

Chapter 3

WHAT YOU CAN DO

There can often be anxiety or worry amongst professionals and people faced with supporting a bereaved child - "What can I do?", "What if I get it wrong?", "Who can I refer to?"

This chapter aims to provide a framework of what sorts of things you can do when working with children individually, with families and with other agencies, and highlights the factors to be aware of when providing this support.

WORKING WITH BEREAVED CHILDREN

When families are faced with the reality of bereavement, it can be very difficult for children to articulate their worries and fears about what is happening, what is going to happen and who is going to take care of them. They may worry about talking about these anxieties with a family member for fear of overburdening them or they may not understand what has been explained to them. It is important for children (and adults) to be able to talk through their feelings, worries and concerns within a safe appropriate environment.

Children faced with bereavement need:

- ✓ to be reassured of the normalcy of many of the feelings they are experiencing
- ✓ to know that someone can 'contain' their emotions and that person will not be hurt by anything that they say
- ✓ to talk to someone who can clarify some of the complex explanations that often go with an illness such as cancer
- ✓ to explore their questions of why and the subsequent feelings of it being unfair – "Why did my Mum/Dad/sister/grandparent die?"

Individual work with children can be offered both pre and post bereavement depending on the child's and family's needs and responses to the situation, and what else is happening to the family at the time.

When working with children individually, it is appropriate to suggest to the family that you will work with the child for an initial number of assessment sessions. This involvement can then be reviewed and the family can be consulted as to how things are progressing or changing. 4-6 sessions may provide an appropriate amount of time to develop a relationship with the child where they feel they can develop trust and consequently open up. It would be quite unusual for children to open up in the first session. After the first set of sessions you can reassess the need for involvement.

It is important to be child focused in these interventions and to go at the child's pace. It may be appropriate to give some specific focus on areas to find out or clarify exactly what a child knows without it being too directive. It is important to find out exactly what the child means when they say, for example, 'cancer', 'chemotherapy' and 'dead'.

WHO SHOULD PROVIDE THE WORK AND SUPPORT?

It is possible for a range of people to offer support to bereaved children and their families. They include social workers, art therapists, counsellors, nurses, psychotherapists, psychologists, play therapists and trained volunteers.

Individuals working with bereaved children must have the following vital skills and knowledge regardless of professional training or prior experience:

- A good understanding of a child's emotional, cognitive and physical development;
- The ability to use supportive listening skills, without necessarily having specific training in counselling or therapy. The importance of being empathic and child focused in listening is a core skill;
- The ability to work at the child's pace and be non directive in many of their interventions, while recognising that some tasks may need to be directive in some circumstances. To enable the child to have a space to say, draw, play and express their feelings;
- The ability to clarify what a child is muddled or confused about while refraining from telling the child what to think or do;
- Consistency, so that a trusting relationship can be established and provided; and
- The ability to recognize their own emotional issues and not let them impinge on their working relationship with a child.

In addition, it is important that individuals working with bereaved children have had access to appropriate training regarding bereavement issues. Individuals must also have access to appropriate support and supervision themselves.

CONFIDENTIALITY AND TRUST

It is important when working with bereaved children that an appropriate level of confidentiality and trust is maintained.

- A child needs to feel safe when talking about subject matter, feelings and experiences that they may not have discussed with anyone else before. This is why working consistently with the same adult can enable a child to build up a trusting relationship. In addition, if the staff providing support change frequently, the children will have to continually retell their story and this may impact upon their coping mechanisms.
- A child needs to know that what he says will not be discussed with lots of people unnecessarily.
- It is important that children know or are aware that the adults working with them are not going to get too emotionally involved or upset when they talk about difficult/emotive topics or memories. It is important to maintain appropriate emotional distance.
- It can be difficult when a child is sharing their memories or experiences to not want to hug them. However, physical contact should be used with limitations, so that it is not misconstrued by the child or used as a barrier to a child openly showing their feelings.

Such an approach helps to develop a positive therapeutic relationship - the child is aware that they can trust you and that you are able to manage their difficult feelings, emotions and questions.

BUT you cannot guarantee 100% unconditional confidentiality with a child.

There are some things that you need to take away from the individual or group session to discuss with someone else.

- It may be necessary to seek clarification of factual information.
- There may be child protection matters or risky behaviour by the child that cannot be kept private as the child may be at risk, and which need to be dealt with by the appropriate statutory agencies.

It is vitally important that the issue of confidentiality is discussed when you first start working with a child or group (during the initial contact) and that the child understands that you cannot guarantee 100% confidentiality and why. Ensure that the rules or guidelines on confidentiality are written down and agreed upon, and that the parent is aware of confidentiality and boundaries.

Refer back to chapter 2 – Situations Where Children and Families May Need Help From Professionals

WAYS OF WORKING WITH BEREAVED CHILDREN

There is not one definitive way of engaging with a bereaved child. The method for engagement with the child depends upon the age of the child, their emotional language and understanding, the particular skills of the worker, what 'tools' are available and developing a language and a space within which a child can explore their emotions using whatever medium they feel comfortable with, in order to give meaning to their experience.

PLAY

Play therapy is growing in its popularity throughout the western world, (writers include Virginia Axline and Ann Cattanach) but the ideas of play are not a new thing. *"Since play is his natural means of expression, the child is given opportunity to play out his accumulated feelings of tension, frustration, insecurity, aggression, fear, bewilderment, confusion". (Smith and Pennells, 1997, pg. 69)*

Children do not often just sit and talk like adults do. Play is a way that they make sense of their world, not just with bereavement. It may be very difficult for children to articulate what is wrong or what is worrying them, but through play they may be able to give more expression to their world and their story. They may dress up/use role play and act out what they are confused or worried about e.g. hospitals, doctors, dying, funerals, what is happening in their family or home, their fantasies about what happens when you die, role playing what happened or how they may have wished it could have been. Non directive play is one the most appropriate ways of engaging with a child as it enables them to tell 'their' story.

If a worker is involved in the play, they may be directed by the child and do what the child wants them to play and be part of the child's story.

Children may use soft toys, dolls houses, dress-ups, puppets and dolls to help explain what is happening or what the child is worried about. They may feel they

can talk 'through' the toy if they are worried about saying something directly themselves.

Play therapists predominately use play in their work and have received additional specific therapeutic training. This is often psychodynamic in its approach looking at a child's internal and external worlds and where the conflict may exist. Individuals often undertake post graduate study to become play therapists. However, skilled and sensitive individuals can incorporate elements of play into their interventions with children, particularly, although not exclusively, with younger children, who quite freely use play as their predominate form of expression both when they are worried as well as within their normal range of daily expression.

TALKING AND COUNSELLING

Sometimes children just need a space to be able to:

- talk about things that worry and confuse them;
- talk about what makes them scared or angry;
- ask questions about why and how things have happened; and
- ask about who is going to care for them now.

Sometimes they may feel that they are not able to talk to family members or parents about these feelings as they may worry about upsetting them and making them cry. They may not receive the answers that they are seeking or they may not know how to put into words what is worrying them. Particularly for older children, it may be important to have a space that enables them to receive legitimization of their feelings and experiences – to be reassured that they are not going mad or thinking the wrong things, and that their feelings and ideas are in fact normal in terms of bereavement.

By enabling children to have a space to talk, you are able to encourage children to 'tell their story' and how they perceive things to have happened or how things are now, without interpretations by siblings or other family members.

It is important when working with a child, who is telling their story, not to guess what the child knows or give them your explanation of the story or events. Sometimes it is most useful when a child asks what or why, to ask them what they think as this not only legitimizes their story but can also assist if there are misconceptions, discrepancies or lack of information.

There are many sorts of 'talking therapies/interventions' including person centred, gestalt, and psychodynamic. Professionals may have had additional specific training in one or several techniques, but talking and listening can also be used in conjunction with other interventions.

What is important to the child is:

- ✓ the use of appropriate language;
- ✓ the use of a safe space;
- ✓ the use of empathy and understanding; and
- ✓ for the intervention to be based upon the child's needs.

DRAWING, ART AND CREATIVE EXPRESSION

Alongside play and talking, children also express their feelings and experiences through art and creative expression. They may show how they are feeling by

using clay, paints, collages, and by drawing alongside their verbal expression of what has happened. They may depict their feelings, memories, fears and images to do with the person who died. By not focusing solely on verbal communication and by enabling a child to demonstrate their experience creatively you may gain a better understanding of what is hard or difficult for them that they have not spoken about before. By using the intervention of drawing, painting, and creating, you can provide a child with permission to get messy, which is important as often feelings and emotions can feel messy and muddled. Children may want to make something tangible when feelings can feel very intangible.

These interventions can be used by a number of professionals as part of the range of support that they provide to children. Art therapists, however, have had specific training in use of these techniques in a specific therapeutic relationship and may work intensively over long periods of time with children and individuals who need this specialist intervention.

SOME PRACTICALITIES TO CONSIDER

Before embarking on individual work with a bereaved child, it is important to think carefully about the following issues.

WHERE ARE YOU GOING TO WORK?

It is helpful to be able to have access to a room or a space that is private and quiet, where you are not going to be interrupted. It can be helpful for that space to be consistently available so that a child becomes comfortable within a familiar space and they know that this is where they can talk about their experience. For many bereaved children they may *“feel that their lives have been turned upside down. Security offered by regular sessions, at the same time and in the same place each week, offer a certainty that the rest of their lives may lack”*. (Smith and Pennells, 1997, pg. 75) It may be that some support is offered opportunistically, but for regular support work a fixed day/time/location is preferable.

This space may be within a hospice, hospital, school or in an office. It can be difficult to work with children within the family home as it is not a 'neutral' space. However, it may be very important to offer to have the initial meeting with a child and their family at home, in an area that they are familiar and comfortable with, before a child chooses whether they want to talk with you somewhere else.

In choosing a location, bear in mind that a child may want to be sure that no one is going to be able to overhear what they say. It may also be important that they are able to make a mess in that room. Ideally the space should be a child friendly room. There should be somewhere comfortable to sit, tables and chairs that are the right size for children if available, drawing and art materials, paint, paper, glitter, glue, pencils, crayons, pastels, clay, plasticine, toys such as dolls, dolls house, sand trays, blocks, Lego, clothes for dressing up and props such as a toy 'medical kit', so that they can act out stories. (Where appropriate and safe, real medical equipment, such as a stethoscope, can be used).

HOW LONG SHOULD YOU WORK FOR?

An individual session may generally be between 50 to 60 minutes, and not more than one hour. At the beginning of the session, let the child know how long you are going to be meeting with them and then give them a reminder near the end of a session, so they know that the session is soon going to be coming to a close.

Often children want to tell you things right in the last 5 minutes which can be difficult when you have another appointment, or you know that you will not have the time to devote to that area. It is important to acknowledge the importance of the topic and to suggest to the child that you talk about that topic in the next session. You can reinforce the importance of what they have said by making a note of the topic with the child and ensuring that you bring it up with them at the next session.

Similarly, it is also very important to allow some time before the end of the session to 'de-brief' with the child, so that they do not return to their parents or care givers unnecessarily full of lots of emotions that they will need to hold onto until the next session. It might be worth suggesting to them the worries or emotions they can leave in the room with you until you see them next time, or asking them what they are going to be doing when they leave you, thereby focusing on their life away from their bereavement experience.

Wherever possible, try to give a child a list of dates of sessions in advance, so that they know when the next session is. It is helpful to provide children with a copy of this list, which they can keep at home. Keep another list with you for the sessions, on which, together with the child, you can mark off each date that he attends with a tick or a sticker.

It is important to consider reviewing the support you provide to a child with their family or care provider. Firstly, this also allows the child to know that there is a planned anticipated ending. Secondly, it is important of this is that a child's experience should not be viewed as separate to the broader experience of the family. A clear role when supporting a child may be to help facilitate difficult discussions with family members or help with explanations, but also it may be to help a child feel a part of a family experience and not on their own. This review may or may not involve the child. However, they need to know that you are meeting with an adult and not talking without their consent. If they want to be involved, check with them beforehand what they want to have included and what they want the adult to know. In this instance, you may need to be directive in that conversation as you may feel, for example, that it is important for the parent to know that the child is worried that someone else is going to die in their family, or that they do not fully understand what dead is, or that they want to attend the funeral but do not know how to tell Mum.

It is important to have an understanding about when to refer a family or child to another agency or when they may require more specialist intervention other than bereavement support. This has been highlighted earlier in this manual. It is important to be aware of when a child or family may be experiencing either pathological bereavement, which requires complex longer term intervention, or when their experience is coupled with a number of other factors which may require intervention from a more specialist service that may offer family therapy or mental health support.

Where you have provided consistent support to a child for over 12 months for example, you might want to consider referring the child/family to another agency that can deal with the more complex family based issues or specific issues separate to the bereavement.

It may need to be considered that children can return to the bereavement service at a later date, if they need support at a different developmental stage or if they experience an additional loss. However, an appropriate assessment and consideration of the child's current needs and difficulties must be carried out.

PRACTICAL IDEAS FOR ACTIVITIES WITH CHILDREN

The following practical methods of working with bereaved children are set out in Annex 3.

- Memory boxes and memory books
- Role play
- Questions and 'Doc Spot' session
- Drawing a picture of the person who has died
- Drawing feelings
- 'Feelings faces page'

IS THERE A NEED FOR BEREAVEMENT SUPPORT?

It is important to remember that not every child who has experienced bereavement is in need of external support or that they will necessarily experience problems.

Prior to bereavement support being provided, it is vital for a thorough assessment to be carried out to find out IF and WHY a child may require bereavement support.

The assessment should cover factors such as how the child is managing the bereavement, other losses that may be impinging at present, how the family is coping, and what the family's communication pattern is like.

Having a good understanding of what are 'normal' or 'expected' bereavement reactions and what is complicated and problematic bereavement is vital for carrying out such an assessment.

WORKING WITH FAMILIES

There are many ways of working with families pre and post bereavement. However, it is essential that you try and help patients and families understand the importance of children being appropriately involved in what is happening rather than being excluded or being told at the 'last minute'.

Although there is no one way of supporting a family, the following activities could be considered:

- Helping dying parents/patients write letters for their children possibly for special life events, for example, when the child turns 18, gets married, has a child;
- Helping parents/patients make a memory box/special container for a child to keep special things in. Children often make these to put in mementos that they have kept to remember the person e.g. photos, letters, clothing and jewellery;
- Helping parents explain to children about cancer, the treatments, what happens when you die, funerals, feelings;
- Helping parents to allow children to be involved in the mourning process with the whole family as appropriate;
- Helping parents share bad news and communicate effectively with their children; and
- Giving advice and making referrals for future care arrangements for children - a new carer may need to be identified where the child's carer is the person who is going to die.

This list is not exhaustive and support has to be based on each family's individual requirements and the need to respect each family's individual wishes.

WORKING WITH SCHOOLS

Children spend large amounts of their time within the school environment from an early age, and for many children, they may spend more time with their peers and teachers on a daily basis than they do with their parents and families. Therefore, one of the key agencies to work with when supporting bereaved children is their schools.

It is important for families to make their child's school aware that the family is going through difficult experiences, not just bereavement, and for the school to be kept updated about what is happening and key events within a child's life. Families should be encouraged to tell schools as soon as they know about something happening at home, so that schools can be as proactive and supportive as possible. If schools are made aware of the situation, they can provide appropriate support and intervention, be sensitive to children's individual experiences, and also raise awareness when a child may be struggling with a situation, if they notice changes in the child's attendance, behaviour, peer interaction and academic attainment.

For many children school is the one place that stays the same before and after a parent dies when everything else changes. The routine, consistency and boundaries it provides can be very important for children when everything else can feel like it is changing on an almost daily basis.

However, as mentioned in chapter 2, some children may worry about how they are going to manage within the school environment. They may worry about:

- what their peers are going to say;
- what questions they might ask about what has happened;
- getting upset or angry in front of friends and then being teased;
- who is going to pick them up from school; and
- what is happening at home whilst they are at school.

Children may want people to know what is happening or they may want to keep it private and this should be respected.

In addition to the child's school being aware of what has happened, it may be helpful for you to consider other issues:

- Communication between the family and the school is a key factor in helping a child return to school after a bereavement. The child may want to choose how their class/peers find out about what has happened - does the child want their class to be told before they return to school?
- The child may want to choose a member of staff other than their class teacher to be their specific contact and support person at school;
- The child may need a space where he can go during the day if he is finding it hard to concentrate, feeling upset or angry, or just because he wants to be on his own for while;
- The child may need access to individual support (with the family's consent) to be able to talk about what has happened. This may be provided in or out of school;
- It may help for schools to have access to age appropriate books and resources which deal with serious illness, death and supporting bereaved children;
- Training and support should be given to school staff, in addition to advice and consultation being available when they are dealing with bereaved children and their needs. Staff within schools may need to have support networks for themselves as their discussions with children may be

- particularly emotive; and
- Schools should provide a supportive environment for children. In particular, schools should be aware of anniversaries and special days for a bereaved child. It must be recognised that children may grieve over a protracted period of time and need support to do so.

OTHER INTERAGENCY COLLABORATION

Children and families faced with bereavement very rarely live in isolation. They are a part of broader social networks and may have concurrent involvement with other agencies alongside the agency that is providing bereavement support. Therefore, at times, you may be involved with a family who also has involvement with social services/statutory agencies. A major function of social services and statutory services is to ensure that the legislative framework for children and vulnerable populations is upheld and they have statutory responsibility for the welfare of children. Child protection concerns including abuse and neglect do also occur with families faced with bereavement and it is important that child protection concerns are dealt with sensitively by the appropriate agency.

When there are a number of other agencies concurrently involved with a child and family the following issues should be considered by all the personnel involved:

- Who is supporting the child at home? Does the child need alternative care now or when the parent dies?
 - Where children are removed from the family or in situations where the single parent of the family dies, every effort should be made to keep siblings together or, where this is not possible, to ensure that regular contact is maintained to avoid secondary losses.
- Who will provide the bereavement support if it is required/assessed as appropriate?
 - It can be very difficult for a child to 'split' their emotional time. When working therapeutically with children, it is not generally viewed as good practice for lots of people to be doing lots of different things around their loss. The important thing is for the right person to engage with that child and provide some consistent time and space. The work should be done consistently and sensitively. It needs to be age appropriate and within the context of what else might be happening for that child and family.

TAKING CARE OF YOURSELF - STEPPING BACK FROM THE FAMILY'S PAIN

It is well known that people who are experiencing acute stress often have to offload these overwhelming feelings on to others, in order to survive emotionally. This can leave the helper with a range of intense feelings from the bereaved including feeling drained, depressed, angry, frustrated, abandoned, alone and sometimes abused as a worker. It is important for helpers to ensure that they can access psychological and emotional support for themselves, as they may well become personally at risk of physical exhaustion, or may unwittingly transfer the feelings back onto those who cannot cope with them in the first place. By revisiting the negative interaction cycle, it is possible to understand how this can happen.

Although workers will be keen to avoid this, often the levels of emotion are so intense in such families, and in particular bereft children, that a transfer of negative emotions back to the sender could happen unconsciously. Those who work with such sad children will know how difficult it is to just stay in the same room for any length of time with someone who is depressed or passively aggressive. It can make the helper feel very inadequate and not good enough, and the same emotional defence mechanism as used by the bereaved person naturally comes into action. This can prompt helpers to react in ways that they otherwise would not do, if they had been able to reflect upon the cause.

Therefore, the ability to stand back and not take the feelings personally, will help the worker to achieve a safe, trusting, calm and consistent relationship with the referred person. It is important that helpers understand that their own need for emotional support is vital to the delivery of a professional service, and should not be mistaken as a sign of personal weakness. Indeed, quite the reverse is true. If workers become overwhelmed by the onslaught of feelings from bereaved people, their ability to deliver a professional service is diminished.

Good professional working relationships between helpers and families are vital to achieving the most positive outcomes for support programmes.

WHAT YOU CAN DO

Points to remember:

- Not every child who has been bereaved will experience problems and need external support. A thorough assessment of the child's needs should be undertaken before any individual or group work is carried out.
- Trained professionals and trained volunteers (with no professional qualifications) can work effectively with bereaved children, as long as they have the right skills.
- An appropriate level of confidentiality and trust must be maintained with children. However, you cannot guarantee 100% unconditional confidentiality and the child must be made aware at the beginning of the instances when a matter cannot be kept confidential.
- When working with bereaved children, physical contact should be used with limitations, so that it is not misconstrued by the child or used as a barrier to a child openly showing their feelings.
- It is important to let a child tell their story without pre-empting what the child knows, or giving them your explanation of events. When a child asks 'what?' or 'why?', ask them what they think instead of immediately giving you own opinion.
- When working with a child make sure you use appropriate language, use a safe space, have empathy and understanding and also make sure that the intervention is based on the child's needs.
- Make sure the child knows how long each session is, how many sessions there will be, and when a review meeting will take place.
- Working with bereaved children can be emotionally draining. To ensure that helpers can provide effective assistance to children, they need to recognise their own need for emotional and psychological support and ensure that they can access such support.

See:

Annex 1 Emotional resilience checklist.

Annex 2 Information sheets for supporting bereaved children – breaking bad news, and funerals and rituals.

Annex 3 What you can do – practical ideas.

Annex 4 Case studies regarding work with bereaved children of different ages.