



Saint Augustine's School, Saint John of God Community Services



## How to Support Children with Intellectual Disabilities through Bereavement



Talk openly and honestly



Give permission and encourage children to express their grief



Reassure



Look after yourself



Work closely together with everybody supporting the child



## Talk openly and honestly

- **Explain the death of a person in simple and concrete language**
  - Explain what “death” or “dead” means in concrete terms. *Example: “the person’s body stopped working; the person does not breathe/walk/talk anymore”.*
  - Explain that the person will not wake up, or come back.
  - Where applicable, refer to the child’s previous experience of death (for example, a pet or plant dying).
  - Explore what the child already knows about death or whether they have come into contact with death before (at home, in school etc.)
  - Refer to the book “When someone dies”, which may help guide you through what to say.
- **Provide as much information as possible**
  - Provide simple and clear information on when and how the person died. The amount of detail you give at one time depends on the comprehension level of the child. *Example: “Your nan died during the night from Friday to Saturday when she was in bed. Her heart stopped beating. Your granddad found her in the morning, and called an ambulance. The men in the ambulance found that she was already dead.”*
- **Avoid Euphemisms**
  - Use the words “death” or “died” rather than “passed away”, “gone”, “gone to sleep” etc. to avoid misunderstanding. This is particularly important for children with an Intellectual Disability (ID) and/or Autistic Spectrum Disorder (ASD).



## Give permission and encourage children to express their grief

- **Take your time and allow for time**
  - Children might not be ready for a ‘big talk’ when you are. Children might take longer before they realise the reality of the bereavement. You may need to have many short conversations with them over time.
  - Prioritise what is important and start with that. Depending on the level of your child’s language and comprehension, do not give too much information at one time.

- Be prepared that you may have to answer the same questions many times.
- Children with ID, especially children with ASD, may use obsessive, ritualistic question asking to deal with their grief (asking the same question over and over again, not ever appearing satisfied with the answer given). If questioning becomes obsessional, you may say to them that you have answered this specific question before, but that you can see that they are still wondering a lot about death, and encourage them to ask other questions that may not have been answered.
- Children with ID and/or ASD may ask questions about death when you would least expect it: In public, in the middle of everyday conversations etc. If you do not feel comfortable or do not have the time to have a conversation about death with them straight away, reaffirm that this is really important, and that you will talk with them another time (be specific: tell them where and when you will talk to them about the death). *Example: "It is great that you want to talk about Nan's death. Let's talk about it when we get home and I have lots of time to listen and answer your questions."* Do not forget to return to the conversation when it suits better.
- Do not be surprised if a child changes the subject abruptly when you are talking about death. This means that they have had enough. You can use active listening here and say: *"I think you may have had enough talking about this. We can always talk again another time, whenever you feel like it."*
- **Help the child identify people they can trust and talk to**
  - In all relevant environments: at home and in school
  - For children with ID and/or ASD, it might be important to discuss with them whom NOT to talk to and why. *Example: "Only talk to your teacher/SNA/best friend. This is very personal, and not everybody in the school needs to know."*
- **Include children in rituals**
  - Some adults avoid having children take part in funerals, wakes etc. to protect them from grief, and also at times out of concern that the child might not behave appropriately. However, funerals, wakes etc. can be a very important way for children to say "goodbye" to the person, supported by the people around them. If at all possible, give children the option of seeing the dead body, attending wakes, funerals etc. You may need to prepare them and use social stories to explain what is going to happen, and what is expected from them at the funeral. If a child does not want to attend, explore the reasons why, and allow them to opt out.

- **Tell the child that you know an important person in their life has died, and give them permission to seek your help when needed**
  - If you are a teacher, a family friend etc. who was not directly involved in breaking the news to the child, tell the child that you know that the person died, how you know, and that the child can always come and talk to you. *Example: “your Mam rang the school this morning to tell me that your Nan died last Friday. I am very sorry to hear your sad news. You may be having a hard time in the next few weeks. I want you to know that I know what happened and that you can always come to me and talk to me.”*
- **Allow children to express their grief creatively**
  - Do not be alarmed if the child includes death in their play. This is a way for children to work through their feelings.
  - Offer opportunities for the child to express and process their grief.
  - There are many creative ways in which you can support children with expressing their grief: You may make a photo album; you may encourage your child to collect mementos; you may plant a plant or a memory garden. For ideas please refer to the book “When someone dies”.
- **Expect and accept changes in behaviour**
  - Children often express their grief indirectly through changes in their behaviour. They may become more anxious or clingy; they may become irritable or aggressive; or they may revert to behaviours they showed when they were younger (For example, asking to sleep in parent’s bed, having to leave the light on at night, thumb sucking, bed wetting etc.) This is all normal and will usually pass with time.
  - If you need to address certain behaviours, do so in an affirming way, and put the behaviour into context of the bereavement: *Example: “I can see that you have been hitting your sister a few times now. That is normally not like you. I am wondering whether you are feeling angry and hurt at the moment because XX died. It is okay to feel really upset and angry when somebody important to us has died, but it is not okay to hit your sister.”*
  - If concerning or challenging behaviours persist, seek professional advice.

- **Use opportunities to talk about feelings**

- The book “When someone dies” may give you guidance on the variety of different feelings caused by grief, and on how to talk about feelings with a child. If the child has difficulties with understanding feelings, you may consider using visual supports.



## Reassure

- **Return to a normal routine as soon as possible**

- This will help the child regain a sense of security.

- **Reassure the child that he or she is protected, safe and will always be cared for**

- Remember that children may not only have to come to terms with the fact that a person important to them has died; they may also have to come to terms with the fact of death itself. This may cause anxiety and the concern that other people will die too. While of course you cannot promise children that other people (or you) will not die, reassure them that this is very unlikely to happen soon. You may say, for example: *“I know you are worried now that your Nan has died, that I will die too. Yes, I will die one day, but I am planning on having a long life, and I don’t expect to die for a very, very long time. I just want you to know that there will always be somebody who cares for you and looks after you.”*
- Some children may become preoccupied with their own death after somebody close to them has died. Again, reassure them that it is normal to think about these things, but that you do not expect them to die for a very, very long time. Example: *“We will all die one day, and, yes, you are going to die too. But remember, most people live until they are very, very old. So I don’t expect you to die for a very, very long time.”*

- **Reassure the child that he or she is not to blame for the person’s death**

- Especially younger children, or children with an ID who are developmentally delayed may blame themselves for the death of a person, and believe the person has died because of their own actions or thoughts (*For example, children might think Nan has died because they were ‘bold’, or because they had been angry at Nan and had mean thoughts about her.*) Children might think that they could have prevented the death of a person if they had been nicer to them, had wished harder that they would get better etc. Explain to children that nothing they have done or thought is the reason for the person’s death. Refer to the facts about the person’s death.

- **Let the child help out in a child appropriate way**
  - Sometimes, children try to take on too much responsibility, especially after the death of a family member (*For example when his father dies, a boy might feel that he now has to be 'the man of the house'.*) Praise children for wanting to help, but allow them to remain a child at the same time.
  - Give children specific 'tasks' they might enjoy, for example making a cup of tea, helping you with preparing a meal etc. If you feel a child would like to do something to comfort you, you might encourage him or her to draw you a nice picture, write a story for you etc. (Remember here: no demands; only if the child likes this).
- **Reassure the child that you are going to be okay**
  - If you are supporting children, and you are grieving yourself, children may be concerned about you, and they may hold back on expressing their own grief so as not to distress you further. It is okay for children to see you upset and cry, but they also need your reassurance that you are going to be okay and that you have support (other than the child).



## Look after yourself

- **Accept that you have needs too**
  - Supporting a child through grief can be tough, especially if you are grieving yourself. If you are a parent/carer, allow time and space to express your own grief, independent from your child. Identify at least one person who can support you. This may be a family member, a close friend or a professional counsellor. You may also consider joining a bereavement support group.
  - Do not worry if the child sees you upset. If children see you cry, you can tell them that you are sad, and that it is normal to cry when somebody has died. Use this as an opportunity to talk with children about different feelings. This will give children permission to express their own feelings of grief.
- **Do not use a child for emotional support**
  - While it can be very comforting for a parent and a child to grieve together, it is always the responsibility of the adult not to use their child for their own emotional support. Children will need the reassurance that the adults are looking after themselves, and they need the adult's permission to remain a child.

- **Do not try to be perfect**

- You may not always have the answers the child is looking for. That is okay. Reaffirm that the child has asked a very worthwhile question, and that you do not have the answer to that question yourself.
- Allow yourself to get it wrong. Your openness and your permission to talk about grief is more important than getting all the answers right.
- Accept that conversations with children may feel uncomfortable. Whatever is said is just an opening, even if the words come out wrong, children will know that you valued them enough to make an attempt.



**Work closely together with everybody supporting the child**

- **Share information**

- If you are a parent/ carer/ next of kin, pass on information to the child's school, club, friend's parents etc.
- Provide information about the person's death, and include what you have discussed with the child. This will allow everybody who is around the child to repeat/reinforce messages given in all environments.
- Whether you are a parent/carer or a teacher: You may consider using a journal to write down what conversations/ interactions you had with the child. This information can be shared with the child's home or school and other environments. This way, messages are consistent across the child's life, which is very important especially for children with ID and/or ASD. People working together will also help reassure bereaved children that they are being looked after, wherever they are.



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