

# Understanding your grief

This information sheet provides guidance about what you can expect when grieving following the death of your child.

Grief is our response to loss. It is the natural response to loss and it can affect every part of our life including our thoughts, behaviours, beliefs, feelings, physical health and our relationship with others.

Grief is also a very personal experience. Your grief is a reflection of your unique relationship with your child and your individual ability to adjust to your loss. So although you may have had the experience of previous grief and loss in your life, this grief for your child may feel very different.

## Grieving before a death

You may have been experiencing grief in the months, weeks and days leading up to your child's death as their condition changes and as you become aware that they may or will die soon. This collection of feelings is called "anticipatory grief". This is as real and as exhausting as the grief following a death can be. Anticipatory grief can also include feelings of anxiety and worry.

## Common grief responses

Even when a death is expected, it may still seem sudden. Although you may have felt prepared and said goodbye, nothing prepares you for the reality of the moment.

Following the death of your child, you may experience intense feelings such as sadness, anger, anxiety, disbelief, panic, relief, guilt, irritability or numbness, you may initially also feel a sense of relief that the uncertainty of what will happen has ended. Grief can affect your thinking and your concentration; it can feel like this intensity of grief will continue forever and it can be overwhelming. Sometimes grief will also cause sleeping and physical symptoms such as body aches, tightness in the chest and headaches. If the symptoms persist, please see your GP to exclude other causes.

Your grief is unique to you, and as long as you are not causing harm to yourself or those around you, there is no 'right' or 'wrong' way to grieve.

Parents/carers often share with us how differently they grieve from their partner, one may be more comfortable talking about their grief while the other may seek comfort in distraction and keeping busy.

We do not always know how people are grieving simply by what we can see. Some people are open and expressive with their feelings of

grief, whilst others are more private, reluctant to share and prefer to keep busy. Other factors such as your previous experience with grief, culture, gender and belief systems can influence the way you grieve. As grief is so individual, it is important to respect other people's way of grieving even if we don't necessarily understand it.

You may find yourself focusing on the 'why's' and the 'what ifs' - there may be things that will never make sense to you and even if you get answers, they may not make things right or fair.

Grief does not come in neat stages, in fact, there is not much about grief that's neat at all. It can come in waves, sometimes making you feel like you are drowning in emotions. These strong feelings will change over time and it is often helpful to talk to a trusted family member or friend. You may also find it helpful to talk to a bereavement counsellor, social worker or psychologist.

## Life grows around grief

It is a common myth that people 'get over' grief or 'move on'. The reality is that you will always grieve the loss of your child. With time, the pain will reduce in its intensity, but the sorrow you feel will always be a part of you. When you grieve you are coming to terms with what has changed in your life, and the death of a child is a significant and distressing change. There is no 'return to normal', rather you have to learn to adjust to a new kind of normal - re-learning the world and re-learning ourselves within it.

Grief can be triggered at any time and it's not unusual for the grief following the death of a child to feel overwhelming for an extended period of time. It is okay to admit that you are struggling with your grief, whether it be for months, years or decades after the death.

## Special days

Events and significant dates throughout the year can be challenging for people who are grieving, with some people finding the thought of Christmas or a birthday celebration without their child very difficult. However many parents/carers also report that it can be every day that is hard. The anxiety leading up to these special days can sometimes be worse than the actual day itself.

## Other people

Some family and friends, and even acquaintances will be of fantastic assistance following the death of your child and be there to offer you emotional support. Other people, even those you are normally closest to, may find it difficult to know what to say or say things that surprise you or make you annoyed. They may feel that they have to cheer you up or offer some words of comfort.

The death of a child can be a challenge for the community. Because it does not happen very often, family and friends may not have the knowledge or skills to provide support to grieving parents/carers in a way that is needed or wanted. Sometimes it can be helpful to be direct and let people know what you need and what you find helpful or unhelpful.

## Looking after yourself

When grieving, or supporting someone who is grieving, it can be all too easy to neglect your own needs. Taking time to look after yourself can make a big difference in your ability to function on a day-to-day basis, especially in the longer term.

Some suggestions that other people have found helpful:

- Rest when possible
- If eating is difficult in the early days, have small, frequent and easily digestible meals
- Limit the use of alcohol, sedatives, and other mood-altering drugs unless at the suggestion of your GP
- A little gentle exercise, like a walk, each day can help
- Share stories, thoughts, and feelings about your child with family and friends as this can strengthen your connection with loved ones
- Use rituals and customs that are meaningful to you - light a candle, listen to special music, continue to celebrate birthdays if you wish

- Draw on your spiritual or religious beliefs if this is helpful for you
- Take time out to do things you would normally enjoy and things that could be relaxing and soothing.
- Try to delay making major decisions that cannot be reversed (such as moving house) for about 6-12 months
- Keep a diary or a journal. Some people even find it helpful to write regular letters to their child who has died
- Sharing your feelings with other people can reduce the sense of isolation and loneliness that comes with grief
- Allow people to help you; don't be embarrassed to accept their help.

## When to seek further help

Some parents/carers are supported in their grief by family, friends and the community. You may find it difficult as time goes on to be open about ongoing feelings of distress and chronic sorrow. For others, family and friends may also continue to feel distressed or have difficulty talking about their emotions and you may feel you do not want to burden them with your own feelings of grief.

If you are finding it difficult to manage on a day-to-day basis, it may be helpful to see a counsellor or health professional. It is okay to admit that you are struggling with your grief, no one will think any less of you if you ask for help along the way.

You can access bereavement support or referrals to local bereavement services from your Care Team involved with your child's care. Alternatively, your GP can make a referral to a counsellor or psychologist.

