Helping parents cope with the loss of a child

JENNY HYNSON MB BS, FRACP, PhD

Much can be done to support bereaved parents. Grief is a normal response to loss, not an illness. Each person grieves in their own way and in their own time as the loss is integrated into the ongoing fabric of their lives, and the relationship with the child is renegotiated.

MedicineToday 2013; 14(8): 60-62

Death ends a life but not a relationship. Robert Anderson[1]

The death of a child is a devastating loss, particularly in a developed country where most childhood illness can be prevented or cured. As a community we rarely experience the death of a child, which makes it all the more difficult when we do. The grief experienced by bereaved parents is more likely to be severe, prolonged and complicated than the grief experienced by any other group.[2] Parents talk of losing the future when their child dies.

It can be hard to know how to support a person faced with such loss, yet there is much that GPs can do.

LOSS AFTER A LONG ILLNESS

When the child has suffered a long illness, parents are likely to have begun to grieve in anticipation of loss. This is important because there are potentially modifiable experiences that occur during the illness that affect parental grief. These include the degree to which the child is perceived to have suffered, communication between parents and health professionals and the level of psychosocial support provided in the months preceding death.[3] These are all factors that can be addressed through the provision of effective palliative care during the child's life.

For parents who have experienced a long or traumatic illness with their child, death may come as a relief. This is not a feeling they may readily admit to and it is certainly something that friends and relatives may struggle to understand. Gently exploring whether parents are experiencing these feelings and normalising them can be extremely reassuring. Feelings of relief generally coexist with or are soon replaced by intense grief.

A SUDDEN LOSS

The sudden death of a child may be experienced differently from a loss after a long illness. Shock and disbelief can mean that it may be some time before the parents are able to deal emotionally with the loss. There may also be a traumatic element to sudden death.

Whether death is sudden or expected, parents often experience feelings of guilt over acts or omissions they believe (rationally or irrationally) may have changed the outcome.

THE GRIEVING PROCESS

The death of a child is not something parents 'get over'. Instead, the loss is integrated into the ongoing fabric of their lives, and the relationship with the child

Dr Hynson is Medical Director of the Victorian Paediatric Palliative Care Program at the Royal Children's Hospital, Melbourne, Vic.

is renegotiated.[4] It is not abnormal for parents to maintain some sort of 'continuing bond' with their child.[5] When a child dies, parents can feel overwhelmed by feelings of anger, sadness, guilt, hopelessness, frustration and fear for their remaining children.

The range of so-called normal or uncomplicated grief reactions is broad. Some parents experience and openly express intense anguish. For others, adaptation requires avoidance and suppression of emotion, and this can be hard for others to understand. Each person grieves in their own way and in their own time and it is important not to be quick to judge expressions of grief as abnormal.

Progress through phases of grief is not straightforward or unidirectional. The intensity of grief can vary over time and many parents report an increase in the third year following bereavement.[6] Even when parents have resumed many of their normal daily activities, a chance reminder of the child who died (e.g. a tune the child sang, a favourite toy) may plunge them back into sadness again. The parent may be unconscious of the actual trigger at first and may find the sudden emotion startling. Parents may also be reminded of what they have lost as they watch others move through life's milestones (e.g. starting school, birthdays, weddings). They describe grieving anew at these times.

Although fathers and mothers experience grief differently, it is a misconception that the incidence of separation or divorce is increased among bereaved couples.[7] Reassuring couples about this is important, as it is a popular myth.

Bereaved parents often face the additional challenge of helping their other children cope with the loss of their sibling. They must explain the child's death, provide reassurance about the wellbeing of other family members, support the siblings through their own grief and try to provide a stable environment, all at a time when they are feeling depleted and distressed.

Most bereaved parents turn to family, friends and their local community for support and will not necessarily need the input of health professionals. Some may even experience considerable personal growth. They find strength they did not know they had, learn what is truly important in life or go on to support other parents or pursue a career in a related field. Others will struggle. Risk factors for complicated grief include multiple losses, pre-existing mental health issues, a pessimistic outlook on life, social isolation and ambivalent feelings toward the child.[8]

Grief is a normal response to loss. It is not an illness. Medication will not resolve or cure it. Medications have a very limited role in the management of uncomplicated grief. Antidepressants are inappropriate unless clinical depression is truly present. Support is usually more appropriate and may be provided formally or informally through counselling, support groups or the provision of literature.

HOW YOU CAN HELP

GPs and paediatricians are often of great significance in a family's life. They care for families during the intense highs and lows of serious illness and may even be present at the time the child dies.

Many (but not all) families will want ongoing contact with people they feel truly understand what they have experienced. A follow-up appointment with the child's paediatrician should always be offered to discuss the child's illness and treatment, the results of any outstanding investigations including postmortem examinations and how the family is coping. This is an opportunity to address ongoing concerns, normalise feelings associated with grief, provide advice on how to support siblings and offer information on potential sources of support for the family should they require it (see the box on this page).

Parents almost universally find these meetings helpful, although some may need encouragement to return to the hospital.

SUPPORTING BEREAVED PARENTS

GPs and paediatricians can provide support to bereaved parents by:

- maintaining contact if that is the family's wish
- listening sympathetically and nonjudgementally
- acknowledging and normalising the emotions they are experiencing
- dispelling myths
- recognising when additional support may be needed
- referring to appropriate supports where necessary

Clinicians who write to families and then follow up with a telephone call appear to have greater success in achieving a meeting with families. Some paediatricians may feel they are intruding on a family by telephoning, but most parents will appreciate this gesture of ongoing support.

Many bereaved parents report that the loss is felt more acutely six weeks to three months after the death, after the time of the funeral. Many of the practical tasks required up to that point will have been completed, and family and friends have returned to their own lives, leaving the bereaved parents feeling abandoned. By this time, family members and friends often give implicit and explicit messages to the parents to 'move on'. Family members and friends can feel lost when confronted with a grieving person and can begin to avoid them physically or emotionally. The GP or paediatrician can offer a safe place for parents to express powerful emotions.

WHEN TO SEEK ADDITIONAL HELP

GPs and paediatricians should refer parents for additional help if, after several months, the person's day-to-day functioning is impaired by:

- intrusive thoughts about the child

- preoccupation with the loss
- loss of interest in usual activities, social withdrawal
- loss of a sense of purpose in life
- disturbed sleep
- an inability to acknowledge the loss and avoidance of reminders of the child.

Earlier intervention is required where there is excessive drug use or evidence of depression, anxiety or suicidality.

WHERE TO SEEK HELP

Most states have a paediatric palliative care service based in their tertiary paediatric centre. These services have knowledge of, and links to, local sources of bereavement support and can be a useful point of initial contact. In addition, the following national organisations may be helpful:

- Australian Centre for Grief and Bereavement (phone: 03 9265 2100; freecall: 1800 642 066; http://www.grief.org.au)
- National Association for Loss and Grief (NSW) Inc (NALAG; http://www.nalag.org.au).

Some parents may need formal psychological or psychiatric intervention.

CONCLUSION

There is no short cut to the resolution of grief. Most of us experience feelings of helplessness in the face of such intense emotional pain and need to be reminded that it is of therapeutic value to provide a safe place for bereaved people to express thoughts and feelings without fear of judgement. It is also crucial that those who need it are referred to an appropriate source of additional support. MT

REFERENCES

1. Anderson R. Notes of a survivor. In: Troup SB, Greene WA, eds. The patient, death and the family. New York: Scribner; 1974.
2. Middleton W, Raphael B, Burnett P, Martinek N. A longitudinal study comparing bereavement phenomena in recently bereaved spouses, adult children and parents. Aust N Z J Psychiatry 1998; 32: 235-241.
3. Kreicbergs U, Valdimarsdottir U, Onelov E, Bjork O, Steineck G, Henter J. Care-related distress: a nationwide study of parents who lost their child to cancer. J Clin Oncol 2005; 23: 9162-9171.
4. Rothaupt JW, Becker K. A literature review of western bereavement theory: from decathecting to continuing bonds. Family J 2007; 15: 6-15.
5. Klass D, Silverman P, Nickman S, eds. Continuing bonds: new understandings of grief. Washington DC: Taylor & Francis; 1996.
6. Rando TA. An investigation of grief and adaptation in parents whose children have died from cancer. J Pediatr Psychol 1983; 8: 3-20.
7. Eilegard A, Kreicbergs U. Risk of parental dissolution of partnership following the loss of a child to cancer: a population-based long-term follow-up. Arch Pediatr Adolesc Med 2010; 164: 100-101.
8. Tomarken A, Holland J, Schachter S, et al. Factors of complicated grief pre-death in caregivers of cancer patients. Psychooncology 2008; 17: 105-111.

COMPETING INTERESTS: None.