

Pre-bereavement and bereavement

Justin Amery, Collette Cunningham,
Nkosazana Ngidi, Eunice Garanganga,
Carla Horne and Jenny Ssenooba

Key points

- ◆ There is more than one way to support children.
- ◆ Choose the things that you and the child feel most comfortable with.
- ◆ Accept that some things just can't be 'made better' in a short space of time.
- ◆ Talk to children using words they understand.
- ◆ When explaining something, ask questions to check that the child has understood you (and also to check you have understood them).
- ◆ Give information in bite-size chunks. Pieces of the 'jigsaw puzzle' can be put together over time to make the picture complete.
- ◆ Encourage children to ask questions and ensure that you keep answering them – even if it's for the 100th time.
- ◆ Answer questions honestly and simply.
- ◆ Try to find ways in which children can be involved.
- ◆ Keep talking about the person who has died/is dying.
- ◆ Be willing, if appropriate, to refer people to child bereavement services.

14.1 Introduction

In this chapter we will look at how we can help children and their families to deal with issues of loss and bereavement during illness, as death approaches, during death and after death. In children's palliative care children may be the ones that die and may also be the ones that are bereaved (as sons, daughters, siblings or other close relatives). They may also be both, particularly where the family is affected by HIV. In children's palliative care we also have to take into account the needs of parents, for whom the loss of a child is particularly traumatic, as well as for different adult family members.

However, this chapter will not deal specifically with adult bereavement alone but in the context of family. Adult bereavement information can be found in more detail elsewhere.

Instead, we will focus on children's bereavement, for those who are going to die (and have to deal with the impending loss of their own lives) and those who are left behind. Similarly, we will not differentiate between those children who are grieving at their own impending loss and those who are grieving for someone they have lost. In general terms, the principles and practise of managing both groups are similar.

14.1.1 Definitions

It is important to distinguish between grief and bereavement as people are often confused and see them as the same.

- ◆ **Bereavement** is a state of having lost someone or something dear to you.
- ◆ **Mourning** is our external expression of loss. It is a style of expressing loss. Families, communities and cultures may mourn differently. Rituals help to bring healing and closure.
- ◆ **Grief** is the emotional and social reaction to loss. In children, grief can come from the loss of parents, siblings, failure of exams, death of pets, etc.

14.1.2 Charter for bereaved children¹

Winston's Wish, an excellent NGO working with bereaved children in the UK, has developed a 'Charter for Bereaved Children', summarized below. The principles work well in both resource-rich and resource-poor settings.

- B Bereavement support
- E Express feelings and thoughts
- R Remember the person who has died
- E Education, truthful answers and information
- A Appropriate and positive response from schools
- V Voice in important decisions
- E Everyone involved should be supported
- M Meeting other children with similar experiences
- E Established routines, including previously enjoyed activities and interests.
- N No blame: children should be helped to understand that they are not responsible
- T Tell their story and for those stories to be heard

14.2 Children and grief

Bereaved children usually experience 'deep pockets of sadness' when they have lost their parents or siblings, and when they know that they have an incurable sickness. They may not easily be able to share this sadness with family members or with their peers. Often this pain can remain inside, and as the child grows the sense of loss may remain with them and be felt differently. Adults generally underestimate the fact that a child may be affected by the loss. Yet children, like adults, experience pain and loss of their dear ones. Children who are not allowed to grieve normally are at higher risk of developing problems and complications at the time and later in life.

In the African palliative care setting, children may have to confront their own death or the death of a loved one at the same time as grieving for many other family members who have died as a result of the HIV epidemic, malaria or other causes.

14.2.1 How children grieve

Generally, children

- ◆ revisit their grief every time their developmental level gives them new insights into what happened
- ◆ grieve as part of a family: grieving for the person and environment they have lost, affecting those who remain, and in turn being affected by them²
- ◆ may have fluctuations in their grief between sudden sadness and equally suddenly appearing happy. This can be very confusing.

14.2.2 Myths and realities of child and adolescent grief

Table 14.1 Myths and realities of childhood grief from 'Pediatric Palliative Medicine' in the NEJM³

Topic	Myth	Realities
Do children and adolescents grieve?	Young children do not grieve	All children grieve
	Children do not grieve as much as adults	Children and adults express grief differently but just as intensely
	Children are lucky as they are too young to understand	Children are vulnerable in their growing
	Children should be protected from pain and suffering	Children cannot be protected in play, the media or life experiences
	Children can resolve grief quickly	Children's grief has no time limits
	Children and adolescents understand, experience and express grief identically	Children and adolescents are developmentally distinct
Should children and adolescents be exposed to a loved one who is dying?	Children will be bewildered by being with a loved one who is dying	Children need to understand and make sense of their experiences in order to help learn that dying and death are part of life
	Children will be traumatized by their last encounters with a dying person	Children value the opportunity to spend time with their loved one during that person's last days and weeks
	Happy memories will be overshadowed by watching their loved one die	Children can learn values through participating in the death of a loved one
	Children should be protected from seeing a loved one die	Children may later resent their exclusion: their involvement will assist in grieving
Should children take part in funerals and other death rituals?	Children should not be permitted to take part in such rituals	Children can benefit by helping plan and by attending funerals, including allowing them opportunities for questioning and learning from emotional responses of adults
	If they are allowed, participation should be limited and they should be protected from seeing strong emotional reactions	Children benefit from the support of others to overcome feelings of isolation

(continued)

Table 14.1 (continued) Myths and realities of childhood grief from 'Pediatric Palliative Medicine' in the NEJM³

Topic	Myth	Realities
	Adults know better whether or not to allow a child to participate in such rituals	Difficulties arise from forcing children to attend or excluding them from attending against their will
Are dying children and adolescents aware of their situation and how can they be helped?	Dying children <10y are not aware they are dying	Dying children know they are dying; adult denial is ineffective in the face of children's emotional perceptions
	Dying children do not experience anxiety because they are unaware they are dying	Dying children experience fear, loneliness and anxiety
	Dying children have no concerns for themselves or others	Dying children worry, may try to put their affairs in order, strive to protect their parents and fear being forgotten
	Dying children's questions should not be answered	Dying children need honest answers and unconditional love and support

Permission 10: reprinted with permission from the Massachusetts Medical Society.

14.2.3 Normal effects of grief in children

It is common for children to experience a regression⁴ in their behaviour during their period of mourning. Young children may experience bed wetting, loss of appetite, tummy upsets, restlessness, disturbed sleep, nightmares, crying, attention seeking behaviour, difficulty in concentrating, increased anxiety and clinginess. These only become a cause for concern when they occur over a prolonged period of time. Older children often display changes in personality and alterations in their normal behaviour including signs of depression, anger and rage, sleep and appetite disturbances, angelic behaviour, rudeness, learning problems, lack of concentration and refusal to go to schools. School work may be affected by underachieving or overworking. They may do everything 'right', even to the extent of parenting their parents. Boys, particularly teenagers, are likely to experience difficulties at school in the early months following parental death, but bereaved children do not necessarily develop long-term learning problems.

In adolescents, bereavement can cause a regression to a younger, more dependent stage in their development. Emotions may be suppressed, resulting in a display of apparent indifference or lack of feelings. In a search for love and affection, they may change their behaviour and become vulnerable in sexual relationships. Some children exhibit exaggerated displays of power to counteract their fears, and this may take the form of super-hero manifestations or may look like what we would characterize as naughty behaviour, acting out, anger and/or belligerence. This can also be an antidote to fear, manifesting in an outward display of personal power: 'I am strong enough to control life with my force.'

The important message is that health workers should advise families to be on the lookout for changes in behaviour. For example, a child who was previously chatty and has become uncommunicative should generate more concern than one who has always been uncommunicative.

14.2.4 Characteristics of grief in different age groups

Table 14.2 Characteristics of grief in different age groups

Characteristics	What you can do to help
Infants	
<ul style="list-style-type: none"> ◆ Sense something missing even if they cannot vocalize it ◆ Miss all aspects of the person: touch, feel of their body, sound of their voice, their expressions, their smell and activities experienced together ◆ Often suffer separation effects ◆ May regress, be more irritable, more clingy or more withdrawn 	<ul style="list-style-type: none"> ◆ Recognize children are strong and adaptable ◆ Create stability ◆ Hold when upset ◆ Try and gently engage if withdrawn (using interactive games such as peekaboo, water play, touch games, singing)
Young Children	
<ul style="list-style-type: none"> ◆ Do not understand death is final ◆ May believe that dead people will return ◆ May not initially respond to hearing that someone has died ◆ Grieve at the absence and separation ◆ Are upset at moments when they feel the 'goneness' but not at other times. ◆ Miss all aspects of the person: touch, feel of their body, sound of their voice, their expressions, their smell and activities experienced together ◆ Often suffer separation effects ◆ May regress, be more irritable, more clingy or more withdrawn ◆ May use their bodies to speak their feelings: it is a physical experience 	<ul style="list-style-type: none"> ◆ Create stability ◆ Hold when upset ◆ Try and engage if withdrawn ◆ Allow and encourage active play and communication ◆ Feedback verbally what you are seeing to help them to verbalize how they feel (e.g. you are bouncing, you are shouting, your face is red because you are sad and cross that your mother is not coming back) ◆ Be ready for contradictory statements such as 'my father's dead' and 'I hope he'll be back before my birthday' or 'He's picking me up tonight' by explaining gently that he won't be coming back because dead people do not come back
Older children	
<ul style="list-style-type: none"> ◆ May grasp the concept of death as final and irreversible ◆ May be curious about what happened to the person who died. ◆ May believe the person is still alive and functioning elsewhere ◆ May have trouble with abstract concepts such as afterlife ◆ May start to show aggressive tendencies, risky or impulsive behaviour 	<ul style="list-style-type: none"> ◆ Ensure that there is no misplaced guilt: e.g. 'You do know, don't you, that your Mother didn't die because of anything you did' ◆ Gently confront and correct magical thinking when it comes up ◆ Ensure that there is a clear and stable routine ◆ Ensure that you always have a clear plan for getting back together when you part 'I will be here at home waiting when you get back from school' ◆ Don't be upset if children become more clingy

(continued)

Table 14.2 (continued) Characteristics of grief in different age-groups

Characteristics	What you can do to help
<ul style="list-style-type: none"> ◆ May have magical thinking (I was mean to Joseph so he died, he might come back if I am good) ◆ May start to express fears about their own future 	<ul style="list-style-type: none"> ◆ Respond if the child needs more affection ◆ Try and stimulate withdrawn children with interactive games such as drawing together, mutual storytelling and so on
Adolescence	
<ul style="list-style-type: none"> ◆ Abstract thinking develops ◆ May show philosophic pondering about the meaning of life and death ◆ Grief may appear as withdrawn depressive symptoms ◆ May think in terms of an afterlife as well ◆ Often have powerful emotions and may be surprised by them 	<ul style="list-style-type: none"> ◆ Be prepared for long and difficult discussions ◆ Be prepared to say 'I don't know' ◆ Try and accept and explain strong emotions ◆ Ensure that they have a stable 'base' without restricting or overprotecting them

14.3 Bereavement support

William Worden describes a useful concept called 'bereavement work'⁵. Children who are going to die or be bereaved, and children that have been bereaved, are faced with numerous emotional, social and spiritual challenges which they will have to overcome. Different children will face different challenges and cope with these in different ways. There is no one right way for any child. However, there is always something that health workers can do to support children along their path. This section describes some of the things we can do to help. The section looks at ways you can support a child and family.

- ◆ Before death – pre-bereavement
- ◆ At the time of death
- ◆ After death.

But before going into details, you might find this general piece of advice useful.

Remember four key things:
'Be loving, be accepting, be truthful, be consistent'.

14.3.1 When should bereavement work start?

Children will begin to feel grief as soon as they understand that they or their loved one is going to die. Therefore, bereavement work should start as soon as a child is diagnosed with a terminal illness. Health workers often feel lacking in confidence in this area, but you do not have to be a bereavement specialist to be able to offer effective help. There are many ways that you can help the child and family before, during and after the bereavement.

14.3.2 The pre-bereavement stage

It is a common misconception that bereavement starts after death. In fact, bereavement starts as soon as a person is aware of his or her impending loss. This might be the loss of a loved one, or loss of one-self. Therefore, bereavement work for health workers does not start after death; it starts at the moment of diagnosis. In the section below, we have outlined some tips on what and how to approach pre-bereavement in children's palliative care. However, as a general rule:

Never lie to children or prevent them from talking. It is immoral, unethical and negligent. Children have as much right to ask questions and be given honest, accurate information as adults do.

14.3.2.1 Encourage the child to talk and communicate

- ◆ Families and carers often feel that children are incapable of coping with the distress and the anxiety of loss.
- ◆ Children are not always given information about their disease or the disease that their loved ones have. They may even be lied to by their loved ones or prevented from expressing their fears and concerns. However, denial and protectiveness by parents are not effective ways of supporting grieving children⁶ or those who are sick.
- ◆ Communicate openly, honestly and factually, giving age appropriate information.
- ◆ Avoid using abstract explanations such as 'your mother has gone to sleep'.
- ◆ Allow the child to express anger or fear and help the child to do so without harming himself or anyone else.
- ◆ Do not impose expectations on the child (e.g. by saying 'you will definitely feel better in time' or 'it's time you got over it now').
- ◆ Encourage normality and continuity in other areas (e.g. school).
- ◆ Try to avoid separation from other loved ones such as siblings.

14.3.2.2 Denial

- ◆ Denial is rarely a fixed state – individuals move in and out of it, sometimes in the same conversation.
- ◆ Accept that it might be appropriate for the child to deny.
- ◆ Try to help the child work through it by gently discussing issues around death and dying.
- ◆ Make it easy for the child to ask questions.
- ◆ Try and explore things that offer reminders (e.g. photos, fond memories and the grave).
- ◆ Try to make the loss real for the child by including him or her in such activities as the burial ceremony and last funeral rites.

14.3.2.3 Anticipatory grief

- ◆ Children can suffer anticipatory grief when they feel that their death or the death of the loved one is near.
- ◆ They might project their feelings onto others (e.g. that parents may die too) and become very anxious about this.

- ◆ They may worry about what will happen to their loved ones when they are gone.
- ◆ They may also express their ideas and fears through play or art.
- ◆ They may become withdrawn, quiet and increasingly irritable.
- ◆ Try to help them communicate what they are feeling (see above and Chapter 2).
- ◆ Involve them in discussions around illness, death and dying and in decisions regarding their care.
- ◆ Try never to go against a child's choice unless you absolutely have to: the more control children feel they have, the less fearful they will be.

14.3.2.4 **Stigma**

- ◆ Stigma affects all aspects of caring for children and adolescents infected and affected by HIV/AIDS and cancers.
- ◆ Stigma in the pre-bereavement stage has the effect of isolating children and their families physically and psychologically.

14.3.2.5 **Fear**

- ◆ Children are particularly scared of pain and separation.
- ◆ They may regress, become clingy and develop nightmares or physical symptoms.
- ◆ You may get asked very difficult questions (see Chapter 2 – Communicating with children).
- ◆ Ensure regular, honest and open communication.
- ◆ Ascertain the child's fears and concerns, and talk them through.
- ◆ Give as much control as possible: once you have an idea of the child's fears and concerns, agree an action plan for how you will deal with each.

14.3.2.6 **Avoidance, separation and rejection**

- ◆ Death and disease may be taboo or too painful for families to mention.
- ◆ For many reasons, family members often clam up, and non-family members or distant relatives may stay away.
- ◆ The combined effect is to isolate the child and family just when they need most support.
- ◆ Try to encourage children and family members to share how they feel, and explain why it is that avoidance and separation are so tempting but so counter-productive.
- ◆ Encourage children and families to be open with each other and others, and to give permission to each other to show emotions, to not know what to say and to value just being together for comfort and support.

14.3.2.7 **Telling others**

- ◆ Encourage children to tell other people what they mean to them, and encourage families to tell the children.
- ◆ Everybody has some regrets in their life, including children, even if these seem trivial to adults.
- ◆ Remember young children think magically, and may attribute huge consequences (even their or their family member's death) to tiny causes (that they upset mummy that day).

- ◆ Try to encourage children to unburden themselves of their concerns and put straight any misplaced fears or concerns.
- ◆ More than any other emotion, regret can be reduced when it is shared.

14.3.2.8 **Handing over**

- ◆ The time will come where you begin to hand over to the child (giving responsibility back to the child for deciding how to approach the impending death).
- ◆ Perhaps the most important thing at this stage is to help the children to understand exactly what will happen to them (if they are bereaved) and what will happen to their loved ones (if they are to die). Try to look at the world through a child's eyes, or you might overlook something which seems trivial to you but might carry huge importance to them (e.g. who will take them to school, whether they will have to change where they sit or sleep at home, who will look after their favourite toy).
- ◆ You can use a number of practical techniques to make this easier. Further details can be found in Section 14.5 below.

14.3.3 **At the time of death**

What happens at the time of death has profound implications for surviving loved ones. A painful, traumatic death will often leave survivors feeling guilty, angry and traumatized. A 'good death' can help survivors to look back on the positives of a child's life, not tortured about the painful moments of death. Therefore, management at the time of death is crucial; yet it is precisely the time when health workers often feel least confident and most out of their depth. This section aims to help you minimize the trauma of witnessing a loved one die. Further details can be found in Chapter 18 – Caring the children at the end of Life.

14.3.3.1 **Don't panic**

- ◆ The best thing you can do is go through all the worst case scenarios in your head in advance and practise exactly what you will do for each.
- ◆ We repeat, the best thing you can do is go through all the worst case scenarios in your head in advance and practise exactly what you will do for each.
- ◆ Have you done it yet? If not, do it now.
- ◆ You might feel very nervous, even out of your depth.
- ◆ But however you feel, the child and family will feel much better if you look calm and in control (even if you don't feel that way inside!).
- ◆ Calm is catching, as is panic. Panic helps nobody, so try and ooze calmness. It really works.
- ◆ If you feel like panicking, make an excuse to go outside for a bit (a mock phone call is always useful) until you calm down.
- ◆ Above all, remind yourself that:
 - the child is dying and there is nothing you can do to stop it
 - it is a very sad experience for all, and you are not going to stop that either
 - it is extremely unlikely you will make things any worse
 - there are almost certainly symptoms you can control and comforting words you can say

- even if you feel that there is nothing you can do, and however useless you feel, just by being around you are helping and making the experience easier for the family, so stick at it.

14.3.3.2 Offer choices and control to the child

- ◆ The child may or may not be conscious and aware at the time of death.
- ◆ If they are aware, try to do everything you can to give them choice and control.
- ◆ Talk through in detail what might happen (best and worst case). For each scenario, explain and agree exactly what the plan is.
 - e.g. *'You might start to get breathless over the next few days. That is to be expected and we can easily deal with it by giving you some medicines. Do you want to ask anything about that?'*
- ◆ Try to involve them in any plans so that they will keep active:
 - e.g. *'If you start to feel breathless I need you to help me. Can you do that? Good. What I need you to do is to concentrate on those special breathing exercises I taught you. Shall we practise them again now?'*

14.3.3.4 Offer choices and control to the family

- ◆ In exactly the same way, you need to do everything you can to give the family choice and control (don't forget siblings).
- ◆ Talk through in detail what might happen (best and worst case). For each scenario, explain and agree exactly what the plan is.
 - e.g. *'Moses might start to get breathless over the next few days. That is to be expected and we can easily deal with it by giving him some medicines. Do you want to ask anything about that?'*
- ◆ Try to involve them in any plans so that they will keep active:
 - e.g. *'If Moses starts to feel breathless I need you all to help me. Mum, I need you to cuddle him so that he feels reassured, but not too tight. Try and make sure he can always see you. Dad, I want you to make a fan and gently fan Moses' face so he feels that there is plenty of air around. Esther, I want you to help Moses think about something else by doing his breathing exercises with him, and maybe singing him some songs when he gets tired. Can you do that? Good.'*

14.3.3.5 Remember

- ◆ Fear of the unknown is always greater than fear of the known.
- ◆ The whole experience will be completely new to the child, and probably to the family too.
- ◆ They will watch you like a hawk, constantly checking to make sure that you are able to guide them through the process with as little trauma as possible.
- ◆ The more they know and understand what is happening, the calmer they will be.
- ◆ So commentate on everything you do and think.
 - e.g. *'Ok, I am noticing that Moses is starting to get a bit breathless, but I am not concerned as we can easily manage that. Mum, Dad and Esther, remember what we agreed for you all to do? Ok, go ahead. I am just giving Moses a medicine called diazepam. It will help him feel less breathless when it starts working in about 15–20 minutes. He will probably fall asleep too. If it does not completely work, I will give him some more. While we are waiting for it to work I will stay around, so don't worry. Do you have any questions?'*

14.3.4 After death

After death, different families and cultures adopt different practises. This is covered in more detail in Chapter 15 – Spirituality. However, we will cover the key generic points below.

14.3.4.1 Seeing the body

- ◆ Seeing the body and attending the funeral is often helpful, but should always be the child's choice. No child should be denied the opportunity by an adult, nor be forced by an adult to see the body. Keep offering the option, and the opportunity to change their mind, for as long as possible.
- ◆ Seeing the body may help a bereaved child to:
 - begin to say goodbye
 - begin to accept the reality and finality of the death
 - begin to understand what has happened
 - be less scared.
- ◆ Tell them that they can change their minds – at any time.
- ◆ Give them clear and detailed information about what will happen:
 - *e.g. 'Daddy is lying in the box called a coffin on a table. He doesn't look exactly the same as when he was alive. He is completely still. If you touch him he won't be warm but a bit cold. He is wearing his pale shirt and his dark grey trousers. There are quite a lot of flowers in the room and also some cards.'*
- ◆ Let them choose what they do when they enter the room: keep still by the door, touch or stroke the body, leave something like a drawing with the body.
- ◆ Give them the choice as to whether they want someone with them, or whether they would like a little private time on their own.

14.3.4.2 Attending the funeral

- ◆ According to different cultures, it may or may not be the norm for children to see the body or attend the funeral.
- ◆ If it is not possible, try and arrange an alternative 'saying goodbye' ceremony (see Section 14.5).
- ◆ If it is possible, make sure the child realizes that they will be welcome there.
- ◆ Try to ensure that they are with someone who will support them. This should not be the person closest to the dead person, who should not be asked to be supportive of a child at a time when they may be feeling their own grief most intently. A favoured aunty might be ideal.
- ◆ Give clear and detailed information about what will happen.
- ◆ Reassure them that it is *all* of the body of the person who has died that is being buried or cremated. Some younger children are confused and wonder what happens to the head, arms and legs.
- ◆ Explain that the dead person can no longer feel anything or be scared.
- ◆ Explain that there might be a 'party' after and not to be surprised or upset by that.
- ◆ Prepare them for some of the things that adults may say to them. For example, boys may be told that they are the 'man of the house now' and will appreciate reassurance that they are not.
- ◆ Create opportunities to be involved (e.g. through placing a drawing with the body or saying something or choosing some hymns).

14.3.4.3 Alternative 'goodbyes'

- ◆ If the child cannot or does not want to attend the funeral, try to encourage an alternative goodbye ceremony. For example:
 - Hold a memorial at home or at the grave with specially chosen music, songs, drawings and little tributes.
 - Visiting a place with special memories.
 - Create a special place of their own choosing.
 - Holding a small ceremony.
 - Releasing balloons to which special messages are attached saying something to the loved one or remembering something special.
 - Lighting a candle and sharing special memories with each other.
 - Starting a memory box.

14.4 Problems that can arise

It is difficult to offer sensible generalizations about how children react to death of different loved ones. Children, their temperaments, personalities and circumstances are so varied. Children and young people will have a range of reactions including not talking about the person who has died, deep sadness, rage, disturbed sleep, nightmares, lack of appetite or overeating, loneliness and a sense of abandonment, anxiety about themselves or other loved ones, a feeling that there is no point in anything, lack of interest in previous enthusiasms, or not wanting to attend school or see friends.

Their response will also vary according to their age, the cause and nature of the death (for example, whether sudden or expected, or by violence), the family circumstances (for example, whether parents lived together, whether major life changes will now be necessary), any previous experience of death or trauma within the family, the age and relationship with their siblings, their position within the family, how long they had known each other, their own resilience and the support and care they receive.

Dysfunctional bereavement may manifest itself in a number of different ways:

- ◆ Regression, e.g. sleep disturbances, food refusal
- ◆ Excessive self criticism and guilt
- ◆ Self-destructive behaviour
- ◆ Self-harm
- ◆ Taking on a parent role
- ◆ Truancy
- ◆ Petty delinquency
- ◆ Silence and withdrawal
- ◆ Overt depression.

Mostly, these changes are temporary and gradually disperse with time. However, sometimes they can persist or even become severe. It is ultimately a subjective judgement as to whether a 'normal' reaction strays into becoming an 'abnormal one'. Your judgement will depend partly on the child, partly on the reaction and partly on the family's capacity to cope. Remember though, when treating any psychological issues in childhood, you have to remember that the child's identity as an individual is heavily wrapped up in the child's identity as a member of a family (see Chapter 4 – Assessment and management planning). Therefore, what appears as a problem for

an individual child is also usually a problem for and partly attributable to the whole family. What constitutes a troubling and abnormal behaviour for one family might be completely understandable and acceptable to another. So try and manage not just the child, but the whole family.

14.4.1 Risks for dysfunctional bereavement

There are a number of factors which can trigger so-called dysfunctional bereavement⁷:

- ◆ Features of the loss, e.g. sudden, violent, mutilating, random or prolonged deaths.
- ◆ Features of the child, e.g. previous emotional or behavioural problems, multiple losses, adolescence.
- ◆ Features of the relationship, e.g. attachment issues, complicated or abusive situations, death of father (particularly for adolescent boys) or the mother (particularly for younger children and teenage girls), unsupported or conflicted family.

14.4.2 Anger

- ◆ Anger is a natural reaction and children may express their anger outwardly or inwardly. Sometimes children might turn their anger on themselves.
- ◆ Try to decide whether the anger is causing any harm to the child (e.g. due to physical self-harm or neglect or because it is leading to ostracism at home or at school).
- ◆ Try to encourage the child to express his or her feelings of anger using verbal, non-verbal communication or play.
- ◆ Try to explain to the family where the anger is coming from and that it will pass as long as it is not reinforced by rejection from other family members.
- ◆ Agree with the child and family what is acceptable and when, and how to discharge anger constructively when it becomes too much.

14.4.3 Guilt and self-blame

- ◆ Try to explore the child's ideas and fears:
 - Children might blame themselves for the sudden traumatic situation in their lives.
 - Younger children often think that the death has occurred because of their bad behaviour.
 - Older children might get a false reassurance from the unwarranted self-blame (i.e. that they can prevent unwanted events if only they try harder).
- ◆ Put right any misconceptions if you can, e.g. *'It's not your fault. You are a child and could not have stopped the germs getting into Daddy's body. Even the doctors with all of their medicines could not do that. The germs killed daddy. You did not'*.
- ◆ Encourage the child to focus on the future instead of things that he/she cannot change.
- ◆ Encourage the child and family to communicate openly with each other rather than keeping feelings of blame bottled up inside.
- ◆ Explore what other sources of support are available to the child.

14.4.4 Sorrow

- ◆ When a child feels sorrow, he or she may be ready to accept the truth of the loss without protest.
- ◆ Sorrow can be an expression of a child's feelings of vulnerability as he or she continues to live without the person who died.

- ◆ The child may grieve a loss of security.
- ◆ Touch is so important: loving arms suggest safety and acceptance in a world that has become more frightening and uncertain.
- ◆ Try to acknowledge the one who has died gently and regularly, particularly on aspects of his/her life or personality that were good.

14.4.5 Sleeping difficulties

- ◆ Sleeping is a form of parting, and perhaps even a form of mini-death, so it is not surprising that bereaved children often have difficulties in sleeping both in getting to sleep through worrying and grieving and in experiencing nightmares or disturbing dreams. The most important thing is to encourage a consistent routine, patience and gentle care. In most cases the problems will gradually ease as children realize that they are safe and the dreams begin to fade.
- ◆ Practical tips include making South American ‘worry dolls’: 5 or 6 tiny doll-like figures are held within a tiny cloth bag with a drawstring. South American children are encouraged at bedtime to whisper one big worry to each doll. The dolls are then placed under the pillow and the dolls take over the task of worrying for the night.
- ◆ Alternatively try ‘Dreamcatchers’ (these can be made on your own). The Native American legend tells how all the dreams of the world flow over our heads as we sleep. Dreams are caught by the dreamcatcher’s web; the bad dreams stick to the strands of the web and the good dreams filter softly down the feathers to the sleeper beneath. Some dreamcatchers have beads woven onto the web – these represent ‘heroes’ and a child can choose their own heroes to help hold back the bad dreams (for example, one could be Dad, another could be a football star, another could be a friend, etc.).

14.4.6 Anxiety on parting

- ◆ Partings are also mini-bereavements and so anxiety on parting is very common with pre-bereaved and bereaved children.
- ◆ The important thing is to make sure that a pre-bereaved or bereaved child has consistent care, and what he or she is told will happen, so that they can gradually rebuild trust and confidence in the world and in people.
- ◆ When parting, encourage the parent or carer to mention something that will happen after reunion. For example, ‘remind me to buy some beans when I collect you’; ‘let’s stop at aunty’s on the way home tonight’; ‘let’s colour a picture together when you get home’. This glimpse of the future that includes both of them can be comforting.

14.5 Practical help

The following section describes some practical interventions that you can encourage before and after the death in order to help and support the bereaved (or pre-bereaved child). Some of what follows below is adapted from Winston’s Wish⁸.

14.5.1 Making a memory box

Children who are going to die will often find it helpful to work with their families to put a memory box together before they die. Bereaved children will benefit from collecting items that remind them of the person who has died and times shared with them. These items can be pasted into a

book or placed into a box. Examples could be anything, an old piece of clothing with the person's smell, cards received, stones collected together, an old toy with particular memories, drawings done together, a piece of writing describing a fondly remembered event, photographs, flowers from the funeral and so on. Videos or sound tapes are even better, if available (but make sure that the child makes copies if at all possible). It is important that the child chooses, as only he or she will recognize what items generate memories that he or she wants to keep. Encourage the child to turn through the items every now and again, particularly at special moments or anniversaries, or when they are feeling sad, or fearful of forgetting or needing strength. Try and encourage the child to make the box or book 'special' by colouring or wrapping it, and by pasting on it items that make it stand out.

14.5.2 Making a family record

Making a family record can help a child or young person gain a sense of where they and the person who has died fits into the family. This is particularly important when a child is to be removed from their old home, or separated from siblings or cousins, and hence when there is a danger of losing a sense of his or her 'roots'. Try and encourage the child to put together a family tree and include family photographs, documents and certificates and mementoes can be included. Stories about the lives of the people who have died and also about the people from whom the child is about to be separated. The stories are even more powerful if contributed by family members and friends, and this is often a welcome way for them to be involved. What was the funniest thing the person ever did? What was their best subject at school? What was the bravest thing they ever did?

14.5.3 Telling the story

Children love stories, and especially when they themselves are incorporated into the story. Try and help children write or tell (with an adult writing) their story so that they remember clearly what happened. This also gives you and other carers an ideal opportunity to pick up misconceptions and misunderstandings, and put them right. With young children, it is often easier to use dolls, model figures or puppets to tell the story. Older children may prefer to use paper and pens. It is easier if you try and get the child to break the story into five or so pieces:

- ◆ What was life like before they died? (some idea of the family before the death)
- ◆ What happened just before they died? (earlier in the day, the day before...)
- ◆ How did they die? What happened?
- ◆ What happened immediately afterwards?
- ◆ What is life like now?

14.5.4 Handprints

Hands are powerful symbols of love and care. Encourage a pre-bereaved child to place his or her hand on a piece of paper. Then do the same with the parents and/or other people important to the child so that one or more fingers are touching. Draw around the hands and repeat it so that everyone has a copy. An alternative, even nicer, is to get everyone to paint their palms different colours and then carefully place their palms against the paper, fingers touching, so that actual prints are left. Encourage children to keep it safe (maybe even laminate it if possible) so that they can pull it out whenever they feel the need to be close to their lost one by placing their hand over their handprint and 'feel' the other hand alongside, supporting and encouraging them.

14.5.5 Writing a 'children's will'

Although children may have few material possessions, they will almost certainly have some items that they treasure and might have a clear idea of what they wish to happen to these. They also might have some thoughts about what they want to happen after death and how they wish to be remembered. All of these things can be captured in a will.

14.5.6 Permanency planning

Children need to be clear about what will happen to them (if they are bereaved) and what will happen to their loved ones (if they are to die). Uncertainty can compound the loss felt by the child. Particularly in SSA, where child bereavement is so common, a child may be separated from siblings and may experience frequent shifts from place to place in search of a proper home. Children whose parents do not complete permanency planning are at increased risk of developing emotional and behavioural problems.

14.5.7 The 'bereavement tree'

The Bereavement tree⁹ (see Appendix 2 of this chapter) is a practical tool that sensitizes people to the feelings and behaviours of individuals and expectations of society, to create awareness about bereavement in order to encourage community support to all bereaved people. It was developed by Jenny Hunt in Zimbabwe and Nkosazana Ngidi in South Africa. The tool involves looking at how people deal with bereavement issues tracking it over a period of time, firstly immediately after death, then after 6–8 months and then after a year. It looks at how they feel, what they show in terms of their behaviour and how they are expected by society to feel, show and behave. It involves using the analogy of a tree, where the person who was looking after it has died. Children are engaged to talk about what they think the tree feels, what it looks like and what other people are expecting it to do, immediately after the death of the person, 6–8 months after the death and a year after the death. This can later be related to their own experiences of bereavement relating it to the tree. It can be used with individual children or groups.

14.5.8 Other useful activities

If you have internet access, the following activities can be found on the 'Winston's Wish' website (www.winstonswish.org.uk)

- ◆ 10 ways to remember someone who has died
 - Some ideas of ways to remember someone
- ◆ 10 things to do on Mother's Day
 - Some ideas of ways to remember a mother on Mother's Day
- ◆ 10 things to do on Father's Day
 - Some ideas of ways to remember a father on Father's Day
- ◆ 15 ways to remember people at important festivals
 - Some ideas of ways to remember people at Christmas and similar festivals
- ◆ Calendar of memories
 - Mark important dates connected with the person who has died on a calendar, which you can then share with other people
- ◆ Memory shapes
 - Make your own coloured shape of memories

- ◆ Feelings
 - Compare your feelings with our feelings grid
- ◆ Remember
 - Add a star to our skyscape of memories.

14.6 Questions for you

1. Which myths about children and bereavement did you hold before you read this chapter? Reflect on how the chapter has affected your beliefs (or not).
2. Reflect on whether you could envisage a situation when it would be acceptable to lie to a child about their prognosis. Think about who you might be trying to protect in such a scenario.
3. Imagine that your own death is approaching. What would you be most frightened of? How would you like to be remembered? What would you put in your own memory box?

Notes

- 1 Winston's Wish (2003). The Clara Burgess Centre, Bayshill Road, Cheltenham, Gloucestershire, GL50 3AW. Available online at www.winstonswish.org.uk
- 2 Talking about Death with Children. The Dougy Center, The National Center for Grieving Children and Families, Used by Permission. Available online at <http://www.dougy.org/>
- 3 Himmelstein, B.P., Hilden, J. M., Boldt, A. M. & Weissman, D. (2004). Pediatric Palliative Care. *JAMA*, 350(17), 1752–1763.
- 4 Ministry of Health and Child Welfare. (2006). Palliative Care for Children: A Training Manual for Communities in Zimbabwe.
- 5 Worden, J.W. (1991). Grief Counseling and Grief Therapy 2nd Edition, Spring Publishing Co., NY.
- 6 Waechter. E. (1971). Children's Awareness of Fatal Illness. *The American Journal of Nursing*, 71(6), 1168–72.
- 7 Watson, M., Lucas, C., Hoy, A. & Back, I. (Eds.) (2005). *Oxford Handbook of Palliative Care*. Oxford University Press, Oxford.
- 8 Winston's Wish. Available online at www.winstonswish.org.uk
- 9 Nkosazana Ngidi (2006). The Bereavement Tree. Hospice Palliative Care Association of South Africa. Available online at www.hospicepalliativecaresa.co.za
- 10 'Dream Catcher' by Enchanted Learning. com. Available online at <http://www.enchantedlearning.com/Crafts/>

Appendix 1: The dream catcher¹⁰

Dream Catchers are from Native American lore; they trap bad dreams and let the good dreams filter down to the sleeper.

For each dream catcher you will need:

- ◆ a bendable twig about 1 foot long
- ◆ a few inches of thin wire
- ◆ some twine
- ◆ beads with large holes
- ◆ a few feathers.

Have an adult make a hoop from a twig. To do this, wrap a short length of thin wire around the overlapping ends. Use thin wire to tie the ends of a twig together to make a hoop.

Cut a few feet of twine. Tie one end of the twine to the twig hoop. String a few beads onto the twine and push the beads toward the tied end. Wrap the twine around the other side of the hoop.

String a few more beads on the twine and then wrap the twine around the far side of the hoop. Repeat until you have an interesting webbing design.

Tie a short length of twine on the hoop. String a bead or two on it and then tie a feather onto the end. Repeat this a few times (2 or 3 hanging feather strings look nice). Hang the dream catcher near your bed!



Appendix 2: The bereavement tree

You can use the analogy of a tree to talk to a child about bereavement. Explain to the child that the person who has taken care of the tree has left or died. Use the pictures below, or draw your own pictures with the child, to help explain and to help the child talk and understand.

Immediate



Felt	Shown	Expected
<ul style="list-style-type: none"> ◆ shock ◆ sad ◆ helpless ◆ alone ◆ scared ◆ angry ◆ worried and confused 	<ul style="list-style-type: none"> ◆ lose colour ◆ lose leaves ◆ signs of withering ◆ no flowers ◆ unhealthy ◆ no fruit ◆ not happy ◆ no shade ◆ no birds 	<ul style="list-style-type: none"> ◆ expected to; provide ◆ shade ◆ shelter ◆ fruit ◆ look healthy and pretty ◆ to protect

At 6–8 months

Tree receives a little rain and sunshine (6–8 months).



Felt	Shown	Expected
<ul style="list-style-type: none"> ◆ abandoned ◆ lonely ◆ worried ◆ angry ◆ deserted ◆ missing a person ◆ feel some hope ◆ feels I need to look for support 	<ul style="list-style-type: none"> ◆ leaves are still falling ◆ still no fruit ◆ no shade ◆ no shelter ◆ not healthy ◆ starting to grow new roots ◆ new shoots ◆ one or two flowers 	<ul style="list-style-type: none"> ◆ same as immediate

A year later



Felt	Shown	Expected
<ul style="list-style-type: none"> ◆ substitute affections ◆ lonely ◆ missing the person ◆ angry sometimes ◆ sad sometimes ◆ hope ◆ sometimes happy 	<ul style="list-style-type: none"> ◆ bears fruit ◆ birds come to it ◆ provides shade ◆ flowers ◆ new leaves ◆ looks healthy ◆ new roots ◆ more support 	<ul style="list-style-type: none"> ◆ as before but explore rituals, etc.

