

# Bereavement and loss support

For children with complex learning and communication needs



Information for parents, school staff and other organisations working with children and young people

# Why the need for support?

Supporting children with the sensitive issue of loss is in itself a challenging task. Couple that with the challenges associated with supporting children who have complex learning and communication needs and this role can, at times, feel overwhelming.

Children with learning difficulties have the same need for understanding, love and support in times of crisis as any child. However pupils with learning difficulties may lack the communication skills that allow them to express their feelings or ask questions in the same way that children without additional needs are able to (Crane 2005). Indeed 'without communication structures you are more likely to behave the way you feel' (Hewitt 1998)

Children are sensitive to the changes in the atmosphere around them, they may feel they are the cause of a situation if information is not made clear to them. Sometimes, there is the desire to 'protect' the child which can mean nothing is said or done about the bereavement. Children can end up feeling confused and alone in trying to cope with strong feelings.

Additionally, this group of young people often encounter more frequent loss. Children who attend specialist provisions are more likely to experience the loss of a

classmate at some stage. The task of supporting a child through his time although daunting, is a worthwhile and rewarding one.

The following information has been provided to help those who may be faced with such a situation. It pulls together information from a range of sources and aims to offer some practical suggestions on how best to move forward.

General guidance and information for schools on supporting children who have been bereaved is also available in '**Remember Me**' by Penhaligon's Friends





## Communicating about the loss

Clarify with the family what language is being used and keep this consistent and concrete.

Repeatedly explain and communicate about the death/loss situation using the form of communication that the child is most familiar and comfortable with, both verbal and non-verbal.

Drawing, role play, symbols and signing are all methods of communication that can help a child to understand and make sense of what has happened.

## Information sharing

Ensure that any direct staff and outside agency staff who provide assistance for the child are made aware of their loss.

Sensitive information should be carefully handled and passed on where appropriate.

Children may revisit grief at a much later date which makes it important that historical losses are known.

## General support

Keep to normal routines where possible

Use the child's usual means of communicating to tell them about any changes that might occur to their daily routines

Maintain open communication between the family and the school

Try to include all children in the rituals of death e.g. condolence cards, or attending the funeral. If this is not appropriate give them opportunities to say goodbye in their own ceremony.

Keep language concrete and avoid abstract ideas. Use examples to explain the non-reversibility of death e.g. balloons, flowers, life-cycles

Avoid euphemisms e.g. Granny has gone to sleep

Answer any questions, repeatedly if necessary

Prepare the child before if possible for any rituals by showing pictures, photographs, taking them to visit.

If a child has difficulty with recognising emotions try to find ways of aiding emotion recognition using verbal and visual labels for feelings.

## Developmental stages

Be sure to consider the developmental stage of the young person you are working with. This will not necessarily match their chronological age and so can have an impact on how the individual may interpret the loss experience. As children move through new developmental stages they may revisit grief as they reach a new understanding.

Conception of Death	Common reactions to loss and change	Strategies for helping the child	Potential signs
<b>0-2 years</b>			
No concept of death but aware of environmental changes	After 4-7 months protests against separation may lead to despair and detachment  Stranger anxiety  Regression  Feeding/sleeping difficulties	Support for parents in crisis so they can comfort the child  Meet the child's physical needs – food rest, warmth, comfort  Follow normal routines where possible	Searching behaviour  Fearfulness  Poor feeding  Sleep problems  Developmental delay  Regression  Increased crying
<b>2-5 years</b>			
Death seen as non-permanent and reversible,  Egocentric so may feel as though he/she has caused the death by thinking 'bad thoughts'.	Greatest fears are abandonment and separation.  Loud protests (crying, kicking, biting, holding on) when separating from other people.	Help parents to deal with the crisis so they can comfort the child  Follow normal routines and activities  Have a favourite toy/blanket available. Include normal play  Reinforce that the child is good and loved  Answer any questions	Delayed grief  Enuresis (wetting)  Sleep disturbances  Nightmares  Tantrums  Hyperactivity  Loss of control of behaviour

Conception of Death	Common reactions to loss and change	Strategies for helping the child	Potential signs
<b>5-11 years</b>			
<p>Beginning to understand permanence.</p> <p>Usually had some exposure with the death of a pet or grandparent</p> <p>Death may be personified.</p> <p>Often connected with violence and mutilations, guns, tanks etc.</p> <p>May role play death and funeral scenes to make sense of them</p>	<p>Withdrawal</p> <p>Sadness</p> <p>Depression</p> <p>May act out in anger with behaviour/learning school problems</p> <p>May become the 'perfect' child</p> <p>Regression may accompany stress</p> <p>Often will try to be brave and a 'hero' may not like to lose control.</p>	<p>Play, stories, and drawings will often reveal a child's inner feelings and fears</p> <p>Children want to understand what is happening so give honest, short, concrete explanations. Continue contact with as many activities and friends as possible</p> <p>Allow short term regression and dependence on parents</p>	<p>Somatic complaints (e.g. tummy ache)</p> <p>Resistance to going to school</p> <p>Decreased school performance</p> <p>Inattention</p> <p>Daydreaming</p> <p>Failure to complete work</p> <p>Acting-out behaviour</p>
<b>Adolescence</b>			
<p>Able to think abstractly and understand the permanence of death.</p> <p>Often denies it can happen to them personally, may engage in risk taking activities</p>	<p>Withdrawal, sadness, loneliness, depression</p> <p>Anger hostility, acting out</p> <p>Covers up fears with joking, sarcasm</p> <p>Regression and dependence</p> <p>Fear of trusting anyone</p> <p>Failure to attach</p> <p>Can seek inappropriate peer attachments</p>	<p>Try to give as much comfort as possible, Involve in planning care and actively setting rules</p> <p>Maintain privacy</p> <p>Take feelings seriously</p> <p>Allow times to talk</p> <p>Keep active with peers if possible</p> <p>Set limits on acting out.</p>	<p>Drug and alcohol abuse</p> <p>Somatic complaints</p> <p>Anxiety</p> <p>Depression</p> <p>Sexual acting out</p> <p>School failure</p> <p>Risk taking behaviour.</p>

## Sensory resources

Comfort cushion made from scraps of fabric belonging to the person who has died

Furry hot water bottle to cuddle when distressed

A particular item belonging to the person who has died to bring into school

Using the person's perfume on a scrap of fabric to smell

Sand tray play

Role play experiences using small world figures

Make a CD of the favourite music of the person who has died

## Practical ideas

Make a memory box which can be decorated and include objects and photos

Use metaphors to help explain e.g. watch how fresh flowers live and die over time.

Make a volcano with feelings exploding out of the top (Muddles, Puddles and Sunshine book)

Offer opportunities for safe ways to express frustration and anger. Reassure them that being angry is okay.

## Visual resources:

Prepare laminated photos to be kept in the child's tray

Use picture/story boards to help the child communicate their feelings or tell their story

Use comic strip conversations and social stories (Carol Gray at [www.thegraycenter.org](http://www.thegraycenter.org))

Use a sequence of visual pictures to explain what has happened

Ensure the appropriate words are available on any augmentative communication devices to help the child communicate (e.g. question words, death-related language/symbols).

Consider the Makaton signing pack (see resources)

Support through Picture Communication Symbols [www.mayer-johnson-symbols.com](http://www.mayer-johnson-symbols.com)



Use blob cards by Pip Wilson and Ian Long (2008) to help children show emotions. Available from [www.speechmark.net](http://www.speechmark.net)

## Children with Autistic Spectrum Conditions (ASC)

Children with ASC may respond to the death of someone close to them in a different way yet this does not necessarily mean they are not grieving.

They may have specific problems with conceptualising the abstract nature of death

It can be difficult for them to see things from another person's perspective which could mean difficulty in appreciating when and why people are upset.

It may be a challenge for them to understand the implications of death and that routines could be different e.g. when they go to Granny's house, Grandad will not be there.

Imagining how things might be in the future can also be a challenge.

Children with ASC may have difficulty with recognising and communicating their feelings

Anxiety related behaviours may increase in response to the changes in routine and familiarity.

## Specific strategies for use with children who have ASC

Be alert to changes in behaviour

Prepare in advance for a visit to the hospital or for attending a funeral e.g. what it will look like, feel like, smell like. Keep this as concrete as possible through pictures and clear language. Social stories (Carol Gray) are ideal for this

Explain any changes in advance and support this with pictures e.g. who will now take them to school and pick them up

Help them to understand the concept of death through answering questions when they arise. Give honest factual information but keep it simple. Use practical examples to help them understand the finality of death.

Help them to understand their own emotions through feelings fans, thermometers, visual pictures.

Comic strip conversations (Carol Gray) can help a child to understand how another person might be feeling.



# Additional resources

## **Makaton bereavement book of**

**signs:** The vocabulary is presented in topics including: feeling and emotions, why and the funeral. Available from [www.makaton.org](http://www.makaton.org)

## **Fact sheet 17 on bereavement**

[www.mencap.org.uk/node/5763](http://www.mencap.org.uk/node/5763)

## **Bereavement and Disability**

[www.bereavementanddisability.org.uk](http://www.bereavementanddisability.org.uk) Useful ideas for support and information on SEN adults and bereavement which can be adapted for children

## **Hand in Hand support pack**

A resource pack with practical ideas including a section on using symbols to explain death and funerals.

Published by Seesaw

[www.seesaw.org.uk](http://www.seesaw.org.uk)

## **Autism and Loss** (Forrester-Jones and Broadhurst 2007):

A complete resource suitable for use with adults and children. Jessica Kingsley Publishers [www.jkp.com](http://www.jkp.com)

**Let's talk about Death:** A booklet about death and funerals for young people with a learning disability

[www.dsscotland.org.uk](http://www.dsscotland.org.uk)

## **Muddles, Puddles and Sunshine**

(Crossley and Sheppard 2000): An activity book to help when someone has died

### **With acknowledgement to:**

Crane, J. (2005) The effects of bereavement and loss on pupils with severe learning difficulties. Available online.

Hewitt, D (1998) Challenging Behaviour is Normal' in Lacey, P & Ouvrey, C. (Eds) (1998) People with profound and Multiple Learning Disabilities London David Fulton Publishers pp88-100.

Koehler, K (2011) Supporting bereaved children and young people with Autistic Spectrum Difficulties (ASD). Child Bereavement Charity Information Sheet.

With thanks to a Year 7 pupil who made a feelings volcano during a Loss and Change Group session (front cover picture)

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