



GRIEF FOR THE LOSS OF YOUR HEART CHILD **For families with children**

When we lose someone we deeply love a reaction occurs which is both painful and disturbing. These experiences of loss and sorrow we call grief. When and how we grieve is different for each of us.

We may be tempted to try having a stiff upper lip. This may not be the best way to deal with the pain of grief. We cannot avoid deeply experienced suffering, and grieving is the way to express these feelings.

Grief can show itself in many aspects of your life.

One of these aspects might be the social side of your life. All those with whom you come into contact will be altered by your grief. Your family, friends and neighbours may feel awkward, embarrassed or inadequate. To reduce their discomfort they may try to avoid you or make sure the contact is as brief as possible. In trying to comfort you they may say things you find very hurtful and unhelpful. You may find it hard to get on with people as your sadness overshadows all relationships. You may feel isolated and alone and believe that no-one understands how you feel. At such times try calling the Child Death Helpline, 0800 282986. The line is open Monday, Wednesday and Friday 10-1pm, and every evening from 7 – 10pm. Bereaved parents staff the line, and they welcome calls from anyone touched by the death of a child, whatever the relationship.

Another aspect might be its physical effects. The need and yearning to touch and hold the child you have lost can be very great. You may feel you are falling apart with no interest in anything or anybody. You may find you have nightmares or are unable to sleep. You may find your need for physical contact and sex is altered. Sweaty palms, headaches and stomach pains are all common to the bereaved.

Grief can also affect you psychologically. You may have feelings of fear, frustration and anger, or feel guilty and continuously blame yourself or other people. Many people can't stop thinking about the events that led up to the death while trying to see how they could have altered the outcome. You may have feelings of 'if only' – if only I had done this, or had not done that.

You may want to keep visiting the hospital where your child died, because you feel close to them there, or some other place of significance.

Information sheet



Grief makes it difficult to think clearly and it's not wise to make major decisions such as changing job or moving house until later.

Grief will affect all members of the family and while it is quite natural to try to protect one's children from the death of a brother or sister they will miss them and need help to grieve their loss. They will notice the distress of their parents and will be affected by the change of routine in the household. You may find it hard to understand their reactions. They may seem very matter-of-fact or even unconcerned. Often they will be difficult and naughty. Don't feel you need to hide your grief from your children. Sharing your distress with them may make it easier for them to express their sorrow. Listen to what your children try to tell you. They often express their feelings in the games they play, or in what they write or draw, rather than in words. Tell them as clearly as you can what you know to have happened and try not to tell them things you do not believe yourself. Tell them their brother or sister has died, and not 'gone away' or 'gone to sleep' because these explanations can confuse and frighten. Children know much more than adults realise and their imagination can be more frightening to them than the reality. If children wish to see the child who has died at the hospital or in the coffin this might help them and should not necessarily be discouraged.

Children often may feel guilty or responsible for what has happened and need reassurance that they are not responsible and that they, or you, will not disappear in a similar way. They need more reassurance and love than usual at this time. This also helps to convince them that they are as important and as loved as the child who has died. If you feel you are unable to cope with them then ask someone close and special to them to help and to be with them at the funeral. Do not forget to inform the school and other groups to which they belong what has happened in case they choose to show their reaction there rather than at home. You may well have moments of depression and overwhelming sadness, but working through your feelings and the passing of time will help you to remember the happy times with your child. Anniversaries, birthdays or some special reminder of your child will probably cause these feelings to reoccur for a little while. The process of recovery is much longer than most people expect, but eventually there will be a time when you can look forward again. In the meantime none of the experiences described is unusual.

You may feel you are going mad but you are not. The support of the family, friends, local support groups, your GP or helplines can be invaluable. Never be afraid to contact someone to talk about how you are feeling, it may help.

Caring for children with heart conditions

Information sheet



Further sources of information for this information sheet can be obtained at:

SANDS Stillbirth and neonatal death charity. www.sands.org.uk
Tel: 0808 164 3332 Email: helpline@uk-sands.org

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