

# 27 Managing Grief, Loss and Bereavement

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## KEY CONCEPTS

- CAMHS clinicians need to be aware of how an unresolved experience of loss can present in different ways and may include physical, psychological and behavioural symptoms.
- Certain states of mind form part of the experience of grief. They do not follow a neat consecutive path but may return repeatedly.
- Helping individuals feel contained enough to safely explore their loss through verbal or non-verbal means requires a consistent and reliable setting, but not necessarily a clinic base, if the setting can be protected from intrusion.
- The loss of a child is not a normal experience and places those affected under the most extraordinary emotional and psychological distress. Grief reactions in bereaved parents are often more extreme and may include suicidal thoughts and feelings.

## Theoretical Underpinnings

We are living in a time where our knowledge of the experience of loss and how it affects us psychologically is increasingly sophisticated. The Western understanding of grief is that successful mourning implies that the bereaved must disengage from the deceased. Persisting in an attachment to the dead person can be perceived as denying the reality of the loss.

Freud believed the purpose of mourning was to relinquish and adjust to the reality of the loss. John Bowlby wrote about how understanding grief is intrinsically linked to what happens when attachments are broken and that the strong emotional reactions that ensue (distress, anger and withdrawal) all have a place in the process of grieving.

Bereavement is the loss of someone significant to you.

- Bereavement is what happens.
- Grief is what one feels in relation to the bereavement.
- Mourning is what one does to express grief.
- To be deprived of someone of value implies attachment. The level of attachment will determine the degree of loss experienced, that leads to grief.

Colin Murray-Parks developed the idea that grief consists of a predictable set of behaviours to be gone through in phases before the final acceptance of the loss. Dorothy Judd (1995)

and Darien Leader (2009) have helped deepen our understanding of grief reactions and the importance of helping the bereaved to mourn their loss. Leader suggested that clinical depression and low mood may result unless this ‘work of mourning’ is carried out adequately. Thanks to the work of Judd (1995) we know more about the workings of the mind of a child facing their own death and how best those around them can support both the individual child and the family.

### The Four Phases of Grief

- **Denial:** shock, disbelief, sense of unreality
- **Pain/distress:** hurt, anger, guilt, worthlessness, searching
- **Realisation:** apathy, fantasy
- **Adjustment:** readiness to engage in new activities and relationships

The experience of loss is a normal part of the human experience. The grief we feel because of the loss is expressed in many different ways by adults and by children. Services, such as CAMHS, become involved in the process when mourning a loss has, in some way, become unhelpfully altered or suspended. In the day-to-day work of CAMHS, clinicians are often faced with a range of symptoms that, once explored, can be seen as linked to the experience of loss. These symptoms may present, often much later, as sleeplessness, angry outbursts, headaches and various anxiety states. The CAMHS clinician needs to be alert in the initial assessment to the losses that the individual may have experienced, but which have been overlooked or unavailable to attend to until now.

We encounter many forms of loss during our work, for instance, the loss parents feel during pregnancy when they are told that their unborn child may have a disability. The process of mourning the healthy longed-for child must be adjusted to, both psychologically and emotionally. Children may have suffered birth trauma that limited their abilities and their parents will need to make huge adjustments, emotionally and in addition, practically, in caring for a child with special needs. Siblings may be living with knowing that their sister or brother may not live on with them. All these scenarios can be encountered daily in the work of a CAMHS clinician. Although some referrals may arrive as clearly needing bereavement work, sometimes it may only emerge after a while that it is the experience of loss that is at the root of the difficulties.

Our views of grief and bereavement have changed over time. The cultural practices ascribed to them range from Queen Victoria remaining in black after the loss of her beloved husband to the introduction of jazz bands and colour at funerals. Dora Black (1978) writes ‘the combination of a heavy death toll by the end of World War 2 and medical treatment breakthroughs led to a taboo on talking about death, for doctors consider death a failure’.

More recently there has been renewed interest in the processes surrounding loss and bereavement and fortunately, bereavement counselling is far more available. Psychologically, death which occurs naturally in old age, at its right time and place, however painful, is different from the death of a child or the unexpected death of a parent that shocks us to the core and tests all of our emotional and psychological resilience.

Through the work of people such as Colin Murray-Parks, we began to think about a recognised emotional process connected with loss and bereavement. There are five or six main identified reactions:

- **Numbness** at the news of the death, denial that it has happened.
- **Regression.** Earlier patterns of behaviour are often brought to the fore in relation to the loss. Returning to an earlier stage of development is quite common in children experiencing loss.

- **Depression.** It is appropriate to have depressed feelings. However, as Donald Winnicott says, 'depression at the normal end is a common, almost universal, phenomenon and relates to mourning'. The CAMHS clinician needs to be able to distinguish between what we would term a 'normal' experience of depression and clinical depression that requires psychiatric treatment.
- **Bargaining.** Kubler-Ross (2008) interprets this stage as an attempt to postpone the death. Superstition and ritualised or obsessional behaviour can often occur in this theological state.
- **Acceptance.** With some acceptance of death, it may be possible to maximise the remaining time before death, and following death, the person who has died can be remembered, commemorated and treasured in both concrete and emotional ways.

These outline the major states of mind that individuals travel through when coming to terms with loss and bereavement. Whereas previously we thought these followed a rather neat consecutive path, it has become evident latterly that different states of mind such as these are visited and re-visited in the process of coming to terms with loss.

Far more is now known about how differently children think about death and loss depending on their age group. Work by Brooklyn in 1959 and 1967 found that children between the ages of 5 and 8 years, and later between the ages of 13 and 16 years have a more emotional response to death. Children in the middle years of 9 to 12 years are generally more defended and less able to access the raw emotion that may be connected with loss. Brooklyn believes children know about death 'as the extinction of all life from early on, but then a range of defences are used psychologically in order to not be fully aware of its implications'. Likewise, Dorothy Judd (Judd, 1995) notes that children 'can both know and deny the existence of death'.

### Case Study (1): Jenny

Jenny (four) was referred into CAMHS by a pre-school nursery worker. She had missed several play sessions and her mother was concerned about her complaints of stomach aches. These had already been investigated physically. Jenny's mother thought they might have an emotional root. The clinic team met with the parents to gain a more comprehensive understanding of the family, including Jenny's early history. It emerged that Jenny's paternal grandmother, who had lived with the family during different times in Jenny's young life, had died suddenly nine months before.

The parents were invited to discuss their own experience of this bereavement, for instance, had the grandmother been talked about in the family since her death? Was she remembered through photographs? And so on. Jenny's father had been taking time off work with unexplained back problems. The parents had believed that Jenny was too young to be spoken to about this loss, but through discussion with the nursery staff, it emerged that Jenny had been playing a repetitive game in the dolls' house at the nursery, centred on people suddenly disappearing.

With the parents' permission, we invited the nursery worker to join the session to think about what Jenny might be expressing in her play and how it linked with the death of her grandmother. The nursery worker offered Jenny some individual play time. She then met with the team to discuss what she observed.

The parents began to mention grandmother's name at home and observe how Jenny reacted. The nursery worker offered Jenny six weekly sessions of play in the dolls' house. She then liaised with CAMHS to relay her observations and receive supervision. After several weeks, Jenny was attending play school regularly and no longer complaining of stomach pains. Talking with Jenny about the figures in the dolls' house disappearing and having permission from the parents to link this to the disappearance of her grandmother seemed to have brought about the relief for Jenny.

### Case Study (2): Stephen

Stephen (nine) was referred to CAMHS by his GP for increasingly aggressive outbursts at home and at school, an inability to concentrate and complaints of headaches. He was listless at home. Stephen was a keen footballer in a local team but had recently made excuses not to attend training sessions. His mother and the school staff were becoming increasingly worried.

Stephen's parents lived apart but were both invited to the first appointment. Stephen's mother, the main carer, gave CAMHS permission to have a discussion with the school to gain a fuller picture prior to the first appointment.

A full family history established that the relationship between Stephen's parents had broken down two years after the birth of Stephen's younger sister, who had been diagnosed with a rare genetic disorder. Over the years this had required intensive hospital visits and the parents were now faced with a decision about major surgery that could either enhance or endanger her life.

Stephen's father had left home when Stephen was four years old, but football remained a genuine shared father-son interest. His parents had tried to protect Stephen from the medical discussions about his sister, but a scarcity of childcare meant this was not always possible. He was thus acutely aware of the life and death issues around her and of the real possibility that she may not live much longer.

The nurse therapist who led these initial appointments thought that Stephen may have signs of ADHD, but firstly wanted to explore these other issues, i.e. the impact of the separation of his parents and the very significant knowledge and experience of living with a sibling with a life-limiting illness.

The team's child psychotherapist met with the family and then with Stephen on his own. Over four individual sessions, Stephen gradually began to relax and play with the cars and with a football game and then to talk about his life at home, the heavy worries he carried in relation to his sister and his concern about his mother's ability to cope. He expressed powerful angry feelings towards his father for having left him at home with so many difficult issues to deal with.

Through a little boy in his imaginative play, clearly recognisable as himself, Stephen was able to say, 'I just don't think I can do anything to help'. In addition, he showed through play that he believed his sister's illness could be infectious and, despite having been told repeatedly and clearly that this was not the case, he had a morbid fear that he carried the same life-limiting illness. Gradually, Stephen began to understand that his anger was an attempt to hide his sadness and act as 'the man of the family' by trying to take control of a situation that was completely out of his control. In parallel, the Nurse Therapist met with the parents to talk with them about appropriate boundaries regarding information for Stephen with regard to his sister and how important it was that his father was in consistent contact with him, making time to listen to his worries.

The teamwork with Stephen ended after three school terms, but his mother continues to be seen by CAMHS to help her cope with the issues surrounding the anticipated grief for her daughter. Stephen had not only suffered the loss of his father but was living with a sister who was likely to die within the next two years. He continues to be monitored by the school and may need further support in the future.

### Case Study (3): Sakiya

Sakiya (15) has muscular dystrophy and is increasingly becoming multiply disabled. She was referred to CAMHS by a community nurse because of vomiting, for which no physical cause

had been found. The family were known to the community services because Sakiya already received home visits following her various operations.

At the first CAMHS appointment, it soon became evident that both of Sakiya's parents were experiencing mental health difficulties, Sakiya's mother with anxiety and her father with intermittent clinical depression. They indicated that they were not robust enough to undergo family sessions but supported individual work for Sakiya.

With their permission, the CAMHS clinician consulted with both Sakiya's paediatrician and her consultant in the acute services to ascertain the likely prognosis for her and whether any further medical interventions might be needed within the next year.

Despite Sakiya's limited mobility, it was clear that she was well able to convey her thoughts verbally. She talked animatedly about her love of 'soap operas' and was completely absorbed in the adult issues they addressed. Indeed, it seemed that Sakiya was almost 'overdosing' psychologically and emotionally on the content of infidelity, abortion, murder and so on. She was often left highly stimulated by what she had watched, with no-one to speak to about it.

The clinic staff were worried that Sakiya may be unable to process much of what she was watching on the television. The vomiting was a response to her inability to 'digest' these adult issues emotionally. Crucially, there were many other underlying questions for Sakiya about the shortening of her life and her hope to live long enough to experience some of the issues she was witnessing on screen.

Sakiya was offered individual work and the vomiting ceased, but it was clear that she needed some safe psychological space to explore her thoughts and feelings about her illness. Although Sakiya's parents appreciated the potential consequences for Sakiya of watching these programmes, they were caught, as many parents of children with a life-limiting illness are, in wanting to allow their child every 'apparent' enjoyment.

## Multiple-Choice Questions

See answers on page 669.

1. What is essential information to gather in the assessment period?
  - a. Number of siblings
  - b. Quality of attachment to significant adults
  - c. Losses the child or young person may have suffered in their life
2. Is supporting the bereaved person best carried out by:
  - a. Teacher
  - b. Nurse
  - c. Professional who knows the individual well and who can access skilled supervision in this area of work
  - d. Professional bereavement counsellor
3. What does the author claim is crucial in bringing about the best possible outcome for the patient?
  - a. Timing of the intervention
  - b. Setting
  - c. Training
  - d. Both (a) and (c)
4. How many of these are true in what we know about the stages of grief? They
  - a. Follow in sequence
  - b. Cannot occur without assistance
  - c. Do not follow a set sequence
  - d. Are completed in a set period

## Key References

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