

Grief and Loss



Supporting children
with SEN through grief

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Grief is a universal emotion regardless of ability or disability. However, the experience of grief is individual and unique. Characteristics sometimes associated with a disability, along with an individual's life experiences effect how a person grieves, and also how others interpret their grief responses.

There is now an increased acknowledgment that people with disabilities experience the full range of emotions and grief reactions. When working with children and young people with SEN it is therefore important to acknowledge that, even where cognitive ability may mean that a full understanding of the concept of death is not possible, the feeling of loss is as palpable by virtue of the fact that an important person in their life is no longer there.

While the advice below is written with SEN children and young people in mind it is just as valid for all cohorts of young people:

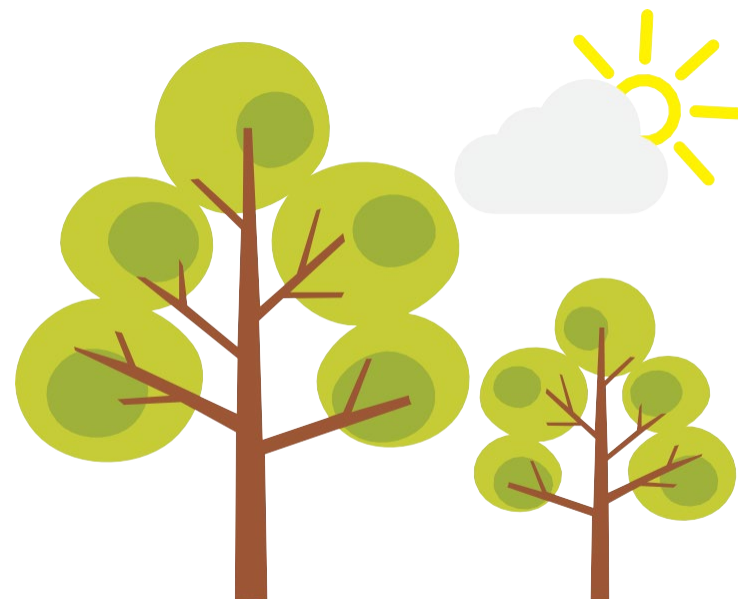
Teachers of children with severe learning difficulties suggest that responses to a significant bereavement may include:

Emotional: feeling alone and vulnerable, sadness, anger, disbelief, shock.

Physical: digestive problems, loss of appetite, exhaustion, disturbed sleep, incontinence, losing weight.

Cognitive: denial, hallucinations, preoccupation with death, confusion.

Behavioural: missing familiar environments and routines, regression in previously mastered skills, withdrawal, searching, over-sensitivity to noise, self-injury.



How can adults help:

1) Encourage open and honest communication

- Don't withhold news of the death but communicate what has happened in a language that they understand.
- Avoid metaphors and euphemisms which can be misunderstood or taken literally. Use clear, simple and concrete phrases and words that describe death in real terms. For example, "(the person) died" rather than "(the person) passed away", or "(the person) has gone to a better place", or "we've lost (the person)".
- Talk about the deceased, ask and allow questions. This gives the person the opportunity to understand that loss has happened; it also reinforces the idea that it is OK to talk about the death, while also giving the listener an opportunity to identify and address any inaccuracies in the person's understanding of the death.
- Accept short conversations. Some people may not feel like communicating their thoughts at the time, or they may not know what to say. However, it is important for the person to know that they can talk about it at some later stage if they feel like it.
- Tolerate silences. Don't be afraid of silences. They are a natural part of the listening process, and can also be useful in terms of giving the person a chance to collect their thoughts. Sometimes, the fact that you are there with the person may be sufficiently reassuring.

2) Encourage and allow expressions of emotion

- Reassure that it is OK to have a range of feelings. This is important in terms of normalising different feelings.
- Communicate understanding of sadness and loss and validate the person's own feelings. This will be important where the young person experiences conflicting feelings, such as both deep sadness, but also anger, towards the person who has died.
- Listen, rather than try to 'fix'. Be aware that it is difficult to 'take the pain away'. The person will need to work through this process themselves. The role of the support person is being there when needed.
- Don't judge. Be aware that we all have our own set of values and beliefs. Particularly in relation to grief and loss, people can have a wide range of belief systems, such as varied spiritual beliefs, rituals and other ways of expressing grief. See Religious and Cultural Considerations document for more details.
- Reassure that it is OK to cry. Crying is a normal human response to a significant loss, and can be useful as an emotional outlet.
- Address fears and anxieties. Listen carefully for any specific fears, such as fear that the person themselves will die, or that their support needs will no longer be met, and reassure the person appropriately.

3) Help the person to understand the reality of the loss

- Talk about the deceased. It is OK and indeed healthy to talk about the person who has died, and this should be encouraged. However, be led by the person who you are supporting in this, and do not force this topic of conversation if the person is not ready or willing.
- Encourage the person to participate in the rituals (viewing, funeral, visiting gravesite etc.). Taking part in rituals can contribute to the person's sense of belonging and connectedness, as well as helping the person's own recovery from grief. However, this should always be presented as an option to the person, or their advocate. Do not force the person to attend a funeral or participate in other rituals if they do not wish to do so.
- Keep the reminders of the dead person present. This is important in terms of acknowledging and confronting the loss, but also as a reminder of the deceased person and their legacy. Once again, be led by the person, because concrete reminders can sometimes be profoundly painful, particularly in the early stages of grief. In these cases, you may wish to offer these reminders again at a later date.
- Where bereaved persons have verbal language repetitive questions are a frequent response to loss. Answer the specific questions carefully and as openly and honestly as possible. Allow questions to continue as long as the person wants. Gradually these will be replaced by memories.

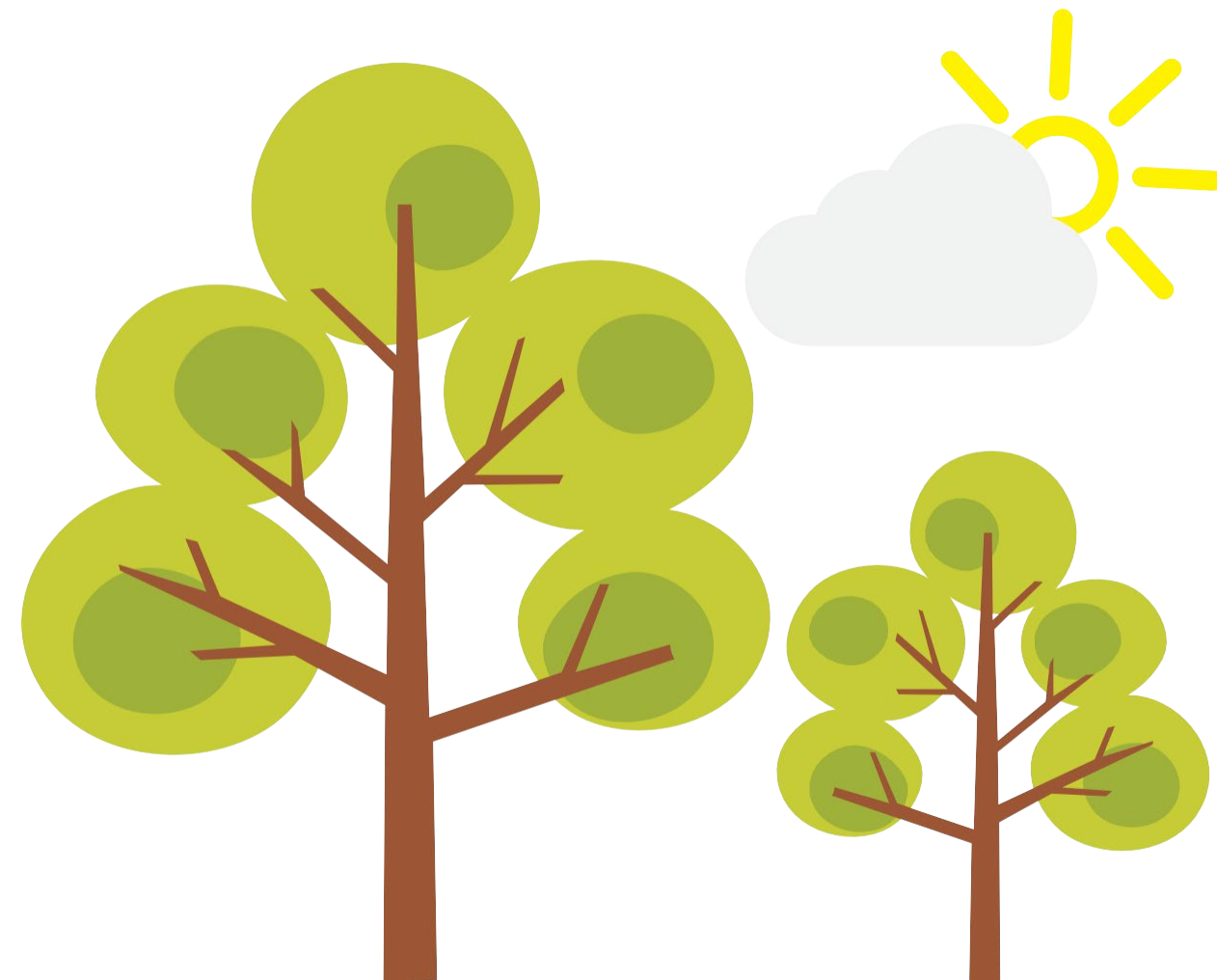
4) Provide reassurance and support

- Keep routines as familiar as possible. Routine gives a sense of stability at times of emotional turmoil.
- Provide a safe environment - ensure contact with familiar people and any information to be given in a familiar place where the bereaved person feels safe and by a person they know and trust.
- Discourage the grieving person from making major decisions. Because of the changes in thinking processes associated with grief, people can have difficulty in concentrating on all the relevant factors for making significant life decisions. If possible, delay big decisions for a time in the future.
- Provide continuity of support in different settings. Try to ensure that people are supported in their various environments and are given consistent messages across these environments.
- Encourage the person to use their local support networks. Talking with someone, such as a friend or family member, who knows the person well and who is familiar with the person's circumstances is often the best and most natural type of support.
- Support structures that are helpful for people with more complex needs who don't have a formal communication system may need to draw less on strategies based on language and draw more heavily on environment based strategies. Strategies may need to focus on providing a sense of security, stability, comfort, routine and continuity for the person. They may also include relaxation supports, such as sensory activities, based on the person's preferences that are conducive to a calm state and/or expression of emotion.
- Grief responses can sometimes be associated with challenging behaviours, particularly when a person's communication channels are limited and they have difficulty expressing their grief in any other way. In this case, the involvement of a behavioural support practitioner (e.g., psychologist) may be useful.

5) Creative ideas and activities to assist the person with disability through the grief process

- These are some ideas that have been found to be useful when supporting people with disabilities to deal with grief and loss. It is very important that support people consider these ideas in the light of their knowledge of the person and what that person may wish:
 - creating a physical resource where a favourite items or photos of the deceased can be kept – this could be a memory box or workbook;
 - use art activities to help the young person express their feelings – examples include creating a painting or collage that represents the deceased or making a book of the sympathy cards that were received.
 - creating a memory garden where a plant is planted and looked after;
 - assisting the person to write an unsent letter to the deceased if they felt they had things to say that they couldn't say at the time, or did not have an opportunity to say;
 - helping the person find a comfortable place to relax if they need some personal quiet time;
 - assisting the person to explore a new leisure activity;

Some of these ideas also appear in "Supporting People with Disabilities Coping with Grief and Loss" by Hrepsime Gulbenkoglou (2007), and published by SCOPE, which is a recommended resource in this area.



4) Frequently Asked Questions

What to do with the pupil's desk/ tray/ belongings?

- Acknowledge with the class that it's a dilemma. If appropriate ask the other children what they think. Ask a child's close friend or desk partner what they think first.

How to manage the first calling of the register?

- Acknowledge that this is the first register since the death. Acknowledge the dilemma and ask the class what they would like to do.

What to do about any imminent exams or planned activities?

- What do you/children/staff/family think the deceased would want us to do? There is no right way. Sound out staff. Explore all options and their consequences.

Should we close the school?

- What would be the effect on the pupils? Would it have to be closed all day? Are there enough staff to keep the school open for pupils to feel that they can come in if they wish to?

Should we contact the parents/ visit the home?

- Is it possible to contact parents? What is the relationship with parents? Is there a particular member of staff who has a good relationship with them? Is there a family member who is managing the communication with parents? Parents usually appreciate contact from school, particularly from a Senior Manager. It is useful if two staff can support each other.

Who should go to the funeral?

- What do the family want? If it is open for anyone to go should the school remain open? What effect will closing the school have on other pupils? Consult with parents of pupils who might be going/ want to go. Consider the wishes of staff.

Is there such a place as Heaven?

- Acknowledge that people have different beliefs - some people believe there is. Show an interest in what child's parents might think.

How long should the memory board/wall stay up?

- This needs to be negotiated with the pupils. The board has to be maintained. If the pupils want it to remain they have to take responsibility to maintain it.

Will they come back as a ghost? – They might think they have seen the person.

- Answer all questions as factually as possible and don't be afraid to say you do not know.

Should the bereaved pupil come into school?

- This is a parental decision, not the school's. If a parent or carer asks for advice say that for some children it can be helpful, others will need more time at home. The decision has to be made by those who know the child best.

What should we do/ say when they come in?

- Have a plan, worked out with the parent, teacher and the child. It is advisable to acknowledge the loss with the child as soon as possible on their own.

What to say to other pupils?

- Plan for this, discuss with staff, parents and the child.

Will I make things worse?

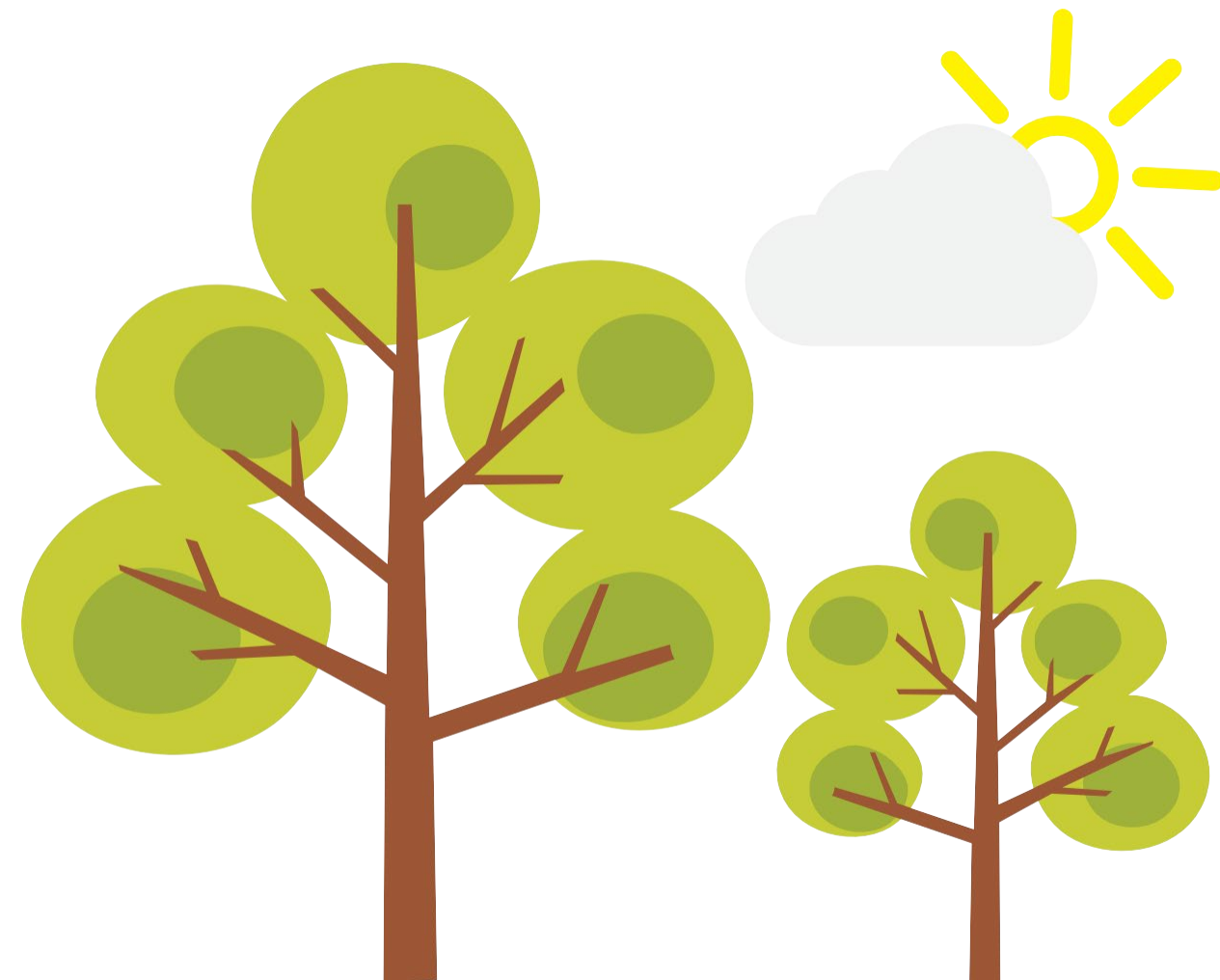
- Silence usually makes things worse.

What do children need?

- Routines which are as normal as possible. Reassurance their own thoughts or behaviour did not cause the death. Opportunities to express how they feel.

How can adult's help?

- Provide opportunities for children to understand what has happened and express how they feel. Reassure children that although grief is painful, it is normal. Provide opportunities for contact with peers for social events. Provide information about the death in language which is accessible.



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