often beneficial. This could be walking, swimming, cycling, dancing, gardening or sports. Keeping active not only boosts our general health and well-being, but also helps tire us out, so that we can perhaps get a better night's sleep. Being outside in green spaces is restorative. Yoga, t'ai chi, aromatherapy, massage and reflexology are relaxing and nurturing. Meditation and mindfulness can help bring calm.

Taking up a creative activity can not only occupy the mind and provide a challenge, but it can also bring us a sense of achievement and even joy. Painting, sewing, crafts, cooking or DIY jobs can be absorbing and give us a much-needed break from our grief. Reading or doing crosswords or other puzzles can also be distracting. Joining classes or study groups – in person or online – can provide the diversion of a new challenge and the opportunity to meet new people.

Watching television, or going to the theatre or cinema, can provide temporary distraction from our feelings. It can be a good idea to check the subject matter beforehand to avoid anything that could distress us more, although we can still be caught unawares.

Music has a unique power to bring emotion to the surface. We can listen to music at home or attend concerts. If we play an instrument or sing in a choir, we can connect with others in the making and

appreciation of music. Dancing, in its many forms, combines exercise and the enjoyment of music.

Writing can be an excellent outlet for our emotions, even if we never show anyone the results, or tear up the pages afterwards. Keeping a diary or journaling can later provide us with a yardstick of our journey through a time of despair to one of relative calm. Some of us start blogs. We might like to write poems and articles for Compassion, the quarterly journal published by TCF.

Some of us draw comfort and strength from our faith, whether alone or in community. While our religious faith may help sustain us, some of us may find ourselves questioning long-held beliefs. We may discover different elements of our faith or even a new faith entirely, or work out our own philosophy.

If we are employed, we may be able to take extended leave, or alternatively, circumstances may require us to return to work quite soon. When we are consumed with grief it can be difficult to manage our professional responsibilities and interactions with our colleagues, who may not always know how to respond to us. On the other hand, some find going back to work helpful, as it opens up social contact and adds structure and purpose to our days.

If we are not employed, we might want to consider finding parttime or voluntary work. This can help bring a new sense of purpose. Similarly, campaigning or fund-raising for charity – perhaps for a cause connected with our child's life or the cause of their death – can help us to find a new sense of meaning.

The stress of our child's death can leave us vulnerable to infection and illness. We may find that our health deteriorates or that new health problems occur. To counteract this, we will need to pay attention to our diet, and the need for rest and exercise, as well as avoiding negative coping techniques such as over-drinking or overeating. We should not hesitate to seek medical advice if we need it.

#### Our child, remembered with love

Many of us fear that we will forget the small details of our child's life. We may wish to make a book or digital record, using photos, schoolwork, drawings, letters and family memories. This could also be a good opportunity for grief to be shared with any surviving children or other family members. A memory box can serve a similar purpose and may be more suitable for a baby or small child, for whom there are fewer physical reminders. This could contain photos, toys, small garments, a lock of hair, a hospital name-band or a toddler's first drawing. Some of us have a cushion made from our child's clothes, or have their ashes made into a piece of jewellery.

We will need to prepare ourselves and find meaningful ways to commemorate key dates like our child's birthday and the anniversary of their death. Some of us mark these dates with a new tradition, such as visiting a place our child loved. There is no reason why we cannot bring a birthday card or small memento to their grave or another special place.

Christmas and other religious celebrations, Mother's and Father's Days, and even our own birthday can be very painful times – particularly if we have no surviving children. Some of us try our best to ignore these special dates; others find new and creative ways to get through these most painful times. It may be helpful to plan ahead. We may also want to talk with other family members and friends so they can understand our needs. We may not feel like joining in the family's traditional celebrations or we might wish to start our own new traditions that reflect the changes in our lives.

# Surviving children, other family members and friends

The death of our child changes us and in doing so, it changes our relationships and how we interact with others. In the early days of our bereavement, we might find chance meetings difficult. We may not be ready to explain what has happened and deal with the reactions of those we tell. We could try changing our routines for a

while, so that we are less likely to encounter people who know us – shopping at a supermarket further away from home, or attending different classes or clubs, for example. We should not feel obliged to attend social occasions, such as parties at work or family gatherings, where the conversation often revolves around children. Even strangers may casually ask us how many children we have. For us, this is a question without an easy answer.

Members of our family, including our child's grandparents or even our spouse, may show their grief in different ways to ourselves. For instance, they might seem more accepting of our child's death, whereas we may focus our time and effort in keeping the memories of our child alive. These differences can lead to misunderstandings and tension. It can help to realise that there is no wrong or right way to grieve. We each must find our own ways to live with this devastating loss.

Friends generally rally round at first. However, as time passes, they may not be able to continue their support; they may feel it is time we "got over it." We have to take care of ourselves. We will never be the same again; some friends will be lost to us, but new ones will also be made. It is here that TCF serves its unique purpose – to provide a safe place for bereaved parents to talk about their child's life and death without feeling pressured to "move on."

Surviving children will be coping with their own grief and will need our support, which may not be easy for us to give. We may become fearful about their wellbeing and will need to avoid being overprotective. Children need support, time and space to grieve, just as adults do. Their grief may manifest in different ways, depending on their ages, levels of maturity and personalities. (There is more advice on this in the TCF leaflet, *Our Surviving Children*.)

#### **Going forward**

When we first lose our child, we count the time in hours and days. Then there are weeks, months and years. As time passes, we observe their siblings and friends moving on. Children who were at school with our child grow up; if they went to university or had a job, their friends will start progressing in their careers. Perhaps most difficult of all, our child's partner may find someone else. It is hard not to feel resentful, to imagine "what might have been", to compare our child's shortened life with the lives of their peers. Our child is frozen in time; there are no new photographs, no new stories to tell. There is no easy resolution to the pain of our loss, but the raw agony of the early months and years will eventually dissipate.

Adjustment means the gradual integration of our child's absence into our lives. We will always love and remember our child, and in time, the memories and photographs that so upset us in the early days will hopefully become a comfort, making us smile as well as weep.

Our lives will never be the same after the death of our beloved child. It will take many months, and even years, to weave the experience into the fabric of our lives so that we find our "new normal". We will have changed, our lives will have changed, and we may now find that we have a different perspective on what we feel is important to ourselves and our families. We will learn to live again, but the ache of loss will never be quite forgotten. We will treasure our child's memory for as long as we have breath.

#### **Further Reading**

The Compassionate Friends (TCF) have published a range of leaflets to support parents who have experienced the death of their child. The following titles could be helpful at this time:

- Grief of the Newly Bereaved
- Remembering our Child (Leaflet and Handbook)
- Coping with Special Occasions
- Our Surviving Children
- Childless Parents
- Back to Work
- The Bereaved Parent and their Faith
- Grieving Couples
- Grieving Child Loss in Blended and Step Families
- A Mother's Grief
- A Father's Grief

TCF leaflets can be read and downloaded at this link:

#### tcf.org.uk/leaflets

Printed copies are available from the office, free of charge for bereaved parents (see contact details on the back page).



## Call our National Helpline **0345 123 2304**

The helpline is open from 10am - 4pm and 7pm - 11pm every day. Calls are always answered by a parent whose child has died.

#### Email our National Helpline

#### helpline@tcf.org.uk

For more information and support visit **tcf.org.uk** 

Find us on social media

ff @tcf.org.uk

**☑** @TCFcharityUK

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General enquiries TCF library

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In memory of Sarah, much loved daughter and big sister, lived on this earth for 27 years, now living eternally in heaven. Until we meet again, we will love and miss you always.