

Chapter 2

UNDERSTANDING LOSS AND REACTION TO DEATH

"To give children ready-made explanations about death is to diminish their bereavement experience. From the age of four, children have the ability to comprehend the facts of death, but information alone is not enough; they also need an opportunity to explore the feelings generated by a death in order to believe the facts and come to a personal explanation of their meaning."

Hemmings, 1997, pg. 31

Many children are faced with the experience of the death of someone close to them whilst they are still young. For some, it is the death of a pet, a grandparent or possibly someone within their class in school, but for others it may be the death of someone in their immediate family, such as a sibling or a parent.

This manual focuses on children who lose a parent or significant carer through cancer and related illnesses, although a number of issues are akin to experiences from other losses.

For many children the simple intervention of being able to tell their story, to be heard and validated and being availed of the opportunity to ask questions is appropriate and sufficient support and may be provided within the family structure or with the assistance of an appropriate outsider. This intervention may mirror the experience and needs of adults. *"Following a bereavement, adults often express a need for opportunities to talk about their experience of the illness, death and their relationship with the deceased in order to discover its meaning". (Stokes et al., 1999, pg. 300)*

There are a number of organisations and professionals who may be involved with families at this time and they may include hospices and medical services, schools, non governmental organisations (NGOs) or voluntary organizations and they may be able to provide a range of different support both pre and post bereavement.

→ For some families, there is either no need for intervention or support or a need only for limited intervention, as they have a strong network of established support around them.

→ For other families and individuals, the support networks may be more fragmented or non existent and professionals and appropriately trained volunteers may need to be more intensively involved in order to assist them in developing and sustaining good emotional resilience.

LOSS

The theories that exist regarding children and their experiences and reactions to loss today generally agree that children are able to grieve regardless of age. However, what makes each child and family's experience of loss different and unique is based upon their age and emotional understanding, their individual circumstances and significant family history.

There have been a number of models relating to the grief process which have been developed and applied in working with bereaved individuals. It must be remembered that models are attempts at providing explanations to people's experiences, but generally individuals do not fit into neat categories regarding their bereavement. It must also be remembered that models need to be viewed within the appropriate cultural context and provide a general framework rather than conclusive definitions and understanding. Some models of loss may be appropriate for the reality of adults experiences but may not transfer so easily in the experience of childhood bereavement.

MODELS OF LOSS

Although this manual is not a comprehensive exploration of these models, an overview of the four predominant models of loss is provided below.

STAGE MODEL OF LOSS

Stage Model of Loss (*Kubler-Ross, 1982*) was developed through work with the patients with a terminal illness and similarly likened to the experience of the bereaved. It is based on a study which indicated that "*patients would pass through various stages including the following:*

- *Shock*
- *Denial*
- *Anger*
- *Guilt*
- *Depression*
- *Resolution". (Holland, 2001, pg. 29-30)*

This model has a number of difficulties. It does not often allow for fluidity of a person's experience and it does not allow for the fact that often people do not grieve in a fixed order of experience, but may return to earlier stages as part of the process.

TASK MODEL OF LOSS

Task Model of Loss is based on the ideas of William Worden (1984) and others. In relation to children, the major tenets were based on the idea that they work through four psychological tasks of:

- Understanding
- Grieving
- Commemorating
- Moving on (*Holland, 2001, pg. 31*)

CONTINUING BONDS MODEL

Continuing Bonds Model is a relatively recent model of grief (*Silverman and Klass, 1996*) which suggests that the *"bereaved maintains links with the deceased: these bonds are not severed, but flow on into time"*. (*Holland, 2001, pg. 31*) For many cultures across the world, there is an understanding of the links between the alive and the dead which may be fostered through models such as this one.

DUAL PROCESS MODEL

Stroebe and Schut (1995) describe grief as a dynamic process – "[The Dual Process] model describes an oscillation between focusing upon and avoiding the loss experience, acknowledging that both responses can occur alongside each other. A child may recognize that a parent is easily upset or anxious when talking about a dead family member (focusing upon the loss) and engage in restorative behaviour such as not talking about the person who died or behaving in such a way that distracts the parent. This can be useful and adaptive for the family (distracting and supporting each other) or it can lead to problems (misinterpreting behaviour and feelings). Developing community based bereavement services that reflect this dynamic process aim to facilitate coping in families and promote understanding of how individual family members are grieving." (*Stokes et al., 1999, pg. 295-6*) This can enable development of services that individuals and families can access when they feel they need it.

EXPERIENCES OF BEREAVEMENT AND INTERVENTION

TERMINAL ILLNESS

When a child is faced with the reality of a parent being diagnosed with a life threatening or terminal illness such as cancer, this is referred to as 'anticipated bereavement'. For many children and families, it can be very helpful to have the offer of support as early as the diagnosis stage. This support does not need to be intensive or ongoing, but should be dependent on individual circumstances.

There are a number of reasons why early introduction of 'helpful' supportive people is appropriate for families including:

- To gain a better understanding of networks within a family and their communication patterns and to appreciate how each individual may respond or what their emotional needs may be;
- To help and assist families in involving children in the process of what is happening – the sooner children aware of the what, how and why, the better their emotional resilience;
- To assist families in providing children with appropriate information and understanding and provide families and children with the space to offload their feelings if appropriate; and
- To avert or lessen the possibility of crisis intervention – although it is not impossible, it can be very difficult to work with families right at the point of bereavement.

There may be some difficulties for children associated with the protracted, although anticipated, death of a parent who may be dying over a long period of time compared with a sudden death as they may be *"grieving both for the suffering of the parent during the time before the death as well as grieving for the forthcoming death itself"*. (Holland, 2001, pg. 185)

A frequently asked question by parents faced with a life threatening illness, alongside "How long?", is "How will my children cope and manage?". By being involved with families before bereavement, you can help and support the patient in the process, possibly facilitate discussions or conversations they wish to have before they die and allow them to understand how their children may be coping with the situation and the emotions that it evokes.

UNEXPECTED BEREAVEMENTS/SUDDEN LOSS

For many children, their experience of death and bereavement may not be anticipated and may occur unexpectedly as in the case of a road traffic accident, suicide, murder or through a health condition such as a heart attack

When working with a child, where the death of a loved one has been sudden, the following factors need to be borne in mind:

- The child and his family will not have had the opportunity to say goodbye or be prepared.
- There may be difficulties associated with what is explained with a sudden death, especially if the cause of death was not known originally or new information comes to light.

A child may not be told the truth or all the facts in the first instance, then told more information. This may cause complications for several reasons - the child may then *"find themselves being angry at adults for not having told them the truth or for lying to them, and being anxious and confused at having their basic sense of trust in adults undermined"*. (Smith, 1999, pg. 62)

- It is therefore important that there is sensitive handling of information and explanations in the first instance to lessen the possibilities of re-emergence of grief, if new information is revealed.
- Additional factors may add to the trauma of a child where he has experienced a sudden death such as parental murder, suicide or an accident that they may also have been involved with:
 - The media may be involved, reporting what happened and covering the court case;
 - The child may need to be interviewed and involved in the court process;
 - There may be difficulties in being able to view the body, if it has been mutilated or significantly disfigured; and
 - Often there are delays in funerals and other rituals if the body is required for an autopsy, which can consequently delay a formal goodbye.
- There may be added complications for the child, if the person who died committed **suicide**:
 - The child may have been living with parents (or other loved ones)

- with mental health problems prior to that person committing suicide.
- The child may be struggling with why a parent would "choose" or want to die and therefore leave the child, which in turn may raise questions of blame and responsibility – "Could I have saved them?", "Did my behaviour cause them to want to die?"
 - There may be some social stigma attached to suicide and mental health problems and children may find it very difficult to explain that a parent took their own life.
 - They may also worry about mental health problems being catching and that they too might choose to commit suicide when they are older.
 - It may also be hard for children bereaved through suicide to be able to think about the positive memories or good things relating to the person who died.

COMPLICATED BEREAVEMENT AND MOURNING

Both anticipated and unexpected bereavement and mourning can be complicated for children (and for adults) by a number of factors which include:

- Relationship factors:
 - the person who died and the type of relationship the child had with that person.
- Circumstantial factors:
 - the nature of the death - was it sudden or expected, and
 - whether the child was involved in the rituals before and after the death.
- Multiple losses:
 - other losses which may have been experienced by the child,
 - events pre and post bereavement e.g. divorce/separation, house move, change of schools, previous deaths, time in foster care.
- Personality factors:
 - how the child deals with situations emotionally.
- Social factors
 - e.g. access to housing, employment, financial and legal matters, mental health factors, substance abuse, domestic violence, etc.,
 - access to social networks and availability appropriate support.

WHAT DO CHILDREN NEED?

- ✓ **INFORMATION**
- ✓ **EXPLANATION**
- ✓ **HELP IN EXPRESSING THEIR FEELINGS**
- ✓ **INVOLVEMENT IN GOODBYES**
- ✓ **REASSURANCE**

RESPONSES TO BEREAVEMENT - HOW CHILDREN GRIEVE

"When bereavement occurs, a child will experience the same range of emotions that adults do, from feelings of shock and disbelief to numbness, despair, anger and guilt."

Smith, 1999, pg. 12

Children's reactions and responses may be as acute as those of an adult, but what they may often struggle with is articulating or explaining "what" or "how" they feel.

They find it hard to identify or name their feelings and emotions sometimes because they do not have words other than "sad" or display their feelings more abstractly through their behaviour or physical manifestations, such as a headache or stomach ache.

Sometimes children find it hard to explain how they are feeling because they do not completely understand what is happening and are in a muddle. They may not have all the information about what has happened or they have been told inconsistent stories and so struggle to believe what is the truth.

"A change in a child's behaviour is often one of the first signs of reaction to a bereavement and [may indicate] they are struggling with these feelings." (Smith, 1999, pg. 12)

DEVELOPMENTAL UNDERSTANDING OF DEATH AND LOSS

It must be remembered that children develop emotionally and physically at different rates and the same could be said about their understandings and responses to serious illness, death and bereavement. Coupled with the uniqueness of each child's experience and other factors that impinge upon their bereavement, the following is designed as a general guide only and each child will need to be assessed within their own individual context, experience and understanding.

0-5 YEARS

As discussed in the previous chapter, the ideas to do with attachment and separation can be viewed as particularly pertinent for this age group. Even a very young child or a baby is aware of separation from someone who cares for them. They can be aware that person is "missing"/not there and may get anxious. Cognitively they may not fully understand the implications of the loss, but their behaviour may indicate their feelings of someone missing. Consequently, if a significant person dies when a child is an infant, it is important that an adult helps them construct a memory of that person and ensure that they have significant/poignant mementos to remember that person by e.g. photos, a letter, a family history. This may be very important for a child at a later age when they want to talk to someone about the person who died and understand their own individual relationship and involvement and know that this relationship was valued as important.

For very young children under 5 (although not exclusively), the concept of death as being permanent, final and forever is a difficult idea to relate to. They may think that death is reversible and worry about who will take care of the dead person - such as who will bring them food, how will they keep warm, will they still have birthdays when they are dead? They may ask questions such as "When is Mummy coming back from heaven?" or "When will granddad stop being dead?". They do not have a general understanding that death is universal and therefore includes them. They may use words such as "dead" without fully understanding its implications or meanings. Children under 5 years can find abstract explanations or euphemisms difficult to understand e.g. someone being buried but also going to heaven, death being described as going on a long journey or as a long sleep. This may raise subsequent problems such as worrying about going to bed or about people going on journeys and not coming back.

'Magical thinking' or omnipotence is a concept which relates to the idea that sometimes children think that their behaviour, thoughts, wishes and actions may cause things to happen to them and other people e.g. because they were being naughty, that is why mummy died. If they are really good, then daddy will get better.

Children of all ages need to be reminded that nothing that they did or did not do caused someone to die - it was not their fault. They need reassurance they are not that powerful and sometimes things happen for reasons that cannot be explained.

This is not exclusive to the under 5's. Sometimes when we are dealing with very complex situations that we do not understand, there can be a sense of responsibility to try to understand what role we played in it happening.

Children of this age may not easily differentiate between feelings as much as older children, but they can demonstrate age appropriate feelings and responses to their loss and experience. As their cognitive understanding is limited, they may not show as much reaction or response to the news that someone has died, e.g. they may be told someone has died and then may respond by asking to go out to play. Similarly, children are often very able to 'dip in and out of their grief' and this is worth considering in terms of their response. Children of all ages are able to grieve as well as engage in other activities and it is important that this is both legitimized as acceptable and encouraged.

When working with parents and very young children, it is important to remember to explain things to the child using simple, appropriate language that the child is used to, and to give them information in small amounts e.g. little and often, not all at one time.

It may be helpful to use toys, role play and play when explaining along with words and talking. If children ask the same question repeatedly, it is important to maintain consistency in the information and responses because that is the way they learn and understand. They are also learning to trust the information they are receiving from the adult as being the same each time they ask questions.

5-10 YEARS - SCHOOL AGE

Children of this age have a broader social network, beyond the immediacy of their family, as they are attending school. This may affect what they know, what sorts of information and ideas they are exposed to regarding death and bereavement, who they can trust with their feelings and worries, and how they can display and share their emotions and experiences. Children within this age group are beginning to develop a sense of independence and identity beyond their family, and their peer networks and friends are beginning to have a more substantial influence.

Children in this age group are developing an understanding of death as permanent, irreversible and that life functions end when you die.

Children are beginning to understand that death is universal and that includes them, that one day they are also going to die. This may also mean that children will worry about other people that they are close to and care about, e.g. if daddy has died, does that mean that Mummy is also going to die? They may want to know about the process of death, what exactly happens, what caused the death or the illness, how long it takes for a body to become a skeleton. They may want to see for themselves and to view someone after they have died. They have a need for details and appropriate facts. Along with the need for factual information, children are beginning to develop an emotional vocabulary in order to fully understand what is happening to them and their family.

Often at this age, when children do not fully understand the 'facts', they may find it very hard to express the appropriate emotional responses. Children may display a curiosity about rituals such as funerals and what happens with the body after it is dead and may act things out as a way of understanding what has happened. They may also use play as a way of making sense of something that they do not fully understand or has not been explained to them in an age appropriate manner.

It is important, therefore, to be honest and consistent with explanations, to use appropriate language, but not to tell them everything at once as it can be too difficult to cognitively and emotionally manage.

Irrespective of age, it is generally better to involve children in what is happening earlier on when someone is ill, so that they can begin to understand and come to terms with what is happening, rather than wait until the last minute or omit their involvement. If children understand what is happening, they are generally able to make decisions about how much or how little they wish to be involved.

Children of this age are becoming more aware of people's reactions and coping mechanisms and this is often the age that we start offering children individual support. Prior to school age, much more the work is offered indirectly via parents/care givers. Children between 5 and 10 years are able to comprehend the perspective of others and may show appropriate compassion to other peers who have also been bereaved and share the experience. There is quite often a sense of not wanting to be the only one and wanting reassurance that there are other children who have also been bereaved and may have similar feelings to them.

Children may copy or mimic the emotional and coping reactions of the adults around them, they may protect adults from their true feelings for worry of

upsetting the adults further, or worry that they will be told off for feeling that way, e.g. they may feel angry when everyone else in the family is crying and upset. They need permission to display all types of reactions and emotional responses and reassurance that there is no one way to grieve. Similarly parents with children of this age may need reassurance that their child is responding in an age appropriate manner.

Children of this age may often ask lots of questions and require honest, thoughtful answers. If you/or the adult do not know the answers, then it is okay to say that you do not know, but that you will find out and let them know. It is vital to remember not to make it up or lie to them. It is important to be aware of not giving any child of any age, "ready made" explanations about serious illness and death. This may diminish their own individual experiences.

Remember that there is no one answer to questions such as "Why did my mum have to die?" It is always helpful to find out what the child knows first rather than provide them with your explanations.

ADOLESCENTS - 11-16 YEARS

Children of this age have developed a greater awareness of death, the long term consequences of loss and especially its emotional aspects.

This may be coupled with feelings around implications such as "Who will take care of me?", "Who is going to pay the bills and look after Mum?" and "Am I ever going to stop missing my dad?". Teenagers often have thoughts around 'the meaning of life' and this may be intensified by the experience of the death of someone close to them. They may also be very busy living their lives and developing independence outside their family and appear to be burying their feelings around their loss. Adolescents are able to grieve a lot more like adults with feelings of sadness, confusion, anger and depression but they may also find these very intense emotions difficult to manage. For example, they may be feeling very angry and getting into physical fights with parents or other people. Teenagers respond to their bereavement experience, like other age groups, in a variety of ways.

They may display **risk taking behaviour**, using drugs, alcohol and self harming as a way of gaining control or dealing with their grief. Such young people may require guidance to adopt safer more appropriate ways of managing their bereavement. They may withdraw or appear detached from the situation and may avoid being around parents or other family members. They may revert to childish behaviour and responses, or alternatively, act grown up and responsible for others within the family. These responses and others may be typical both for how an adolescent is coping with the bereavement as well as for adolescence and growing up itself. There may be an expectation within families that a teenager take on adult roles within a family, especially if it is a parent who has died.

However, it is important to remember that a teenager is still not fully grown up emotionally and cannot be expected to be treated like or behave like an adult.

Teenagers, like all children, need limits and boundaries and an awareness that the adults around them are still able to protect them. They require reassurance that they are loved and cared about when faced with these experiences. They also need information and access to support when they feel they need it.

RESPONSES AND FEELINGS

FEELINGS

DENIAL

For many adults and children, their initial response to the death of someone close to them may be of denial – “it does not feel real”, “it feels like a dream”, “it cannot be happening”, “it is not my parent who has died”.

Denial and feeling numb can often be the body's way of initially dealing with the experience, so that a person has time to assimilate their feelings and experience.

Children may engage with denial as a way of pretending that the death has not happened and life has not changed irrevocably. Their denial may be part of the family pattern of dealing or not dealing with the situation. They may demonstrate denial to mask their feelings, if they do not want to show their parent or family how they are really feeling.

However, children may be described erroneously as being ‘in denial’ just because they do not sustain their sadness and grief. It must be remembered that children actually respond to situations by dipping in and out of the experience. Children find it very difficult to sustain long periods of being sad in the same way adults do. It may perhaps be viewed as ‘healthier’ to dip in and out of grief rather than display long sustained periods of mourning which adults may, at times, feel compelled to demonstrate.

Children like adults may feel or demonstrate a range of other feelings that can include the following:

SADNESS

This may be the feeling that is most commonplace in discussions with children and adults alike when we talk about how they are feeling after a bereavement. It should not be undervalued or underestimated in terms of a very real and intense feeling.

ANGER AND ‘ACTING OUT’

Children may express feelings of anger about feeling abandoned, and about the parent not being there when they grow older and for special occasions such as weddings. They may feel angry towards the surviving parent especially if they are not told correct information or are excluded from important rituals such as the funerals and goodbyes. Sometimes children may feel angry as they worry life will never be the same and they will not be happy again.

GUILT, SHAME AND SELF REPROACH

Children, especially very young children, are quite egocentric and feel the world and its responses are because of them. They may worry that their behaviour has caused the person to die, e.g. that because they were angry, mummy died. Therefore, they may feel guilty for their behaviour or for subsequent feelings and emotions. They may perceive themselves as being ‘naughty’ or bad or having not done something to save their parent.

Children need to have reassurance that they did not cause someone's death.

ANXIETY AND WORRY

As a result of their experience of having someone close to them die, children may

naturally show worry and anxiety that someone else close to them will die. They might worry about forgetting the person who died, what they looked like or sounded like, so may feel that they need to re-tell the story or events over and over again or need reassurance that they will not forget. They may worry about their own mortality and that they too are going to die one day.

HELPLESSNESS

Children may feel helpless if they feel they are unable to help adults through their grief, stop them crying or make them happy again. They may behave as a good child in order not to overburden the surviving parent, but therefore may not have adequate opportunity to explore their own grief.

RELIEF

Many children and adults may have a sense of relief following the death of someone especially, if they had been ill for a very long period of time as the experience prior to the death can be very exhausting both physically and emotionally. There may also be a sense of relief if their relationship with the parent had been ambivalent, difficult or abusive.

CONFUSION

Children may be confused by the words or explanations that adults have given them around what has happened, especially if the situation was very complex. Children may be confused about how they should respond, particularly if they receive conflicting messages about "being grown up and not showing your emotions" then being told that it is okay to cry.

Children like adults may also show many other feelings in relation to their bereavement and these lists are neither definitive nor conclusive but include:

- Shock
- Disbelief
- Sense of presence
- Yearning
- Absent mindedness

Physical symptoms might include:

- Feelings of a hollow stomach
- Tight chest or throat
- Breathlessness
- Depersonalization - feeling out of body
- Weakness in muscles and general lethargy
- Lack of energy

PHYSICAL REACTIONS AND RESPONSES

When children are finding it hard to say what they are feeling or finding difficult, they may demonstrate their anxiety, worry or distress through their behaviour and play. This may be particularly typical of younger children, but is certainly not exclusive. Older children and adolescents, who are finding it hard to articulate their experience, may show indicators of their difficulties through a change in their regular behaviour. The following reactions should be considered in understanding how a child grieves through behaviour indicators.

DISPLAYING PHYSICAL AND VERBAL AGGRESSION

Children may use naughty behaviour and/or have tantrums when they shout and scream. This behaviour may frequently be directed at the adults who care for

them, either the surviving parent or possibly another relative or someone close to them like a teacher or counsellor.

It is important when children display behaviour like this, not to label them as good or bad. The child is not being bad, but is actually displaying their difficulties with sad feelings. It is important to ensure that along with permission to feel sad, that they also adhere to appropriate boundaries such as “it **is okay** to feel angry, mad, sad... but it is **not okay** to hit someone or hurt someone including yourself when you are feeling this way”.

Adolescents may demonstrate their behaviour through mood swings, which may be either frequent and/or unpredictable in their outbursts, as they deal with a wide of range of varying and intense emotions.

REGRESSIVE BEHAVIOUR

Regressive behaviour is not exclusive to bereavement, as often when a child is struggling with a change in their environment and situation that they do not feel comfortable with, they may revert to earlier forms of behaviour. Children may unconsciously revert back to behaviour indicative of when they perhaps felt safer or more secure. Examples of this behaviour may be sucking thumbs, baby talk, using fingers to eat food, tantrums, bedwetting and soiling. This behaviour will generally improve as the child has opportunity feel safe again and express their fear or worries.

SLEEP PATTERNS

Children's sleep patterns may alter as a result of bereavement. Children may experience nightmares or bad dreams, not wanting to sleep with the light off, not wanting to sleep, or waking during the night. This might be more complicated if a child was told that when someone died they ‘fell asleep’ or if someone dies in the night while the child is asleep. They may also be vigilant and watchful at night in case something else happens.

EATING

A child's eating may be disturbed by not having much of an appetite, comfort eating, or being fussy about what they eat. This may also be exacerbated if family routines and patterns have been altered due to the bereavement. For example, the person who usually cooks the meals is different and the child is eating at different times and in different places.

It must be noted that only drastic and persistent changes to a child's eating behaviour should be viewed as an indicator of distress and extreme difficulty, unless it occurs in conjunction with other difficulties.

PHYSICAL MANIFESTATIONS

Bereavement and mourning can be a physically exhausting experience for adults and children alike, particularly if the experience has been protracted or especially traumatic. Children may complain of physical ailments as a response to the emotional pain they are experiencing. They may complain of headaches or tummy aches or may try to explain how they are feeling as being like a sore head or a sore tummy. They may be able to understand that sometimes feelings can actually hurt inside, especially if they are kept inside and not talked about.

Children may worry about contracting an illness and getting very sick, possibly worrying about theirs and others own mortality through their experience of someone dying. They may demonstrate some of the same ‘symptoms’ as the person who died. For example, where daddy died from a brain tumour and a child complains of persistent headaches, or where a parent died from lung cancer and

suffered from breathlessness and a child experiences panic attacks and feel they are having difficulties with their breathing. It may be important for a child at this time to see a doctor for some reassurance that their responses are in relation to grief.

SCHOOL DIFFICULTIES

One of the places that children may indicate how they are feeling is at school. Unlike everywhere else, it may be the one place that has not altered following bereavement. Consequently, school may be viewed a safe place to either not talk about what has happened or conversely express their worries. Some areas to consider in terms of child's bereavement response and school include:

- They may worry about attending school. They may worry about leaving a surviving parent at home and may worry that something may happen while they are away at school.

- They may find it very hard to concentrate on lessons or find it hard to contain their emotions throughout the school day. Alternatively, they may become highly focussed on achievement and being good as a way of forgetting their grief. This behaviour may in fact mask or hide how a child is truly feeling.

- They may find it hard to relate to their peers for fear of being perceived as 'different'. They may worry about being asked questions for which they do not have the answers or they may not want to disclose specific information about regarding the death. They may worry about being teased by peers if they display emotions such as crying, or worry they will not be believed when talking about their experience.

Ways of working with schools along with the child and the family will be discussed in more detail in chapter 3 – "What You Can Do".

SITUATIONS WHERE CHILDREN AND FAMILIES NEED HELP FROM PROFESSIONALS

There may well be times when the helper becomes concerned that the welfare of the child is at risk, either that they are at risk physically or emotionally from others, or their psychological condition has deteriorated. On such occasions, it is important that the helper personally seeks advice from the statutory agencies, or encourages the family to refer themselves. In cases where there is immediate risk to the child, such as neglect or abuse, the helper should actively seek professional help for that child.

ENSURING THAT THE CHILD IS CARED FOR

Some families may not be able to cope with their own grief, to the extent that their parenting capacity is completely diminished, or their personal circumstances prior to the loss ruled them out as alternative carers for the child. If the child has no surviving parent, there may be times when the extended family may help. If this is not possible, then a viable alternative carer will need to be found. This is where professional help will be needed.

In such cases, there may well be an ongoing task for the helper in ensuring that the emotional health of children who are separated from the primary carers is promoted, and that they have the opportunity to form positive attachments to alternative carers. Given the long-term effects of a lack of attachments, the work of alternative caregivers is crucial, as children need ongoing relationships to continue their growth and development. Some children, who end up in alternative care settings and have no viable family to care for them or have moved from one family to another during the demise of the primary carer, do not experience the continuity in relationships necessary for identity formation. They often have not received the help needed to grieve the separation from their significant others. This is important as unresolved separations are known to interfere with the formation of new relationships.

Advice and help to alternative carers may be needed to facilitate healthy attachments, particularly when some children have experienced adults as 'unsafe'. Frustrated and abusive parents often have no experience of discharging their emotions in non-harmful ways, and turn these feelings on to the child by harming them physically or emotionally. Some adults withdraw and neglect their children, and some misuse harmful substances. None of these behaviours are a good role model for helping children to interact appropriately.

This could mean that many children are unable to tell others how they are feeling, and as a result, expressions of emotion are associated with getting physically hurt, so they do not verbalise these. However, often these children have good reasons for having strong emotions, which if not understood can result in severe behavioural and mental health problems in the future.

Helping alternative carers understand the meaning of children's interaction with adults could make a significant difference to the outcome for children who have been separated from their primary attachment figure. Such children have a better prognosis if their attachment difficulties are understood, and appropriate intervention or treatment from a mental health professional is provided.

SITUATIONS WHERE MENTAL HEALTH PROFESSIONALS SHOULD BE CONSULTED

Briefly, the main stages of grief are:

- **Shock**
→ This stage is evident by the child's mechanical behaviour and such reactions as disbelief, denial, numbness, and concern for self.
- **Suffering**
→ The child shows despair, depression, sadness, hurt, anger, and worthlessness, suicidal thoughts, fatigue, and a variety of psychosomatic symptoms.
- **Recovery**
→ The child begins to look ahead and become involved with life once again but may regress into a previous stage during holidays, anniversaries, or other special reminders of the dead person.

However, if the child becomes stuck in one phase and fails to reach the recovery stage, then this may be an indicator of a pathological state and professional help will be needed. The important factor in this is the length of time for which the person experiences the symptoms. Separation by death may not be the only situation where depressive illness can develop. The loss of family members as a result of other circumstances can be just as traumatic for the child. Children of all ages are capable of demonstrating 'unhappiness and misery', but the concept of a depressive disorder, which is an enduring affective state producing functional impairment, has evolved over the last two decades.

It has been found that mood disorders in children appear to resemble those seen in adults, except with an earlier onset. (*Beardslee et al, 1983*) Prolonged and severe primary symptoms of a depressed or irritable mood, and a decreasing ability to experience pleasure, may indicate a depressive state. Depression can occur even if there is no family history of it. Major depression usually displays itself in episodes (i.e. it comes and goes without remaining constant), and may affect academic performance and family life. However, it may be more prolonged, leading to a gradual decline. Major depression in childhood has far reaching implications with respect to cognitive function, social interactions in childhood, and lingering impairment in adulthood.

Since there are many features of depression, such as anxiety symptoms, poor concentration and conduct problems, these need to be viewed in the context of where and when they occur in order to establish a diagnosis. This is where professional help is clearly needed. In very young children, where verbal accounts cannot be taken, non-verbal presentations such as a persistently sad or expressionless face and a failure to smile may indicate a pathological condition. Older children are more reliable informants in describing inner experiences such as mood status, hallucinations, or suicidal and other subjective thoughts.

Adults should be alert to any changes in the child's usual 'personality style' and where they exhibit behaviours such as severe temper tantrums or poor frustration tolerance. New onset or marked increase in anxiety symptoms, separation difficulties, phobic symptoms regarding school, fears of the dark or preoccupation with impending doom, need to be taken seriously. Deterioration in school performance, poor concentration, decreased confidence and increased

sensitivity to criticism, should also be noted. Refusal to go to school is a manifestation of distress that is often associated with depressive or anxiety disorders. (*Bernstein and Garfinkel, 1986*)

Somatic symptoms, and feelings of hopelessness particularly in younger children, are not uncommon in depressive illness, and suicidal thoughts are cognitively linked to this. There is now a steady increase in completed suicides through puberty and adolescence. (*Shaffer and Fisher, 1981*) Although major depression at any age may have serious and long term ramifications for the individual and family, there is evidence to suggest that the earlier the onset, the slower the recovery. Furthermore, once a child has experienced one episode of major depression, the probability of another episode within five years has been found to be 72%. (*Kovacs et al, 1984*) For this reason, it is important for adults to be aware of the possibility of children, including quite young children, developing depressive illness, particularly following a traumatic event like the separation from and loss of a parent or significant attachment figure.

A suspicion by the helper that a child's emotional state is giving cause for concern should be discussed with a mental health professional without delay.



UNDERSTANDING LOSS AND REACTION TO DEATH

Points to remember:

- Children of all ages are able to grieve.
- Children of all ages may need to be reminded that nothing that they did or did not do caused someone to die. They need reassurance that it was not their fault, they are not that powerful and sometimes things happen for reasons that cannot be explained.
- Irrespective of age, it is generally better to involve children in what is happening earlier on when someone is ill, so that they can begin to understand and come to terms with what is happening.
- It is important to use appropriate language and be honest and consistent with explanations.
- Children may ask you detailed and complex questions about illness and death. Before giving an answer, it is always helpful to find out what the child knows first. It is OK to say that you do not know the answer but will find out and let them know. Do not lie or make up an answer.
- Children may find it difficult to sustain long periods of being sad in the same way adults do and may, instead, dip in and out of the experience.
- Sometimes children and families need help from professionals. Where you become concerned that the welfare of the child is at risk physically or emotionally, it is important to seek advice from statutory agencies and encourage the family to refer themselves. In cases where there is immediate risk to the child (neglect or abuse), you should seek professional help.
- If a child's emotional state is giving cause for concern, the situation should be discussed with a mental health professional without delay.

See Annex 1 for the Emotional Resilience Checklist.