

# family support



Stacey Sangster

## I've just found out my child has liver disease . . .

**Stacey Sangster, family support officer, on understanding loss and some issues to consider.**

As adults at some point in our lives we will all experience loss; this is a normal part of living. For parents who find out that their child has a serious illness, a sense of loss can be felt from the time of diagnosis — sometimes even before if it takes a while to get a diagnosis. It's a loss of a normal life for you, your family and your child and all the hopes for the future, many of which are unspoken but taken for granted by us all.

Grief is a normal and natural reaction to any type of loss. It can be helpful to understand grief as part of the human experience, just as much as giving love and being loved. Understanding what happens in loss may help you to recognise some of the feelings and emotions you may experience.

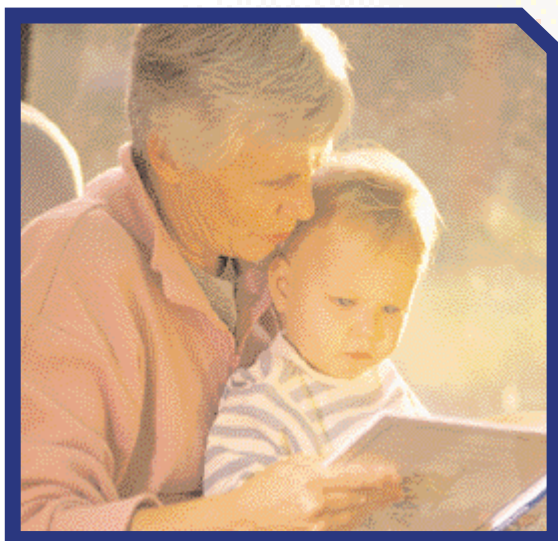
From our experience at the Children's Liver Disease Foundation we know that everyone reacts to loss differently and no way is right or wrong. A couple in a relationship sometimes have quite different styles of reacting and dealing with loss. Not surprisingly, this may cause friction, particularly if one half of the relationship is dealing with things by keeping it inside and working it through by themselves. To the other they may seem as though they're bottling it up or even uncaring. It is a stereotype of course that women like to talk about things where men may not feel the need; however, as with many stereotypes, this can be based in truth.

I thought it would be useful to describe a popular theory used by many professionals to understand grief, the Kubler-Ross theory. This describes five stages of grief, which are as follows:

- **Denial** (and numbness or shock) 'it doesn't seem real'
- **Anger** (as a result of feeling powerless) 'why has this happened to us'
- **Bargaining** (thinking about things that could have been done to prevent the loss) 'maybe we weren't meant to have children'
- **Depression** (The most well-known stage of loss. In this stage there is a realisation of the loss and true grief.) 'the world seems very bleak at the moment'
- **Acceptance** will come eventually and a feeling of being at some peace with the world.

Moving through the stages is different for each person; some people can find that they spend months or even years stuck in one stage. Someone stuck in a stage may need help to move on. Friends and family may help but so too can a trained counsellor who is away from it all. Parents may feel that they go through stages only to find themselves going back again. This can occur because of all kinds of triggers. Some of you will be aware of how upsetting it can be to establish some sense of normality, everything going well, only to have a setback. Some people will not experience all the stages and not in the same sequence, they may skip a few.

Another feeling it is important to mention here is one that can be all-pervading: that is guilt. Guilt can be related to a feeling that you have in some way failed in your role as a parent or you may have negative thoughts about the person with the disease which you then feel guilty about.



# *In loving* memory

## **Zainab Umar**

10 February 2004 – 24 August 2005

## **Noor-UI-Hasan Shakeel**

27 March 2004 – 23 August 2005

## **Josh Mulvenna**

24 June 1999 – 29 August 2005

## **Lucas Roaden**

6 July 2005 – 5 September 2005

## **Ellie May Stevens**

20 September 2003 – 12 September 2005



There are some ways to help as you progress through the stages — particularly at the time of diagnosis. Here are some ideas:

### **Ask for help/support**

People do not always know how best to help and so they wait to be asked. Support could be from friends, relatives, religious groups, and the CLDF support team. You do not need to be alone.

### **Be gracious and accept offers of help**

Sometimes you can let your guard down. If people ask what can they do, why not ask for practical help — a casserole for the freezer, mowing the lawn, running a vacuum cleaner around the house.

### **Take care of your health**

Try to eat well and get plenty of rest. Using drugs or alcohol as a way of numbing the pain is not a good idea.

### **Acknowledge and accept your own feelings bad or good.**

Try to accept that the feelings of those around you — your partner, children, your parents — will not be the same as yours.

Take time for yourself and to do something that you like to do.

This could be something as simple as having a long bath with your favourite magazine.

### **Don't take on too many other big decisions**

For example, moving house or changing jobs, these alone can be very stressful events.

As always, CLDF would like to hear your comments on the above and perhaps any tips for other parents on how you have learned to cope.

**Stacey and Ellen would also like to hear if you have any suggestions for future support-focused delivery articles. Please contact them on 0121 212 6023 or e-mail [fso@childliverdisease.org](mailto:fso@childliverdisease.org)**