



Introduction

'I did not know what to say to him. I felt awkward and blundering. I did not know how I could reach him, where I could overtake him and go hand-in-hand with him once more. It is such a secret place, the land of tears.' "The Little Prince". Antoine de Saint-Exupery (1943)

'Children with learning difficulties do not exist in isolation. They have the same need for understanding, love and support in times of crisis as any child. They are not separate from the world and its effects. Their needs, however, can appear so overwhelming that caring families and professionals can themselves feel disabled.' (Judy Sanderson, *Interventions with bereaved children*, 1998)

Supporting bereaved children with learning difficulties presents particular challenges. Communication is often the main difficulty and relying on verbal communication alone when supporting bereaved children with learning disabilities is extremely limiting. So we must find different ways to reach each individual child. Every child is unique and different and there is no set formula for success.

Prout & Strohmer (1994), suggest that when working with people with learning disabilities there are two specific tasks to be considered: -

1. Providing the client with a language or way to communicate thoughts, feelings and concerns.
2. Providing avenues and activities to encourage expression.

It is our aim in this pack to try to address these challenges. We hope that you will find practical ideas to help you support the children in your care. Specific resources for this client group are few and far between but always remember that **you** are the best resource. You know the child, you understand their needs you have the skills - you know how to listen and you know how to communicate.

Many professionals feel de-skilled when dealing with bereavement and feel that they could do more harm than good. Hopefully this pack will help you to feel more confident in your own ability to 'share the journey' of bereavement with the children entrusted to your care.



SOME BASIC PRINCIPLES

- Remember every child is different. What works for one might not work for another. Your approach must be tailored to match the child's cognitive and developmental level.
- Use language the child can understand. Remember a child has a "concrete" understanding of language. Always be consistent with language - for example, using the word 'dead' rather than "lost" or 'gone to sleep' which might lead to confusion and misunderstanding.
- Liaise with other staff and family members to ensure consistent vocabulary. It is not helpful if one person is saying 'Mummy has died' and another is saying 'Mummy is with Jesus'. The child will wonder who is telling the truth and feel confused.
- Always try to check that what you have said has been understood.
- Encourage creative ways to express feelings e.g. music, art, dance and drama.
- Be truthful, if you don't know the answer to a question - say so.
- Be led by the child. There will be some days when the child simply will not want to talk about what has happened. Respect this and never try to force a conversation about the person who has died.
- Try to give children choices. For example, if the class is making father's day cards you might worry about the child whose father has died. Children have told us that in these circumstances they like to be asked what they would like to do. Some children want to make a card to take to the grave or to put in their memory box. Others may want to make a card for someone else. A few children choose not to participate and would prefer an alternative activity.

- Differentiation of materials and techniques is a key to supporting children with special needs. This may simply be a case of altering the language used, making concepts more concrete, reducing the number of ideas discussed and shortening the length of the session.
- Remember it is impossible **not** to communicate with children.
Children are sensitive to the changes in atmosphere around them and pick up on the emotions of adults. They sense tension, anger and sadness around them and may wrongly feel that they are the cause if the reality of the situation is kept from them. Often there is a desire to 'protect' the child which means that nothing is said or done about the bereavement. But the child already knows that something terrible has happened and feels confused and isolated and very alone with their powerful feelings.
- All bereaved children need the security of routine and firm boundaries. You may be tempted to relax rules and permit poor behaviour but this may not be helpful for the child. School becomes an oasis of calm and normality in a world that has been rocked, and maintaining routine and normal discipline is important.
- Remember that looking after yourself is important. Supporting a bereaved child can be stressful and can awaken the feelings and pain of your own bereavements. Staff supervision and sharing with colleagues can help you to feel supported.
- Access other sources of support such as your local Social Services Learning Disability Team. They have great expertise and will often be able to loan or recommend books and resources.

CHILDREN'S UNDERSTANDING OF DEATH

Children's understanding of death will vary with their age and stage of development. Young children may not have the language to talk about their feelings, and adults have to interpret their behaviour to be able to offer appropriate support. Likewise for adolescents who, although they may have the understanding and language, are often unwilling to communicate with the adults around them!

Pre-school children

- Are influenced by emotions of adults around them. React to loss, rather than death.
- Do not understand the meaning or finality of death - they think that the person will return or can be visited, so often react casually to bad news.
- Cannot grasp abstract concepts such as heaven, soul, etc.
- May show signs of sadness, but only for short periods before escaping into play.
- May use play to act out feelings about the death /funeral
- May transfer their attachment to another person quickly for security.
- May regress in language and behaviour,
- Will have a strong need for routine, boundaries, affection and reassurance.

Primary school children

- Begin to understand that death is final
- Begin to fear death for themselves and others - separation anxiety.
- May feel guilt/"magical thinking" (i.e. my thoughts/actions caused the death).
- Still may not have the language to express complex feelings
- Often need to know details of the death and will ask specific questions to try and make sense of the situation. May need to go over facts again and again.
- May exhibit attention seeking or regressive behaviour
- May use play to act out feelings about the death /funeral.
- May have difficulty concentrating/settling at school,
- Need routine, boundaries affection and reassurance.

Secondary school children

- Understand that death is final so may become depressed/feel overwhelmed.
- May become obsessed with thoughts of own death, or that of others.
- May act recklessly in defiance of death - drugs, alcohol, sexual activity,
- Dislike appearing different from peers so may reject offers of support.
- May question/reject beliefs, values and religion.
- Want some control over, and choices about, how things are managed at home/school.
- May withdraw from academic/social activities due to changed circumstances.
- May become work focussed in an attempt to blot out pain.



CHILDREN'S REACTIONS TO BEREAVEMENT

Grief is the price we pay for loving. It is a natural response to the loss of someone we love and can be a distressing and overwhelming experience that affects us emotionally, physically, behaviourally and spiritually. Reactions vary and may not occur immediately.

Remember, every child is different and will grieve in their own unique way

Children's reactions to bereavement will be influenced by a number of factors:

1. Their age, stage of development and understanding
2. Degree of attachment to the person who has died
3. Previous experience of illness, loss and death
4. Manner of death - long illness, suicide, accident
5. Support networks - at home and at school
6. Religious beliefs and practices
7. Ethnic and cultural background - specific belief system/rituals
8. Gender - boys are less likely to show emotion/talk about feelings

Some of the normal **emotional** reactions to bereavement might be:

- *Shock/numbness* - child may not show any immediate reaction as they struggle to absorb the implications of the news.
- *Denial/disbelief* - child may continue to talk about the dead person in the present tense - may try and find the person, be restless.
- *Panic/separation anxiety* - child may fear own or other family member's death, world becomes insecure, and child feels vulnerable.
- *Sadness* - child may be tearful /prone to sudden emotional outbursts.
- *Anger* - may be expressed in words or behaviour - signals intense pain.
- *Guilt* - child may feel something they did or did not do contributed to the death - often linked with anger and may lead to withdrawal or depression.
- *Exhaustion* - child may find grief physically and emotionally draining.
- *Despair* - child may feel overwhelmed, nothing will ever be right again
- *Helplessness* - child feels out of control of events
- *Regression* - child may need to revert to a time when life felt more secure

Some <u>physical</u> reactions might be	Some <u>behavioural</u> reactions might be:
Distress, tiredness, minor illnesses, loss of appetite, self neglect, decrease in activity, panic attacks, nausea, headaches, feeling cold.	Separation anxiety, school refusal Aggression, restlessness, regression poor concentration, forgetfulness, detachment, loss of motivation,

CREATIVE WAYS TO EXPLORE LOSS AND DEATH

(From 'Creative Ways of Working When Exploring the Bereavement Counselling Process' by Sue Read in 'Living with Loss')

- **ARTWORK** - The use of colour, paint and design can aid self expression and tension release. Barber C. (1999) has explored the therapeutic use of colour in conjunction with music therapy in an effort to help and relax individuals who have a learning disability and complex needs. This might include the use of drawings or pictures with a special focus and which need colouring or labelling. Such pictures can be found in the book 'When Someone Very Special Dies' (Heegaard, 1998). Copies of this resource are available at SeeSaw. Working at colouring or painting takes the direct focus off the child, lessening the intensity, yet providing a powerful trigger to both prompt and encourage inner thoughts and feelings. (Children who come to SeeSaw have told us that they feel more comfortable sitting alongside an adult rather than being face to face.)
- **FAMILY TREES** - Exploring family relationships can be a useful exercise and can give insight into the child in their family context. The family tree can be imaginatively designed or can be mapped out using stones, shells or buttons.
- **LIFE STORY** - At SeeSaw we are often asked to recommend helpful books for the children featuring stories about bereaved children. This can be difficult as the children cannot always identify with the pictures in the book and say things like 'but I haven't got black hair'. The solution to this is simple - make their own story book using drawings, photographs etc. This book can then be a vehicle for the telling and retelling of the story which is so vital in enabling children with learning difficulties to understand what happened. Families can find this constant need to re-visit the story very difficult so the book can really help the family to communicate. It also ensures continuity in the use of language. SeeSaw produced a whole series of books with one child covering such diverse themes as; 'My Mummy's favourite foods', 'When My Mummy Was in Hospital' and 'My Mummy's Funeral'. These books were very precious to the child and helped her to come to terms with what had happened to her. Sue Read writes, "life stories can be a very powerful way of identifying with an individual, and can be cathartic in bringing back memories (both good and bad) of issues and people that could be forgotten". They can also be a concrete record of work undertaken to review at appropriate times through the process of bereavement support". It is also possible to record stories on audiotape which the child can listen to.
- **MEMORY BOXES** - These are a way of storing memories. The child may like to decorate the box themselves. It could contain anything that has meaning for the child such as perfume or aftershave, favourite books, photographs, videos and tapes, clothing or jewellery. Most children find their memory box a great comfort and like to show its contents. This provides a different way to 'tell the story'.

- **VIDEOS** - These are a powerful way to explore reactions to (and preparation for) funerals, associated rituals and death. The Speak Up video 'Coping with Death' is just 10 minutes long and narrated by people with learning difficulties. The video represents the funeral in a simple way and repeats issues frequently to aid memory and recall. The video 'Grief in the family' and "Never too Young to Grieve" produced by The Leeds Animation Workshop are animated films exploring the way children respond to grief and what the adults around them can do to help
- **DRAMA AND POETRY** - These can be used to facilitate emotional expression. Children can make up their own poems or look at other people's work.
- **MUSIC**- A tape of the music that the dead person loved can be helpful. Judy Sanderson (in 'Interventions for Bereaved Children' 1998) tells the story of Peter. Peter had suffered severe brain damage in a car accident when he was 7 years old. Some years later his father died. Peter was quite unprepared. He did not see his father after death and because of his unpredictable outbursts did not go to the funeral afterwards. However, his mother felt strongly that he needed to know what was involved and arranged for photographs to be taken of her husband's body as well as the funeral itself. As he realised his father was not coming back Peter expressed a lot of anger. He regularly shouted and sobbed and became especially disruptive at mealtimes. It was important for Peter that staff and family understood why he was exhibiting such difficult behaviour. His expressions of loss, abandonment and grief were certainly very challenging but were understandable in the context of his father's death and Peter's inability to express his feelings easily. A supportive programme was arranged to help him.

Regular times to look at photographs were set aside and special efforts were made to praise positive behaviour. He had always enjoyed listening to traditional Scottish music with his parents so Peter was given a Walkman of his own with a special tape on which his mother introduced many of the tunes and songs. The music became very precious to Peter. It helped him to grieve and express many of his feelings. Sometimes when listening he would bang loudly on the table and he obviously found this a great relief as he sometimes laughed and sometimes cried.

- **CLASSROOM EXPERIENCES** - taking the opportunity to explain death in the course of everyday classroom life is helpful for all pupils. For example, if a classroom pet dies it is a great opportunity to show the children the difference between being alive and being dead. It is also an opportunity to give the pet a 'funeral' and involve the children in planning and talking about loss.



TALKING ABOUT DEATH WITH CHILDREN WHO HAVE

LEARNING DIFFICULTIES

When talking about death and bereavement with a child with learning difficulties it might be helpful to consider: -

- WHO should be key worker working with the child and family - inform parents who this person will be and keep in contact.
- WHERE is the child most receptive to new ideas? - quiet room, pool, outside. Use this space for talking with the child.
- WHAT should be talked about? (as agreed with parents). Ensure that you use the same language and ideas as the family to avoid confusing the child.
- HOW is new information normally given? - signs, verbally, pictures. Use the same format to talk about illness and death.
- HOW is new information normally backed up? - you will probably need to repeat information a number of times over a long period.
- PROCEED at a level, speed and language appropriate to the child.
- BUILD on information given - small bites of the whole, given gradually will be easier to absorb.
- REPEAT information as often as needed.
- WATCH for reactions to show the child understands - modify and repeat as needed.
- FOLLOW child's lead - if indicating a need to talk or have feelings acknowledged, encourage as appropriate.
- WATCH for changes in behaviour to indicate the child is struggling more than they can say and offer support as needed.
- LIAISE with other agencies involved with the child to ensure accuracy and continuity of information.



Using symbols to explain death and funerals

(taken from Erica Brown's book *Loss, Change and Grief*)

All children benefit from being given simple, honest "bite size" pieces of information about difficult issues - often repeated many times over. For some children with special needs, it might be more appropriate for symbols to be used to convey ideas rather than language. Here is how one mother explained a father's death and forthcoming funeral to her child.

Saying Goodbye to Daddy

(Symbols pages from Ericas book)

INFORMING PUPILS AND STAFF OF A DEATH

The death of a pupil, member of staff or a parent can have a profound effect on the school community. It is advisable, with the family's consent, to share factual information about the death with staff and pupils as soon as possible to avoid rumour circulating. It is also important to establish support networks for all who may be affected, and an on going action plan. You may find the following suggestions helpful.

Immediate Actions

- Identify a member of staff to be the contact for the bereaved family, and initiate contact to offer support. Discuss what information the family want disclosed, making sure you get the facts down accurately. Some families may not want all facts known, but it is important to point out that information gets around by other sources and can be more distressing in the long run if not accurate. If not done by staff, it means that the pupil is responsible for "setting the record straight" in school and that can be very distressing for them.
- Arrange a staff meeting (identify absent staff who will need to be told later) and give the information about the death as agreed with the pupil/family beforehand.
- Be aware of the impact on some staff for whom the news may have special significance - i.e. reactivates memories of own losses, or they may have been particularly close to pupil/family. Ensure appropriate support is available.
- Identify member of staff who will liaise with press/ governors/LEA/other parents/other agencies in the event of a major incident or death due to contagious illness e.g. meningitis. (refer to Emergency Planning Guidance).
- If acceptable to the pupil and /or family, explain the situation to the other students simply, factually and using correct terminology to avoid confusion, e.g. *"I have something very sad to tell you today. You may have heard about the accident on the motorway yesterday when two cars crashed into each other. Well Mrs Y was in one of those cars and was taken to hospital. I am sorry to have to tell you that she was so badly hurt that the doctors could not make her better and she died this morning"*. **This is usually best done in class groups by known teacher.** It is important to bear in mind the impact on key friendship networks. These may span different classes. It might be appropriate to give extra support/time away from the main group to those pupils particularly affected.

- Answer questions honestly and do not be afraid to acknowledge your own feelings. Help pupils identify theirs and give them the opportunity to talk about any concerns they may have and what the death means to them.
- If appropriate, after checking contents with the bereaved family, send a note home to other parents to let them know what has happened, what actions the staff have taken and what support is available for the children so that parents may be aware of possible repercussions at home. Keep lines of communication with families open.

Ongoing Actions

- Be prepared to go over the same information several times as bad news is sometimes hard to take in first time around.
- Taking into account religious or cultural backgrounds, (and if you are not sure then ask), arrange for staff/pupils who wish to, to visit or send cards, flowers, drawings etc. to the bereaved pupil and family - this will send a message of support to the family and also help pupils to express their emotions and feel they are doing something positive.
- Be aware of any changes in behaviour or attitude which may indicate that someone is more affected by the death than they may be able to say. Ask them how staff could help.
- Discuss with child/family/staff/pupils the development of a memorial if appropriate. You may need to obtain advice from the local authority before agreeing to any financial setup or memorial fund.
- Use books/activities to help pupils explore feelings and ideas about death.
- Record significant dates that may be difficult for the pupil and family as time goes by; - e.g. anniversary of death, birthdays, etc. - remembering that grief is a life long process and can resurface at any time. Ensure all relevant staff are aware of these and the possible reactions from the child. The school calendar can be used to remind key staff in advance of significant dates, and you can discuss with the family what to note in child's school file.



ON THE DEATH OF A PUPIL

What the school can do

The death of a pupil is one of the most difficult experiences a school community has to face and sadly, for most special schools, it is all too common. The following guidelines may help you when thinking about the best way to manage this difficult situation.

- Inform all staff giving them the information as agreed with the family. Ensure sufficient time and support is given to those who are particularly affected.
- Tell the children simply and honestly about the death using the correct terminology to avoid confusion. Ensure they are told by someone they know, in an appropriate setting, and using ways of communication which best aid their understanding.
- Send a letter to parents telling them about the death, what the school is doing to support the children, what reactions they might expect and how they can help their child.
- Show a copy of the letter to the child's family beforehand to make sure that they are happy with the contents. If that's not possible, agree the main points and ensure you read it through with them later.
- Hold an assembly to remember the child who has died. Tell children this is an opportunity for them to remember their friend who has died and who they will not see any more. Encourage thoughts about happy times and memories. Maybe light a candle or make a memory tree where each child can decorate a leaf with a picture or a written memory of their friend. Perhaps the children could identify some special music, songs, poetry or story that their friend particularly liked which could be played or read.



- Be aware of the impact on staff - especially if they were particularly close to the pupil or have had a recent bereavement themselves. It is a good idea to check on how staff are coping on a regular basis but particularly at the end of the first few days following the death. Ensure appropriate support network is in place for all staff.
- Offer pupils and staff a place to go or a person to be with if particularly affected by the death.
- Maintain contact with the bereaved family. Remember the first anniversary and birthday.
- Remember that families may want to keep in contact with school for some time following the death.
- Ask the family if they would like the child's work and profile to keep. They may say no at first and then regret their decision so if it is possible work should be kept safely for them in case they change their mind.
- Keep child's work, photo, up in school for a while to allow other pupils to talk about their friend and remember. Prepare them before you take things down.
- Any photos, examples of work, classmate's memories, etc., could be collected into a class book. Some children may need to use this for some time as they come to understand what has happened. Eventually the book can be passed onto the family if they would like it.

HELPING CHILDREN THROUGH GRIEF



Most grieving children do not need specialist help. Many of the actions needed are those you would use with any troubled child and are simply an extension of your existing professional teaching and listening skills. The following ways to help have been adapted from "Healing and Growing Through Grief" by Donna O'Toole.

Be there..... Grieving children need support much more than advice. It is important to offer support over a flexible length of time. Children often jump in and out of the "puddles" of grief - lack of constancy does not mean that grief has gone away.

Initiate and Anticipate..... Intensely grieving children often don't know or can't ask for what they need, so watch out for changes in behaviour and perhaps offer special times when the child could see you if they wished.

Listen..... Grieving children often need to tell their stories repeatedly. Listening without judgement or interruption can be the most important gift you can give.

Silence is Golden..... Sometimes there are no words that bring enough comfort to take away the pain. Touch can sometimes say what words cannot.

Accept and Encourage the Expression of Feelings..... Reassure the child that grief is made up of many feelings and that it is OK to cry, be sad or angry - in fact, it is important to encourage them to talk about how they feel.

Offer opportunities and Safety for Remembering..... There are many times during grief that remembering helps the healing. Offer the opportunity for sharing memories and remembering special anniversaries.

Learn About the Grief Process..... Knowledge helps allay anxieties.

Help the Child Find Support and Encouragement..... If they want, help the bereaved child find a variety of support. Beware of isolation at play/lunch times.

Allow the Child to Grieve at Their Own Pace..... Grief is individual. Your ability to not judge the length of time it takes will lighten the pressure.

Be Patient..... With yourself and your pupil. You may need to give more of yourself over a longer period than you imagined. Make sure you too have some support.

Provide for Times of Fun..... Grief can be exhausting - like swimming against the tide. Let the child know that it is OK to laugh and have fun.

Give a child choice..... When the rest of life feels out of control children like have some choice about what could be most helpful for them at home and school.

Believe in the Child's Ability to Recover and Grow..... Your hope and faith in their ability to recover may be needed when theirs fails them. Your trust in their ability to heal is essential.



PRACTICAL IDEAS FOR SUPPORTING CHILDREN

WITH PROFOUND AND MULTIPLE DIFFICULTIES

Here are a few ideas that have been helpful for some of the children that we have worked with which you could adapt for children in your care.

- Making a 'comfort cushion' from scraps of fabric belonging to the person who has died (shirts, dresses, blouses etc.). It is also possible to have a photograph of the person printed on the cushion. The child can cuddle this when they are feeling sad.
- Laminated photos kept in the child's tray/locker.
- School memory box, with photos etc. which can be used to talk through the story from time to time.
- Using the person's aftershave or perfume sprayed on a scarf or hankie to bring comfort.
- A furry hot water bottle to cuddle when distressed.
- A particular item belonging to the person who has died which the child could bring to school.
- Making a picture or story board to help the child communicate their feelings or tell their story.



LOOKING AFTER YOURSELF

Caring for bereaved pupils can be a very stressful task, particularly when, in a school setting, the ripples from one bereavement might affect a whole class in different ways. Meeting the needs of all these children is very demanding and the following tips are intended to remind you that you are important too and need to find ways of ensuring that you receive appropriate support for yourself.

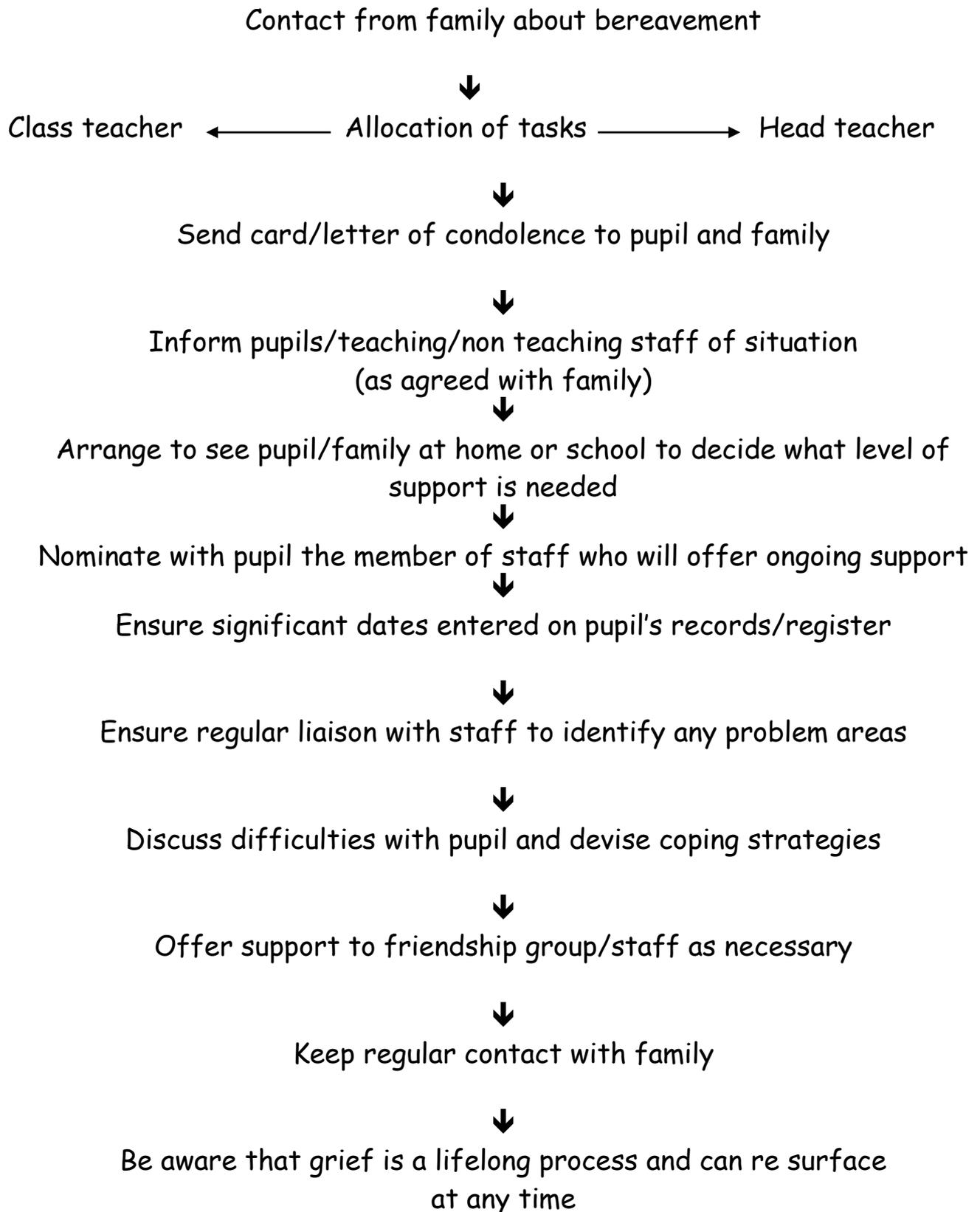
So you might find it helpful to:

- Learn about grief reactions in children and ways to support them so that some of your anxieties can be allayed.
- Anticipate that the circumstances of the bereavement might provoke a grief reaction in you and think about what effect that will have on you and how you will cope with it.
- Use your colleagues as "sounding boards" to talk through issues
- Ensure you have a supportive management structure which understands the demands of responding to a bereavement - and is aware of the effect on you.
- Know where to go to for additional professional help and information
- Remember that you cannot carry children's grief for them, but you can support them through it.
- Remember that it is OK for you to be affected by another's grief - it is because you care - but it is not OK for you to carry the burdens of bereavement alone

Remember - to be of help to the child you need to take care of yourself - this is not an indulgence but a necessity!



Flowchart of actions following notification of a death





FRAMEWORK FOR DEVELOPING A SCHOOL BEREAVEMENT POLICY

Introduction

Could include a comment about why it is important to devise a bereavement policy, the school ethos and how this policy fits into the overall approach adopted by school towards the care of its staff and pupils. It should include the date when the policy came into operation, the review date and by whom it will be reviewed.

Who is involved and the roles adopted

This should include the name (or designation) and specific role of each member of the team

e.g.

- Key Co-ordinator (usually the head teacher) responsible for liaising with all parties
- Member of staff (? pastoral team) to coordinate support to pupils
- Media spokesperson
- School Health Nurse (if available) to offer support to staff and students
- Member of Governing Body to ensure staff are supported

Aims of policy

This should identify who should benefit and by what means -

e.g. All staff and pupils faced with a bereavement will be provided with appropriate support.

This will be by way of:

- offering opportunities to express feelings in a safe and supportive environment,
- the development of an action plan to support staff and pupils
- gaining access to specialist help if necessary (a note should be kept of local and national organisations which could help and any resources and information on grief, loss and trauma).

Procedure

This should include steps to be taken and by whom from the moment staff are informed of a death



e.g.

- Contact with family - to express sympathy, confirm details of what has happened and agree what information can be shared
- Informing staff and pupils (how and by whom)
- Allocation of lead responsibility for ensuring pupil/staff welfare
- Contact with media (see LEA guidelines)
- Contact with external agencies as needed
- Arrangements for funeral/memorial services
- Responsibility for reviewing the situation
- Responsibility for record keeping

Training

e.g.

- Plans to address any training needs of staff involved in implementing policy and staff involved in pastoral care.

Evaluation, review and publication of Policy

Explanation of how the policy will be evaluated e.g. feedback from bereaved pupils and parents, feedback from staff.

e.g.

- How often and by whom the policy will be reviewed.
Where the policy can be found.

Notes

Policy needs to be cross linked to other guidance and policies from DfES, LEA and any Health and Safety documents (e.g. school policy on school trips)

Schools should already have "Wise Before the Event" (Yule and Gold)

Policy should be drawn up in conjunction with Model Emergency Plan (LEA white A4 ring binder)



CHILDREN'S STORIES

Sophie's Story

Sophie was 12 years old when her much loved father was killed in a road traffic accident. Sophie has Downs Syndrome and was away at weekly residential school. Her two siblings lived at home with their mother, and they were gradually putting their lives back together again. However, each Friday night when Sophie returned home she expected to find her father there and became very agitated and distressed when he did not appear. This behaviour upset the fragile balance the rest of the family had created and they learned to dread Sophie's homecomings. As her unsettled behaviour extended into her school life, staff met with Sophie's mother to try and find the reasons behind it and work out how they could help her. Through discussion, Sophie's mother came to realise that Sophie did not have the daily reminders of her father's death that the other two children had and therefore would need to revisit the situation each time she came home. So, over the following months, Sophie's mother retold the story of her father's accident, showed her pictures of the funeral and reminded her that because he had died he would never be at home with them again. Eventually as Sophie's understanding grew, her distress lessened and weekends were no longer the dreaded and painful times they once were. In addition, her behaviour in school settled down and she was able to engage happily with school life again.

Jonathon's story

Jonathon's father died after a long illness. Jonathon had moderate learning difficulties but, as a result of simple, factual conversations, often repeated at home and school, was able to understand that his father was too ill to do the things he used to and had to spend long periods of time in hospital. When he died, Jonathon's mother felt it was important that Jonathon went to see his father so that he could distinguish between his father alive (warm, breathing, moving) and his father dead (cold, still unresponsive) so that he would better understand why his father was no longer at home or in the hospital. Jonathon participated in the funeral and needed these reminders over many weeks to enable him to eventually understand that he would not be able to see his father again. School staff used the same terminology as the family to sustain the story and understood his need to have the details repeated many times as the story took hold in his mind. Gradually staff were able to shorten the information until Jonathon no longer needed it told. Staff kept a jumper belonging to Jonathon's father at school so that when he got upset he could cuddle the jumper from which he derived great comfort. It was used less and less as time went by, until Jonathon voluntarily took it home.



Tim's story

Tim was a pupil at a special school. He had a life limiting illness and gradually became too ill to attend. Following consultation with his parents, and with the help of the school nurse, the class teachers explained his condition simply to his classmates and told them he was too ill to come to school. Pupils were encouraged to send cards and drawings to Tim and from time to time the teacher gave updates of Tim's deteriorating condition until eventually the school learned of his death. With his parent's consent, a letter was sent to the parents of Tim's classmates telling them what had happened and the plans school had made to support the pupils. The teacher then told the class using simple, correct terminology, that Tim's illness had got worse and worse and although the Doctors had tried very hard to make him better, in the end they were unable to do so and he had died. She then talked about some of the feelings pupils might be experiencing, and explained how the news made her feel. She told them that everyone feels differently when someone dies and she understood and would be happy to talk further to those who wanted to. The class were then given the opportunity to remember their friend by talking about him, drawing or writing their memories.

In the afternoon there was a whole school assembly where a candle was lit and pupils and staff were invited to think about Tim and share some of their memories. Some of Tim's favourite music was played and a book of memories began to take shape. This was added to over time until Tim's work was taken down from the classroom, and it was all passed onto the family. The Head teacher recognised that Tim's death had had a significant impact on the staff too, so the school nurse was asked to support those teachers for whom Tim's death had special resonance.

The family purchased a bench in memory of Tim and it was placed in the school grounds at a simple dedication ceremony. It remains as a reminder to all of his time at the school.



WHY ME?

Grieve for the loss, the separation
-why me, why me?
Grieve for the loneliness, the rejection,
-why me, why me?

Feel the shock, the desperation,
-Why pick on me? -
So stamp, so scream and shout destruction,
-my fault, my guilt? -

Feel the gloom and depression,
-no talk, no talk! -
The most unutterable oppression.
-Don't speak, won't speak! -

Unspoken thoughts, so silent home. Home?
-Bursting, Breaking-
Help me oh carer to mourn, to moan,
And in mourning, peace!

Sally Crosher
'Good Grief'



Reading for Adults

Noelle Blackman - 2003

Loss and Learning Disability

Erica Brown - 1999

Loss, Change and Grief - An educational perspective

Atle Dyregov - 1991

Grief in Children - A handbook for Adults

Couldrick, A. 1991

When Your Mum or Dad Has Cancer

Grollman, E.A. 1991

Explaining Death to Children and to Ourselves

Ward, B. 1993

Good Grief - under elevens/over elevens

To Read with Children

Cathcart, F

Understanding Death and Dying

Heegard, M. 1998

When Someone Very Special Dies (workbook)

Hollins, S. and Sireling, L.

When Mum/Dad Died

Jordan, G. 1997

Has Someone You Know Died? A pocket book for children/teenagers

Meditec Tel: 01932 244899 e-mail: enquiries@meditec.co.uk

Mellonie and Ingpen

Beginnings and Endings with lifetimes in between

Thomas, P.

I Miss You - A first look at Death

Varley, S. 1985

Badgers Parting Gifts



References and other Reading

Barber C. 1999

The use of music and colour theory as a behaviour modifier
British Journal of Nursing 8. 443-447

Brearley, G. & Birchley, P. 1994

Counselling Disability and Illness

Conboy-Hill, S. 1992 in Waitman, A. & Conboy-Hill, S. (edits.)

Psychotherapy and Mental Handicap

Couldrick, A. 1998

Grief and Bereavement: Understanding Children

Doka, K. (edit.) 1989

Disenfranchised Grief: Recognizing Hidden Sorrow

Elliot, D. 1996

Learning Disabilities: A practical approach to helping people to grieve
British Journal of Community Health Nursing 1 (4) p209-213

Geldard, K. & Geldard, D.

Working with children in groups:
A Handbook for Counsellors, Educators and Community Workers

Jewett, C. 1984

Helping Children Cope with Separation and Loss

Leeds Animation Workshop -Video

www.leedsanimation.demon.co.uk

Macin, L.

Working with Young People in Loss Situations

Brenda Mallon - 1998

Helping Children to Manage Loss



References and other reading (cont.)

Oaklander, V. 1987

Windows to Our Children

Oswin, M. 2001 (2nd Edit.)

Am I Allowed to Cry? Human Horizon Series

Oxfordshire Learning Disability NHS Trust

Bereavement & Loss in People with Learning Disabilities

Pennells, M. & Smith, S. 1995

Interventions with Bereaved Children - Chap. 13

Prout & Strohmer D.C. (1994)

Counselling & Psychotherapy with persons with mental retardation and borderline intelligence.

Read, S. 1996

Helping People With Learning Disabilities to Grieve
British Journal of Learning Disability Nursing, 5 (2) p91-95.

Read, S. 1999 (1)

Bereavement And People With Learning Disability
Nursing Times Monograph. London: Emap Healthcare

Read, S. 1999 (2)

Creative ways of working when exploring the bereavement counselling process. In BLACKMAN N. (Edit) 1999 Living with loss: Helping people with learning disabilities cope with bereavement and loss

Sanderson, J. 1998

Interventions for Bereaved Children

Speak up Self Advocacy (1007) Rotherham

Widget Software (symbols)

Cambridge Tel. 01223 425558



Suggested format for Letter to parents following the death of a pupil

Dear

I am very sorry to have to tell you of that died yesterday. As you know she had been ill for some time and yesterday she was taken to hospital where she died peacefully with her family by her bedside.

We have been in touch with 's parents who wanted her friends to know what had happened. Mrs..... has therefore told the class today of death and has taken time to answer some of their questions. We will be having an assembly later this week where we will be sharing our memories of and talking about what she meant to us all.

When someone dies, friends and family often experience a number of mixed emotions and you may find that your child will be upset, confused, anxious or fearful about what has happened. The staff will be offering support to the children in school but you need to be aware that their feelings of grief may also be expressed at home.

Advice about supporting a grieving child can be found on >>>(various websites) or you can contact the school office for an information sheet

If you have any particular concerns about your child, please do talk to the class teacher.

Yours sincerely