

Supporting someone with an Intellectual Disability through bereavement

People often use euphemisms for death such as “went to sleep”, “has gone to heaven”, “turned into a star” and “passed away”. These sayings can be confusing for someone with an intellectual disability and children, who may be more comfortable with concrete words such as “died”.

Include and explain certain specific words (ie. tumour if that was the case) as they may well be hearing these words said by people around them who are unaware they are listening. Using correct words gives the individual the tools to understand what people are saying around them.

If repeatedly asking the same question, often the individual is **not** looking for a different answer but needs to be told the same thing consistently while they are processing it.

Bereavement can cause changes to routine and behaviours of grieving people. This can cause extra anxiety for someone with an intellectual disability. Therefore one of the most important things we can do is keep routines as normal as possible. Predictability can be a comfort.

Intense grieving can cause people to regress. Examples include wetting oneself, wanting to eat more comfort foods as in mashed food like a baby, acting younger than they would normally, sudden inability to do tasks one could previously master. This is all normal and given time and good support will eventually revert.

People generally grieve according to their personality type. For example a reserved, shy person may not suddenly want to talk a lot about their grief or an extravert may not be able to observe the decorum expected. People may laugh at times that may be considered inappropriate by others.

Physical movement can be helpful in shifting some grief and moving toxins out of the body. Exercise, dance, gardening etc. can be helpful especially if someone is not crying to shift those toxins.

If writing a social story, present it in chronological order. Something like “Johnny had a bad sore inside his head called a tumour. (don’t say brain as it can’t be seen, what is seen is a head). Johnny went in an ambulance to hospital lots of times. Then he came home. But not this time. This time is different. Johnny can’t come home anymore. Johnny died.”

Many people will want to acknowledge the bereavement and pass on sympathy. Encourage people to interact at a level similar to their usual interactions. If they normally high 5 then that’s what they should do. Explain to the bereaved person some people may say they are sorry to hear of the death, explain it’s called *sympathy* and help them come up with a simple response, something like “this is my sad news” or “thank you for caring”. Preparing an automatic response can help reduce a lot of anxiety.

If the bereaved person is very tactile it can present a challenge during Covid times. If you are comfortable with it, and it is appropriate, allow it and wash your hands/follow best hygiene practices after. They may be looking for this physical reassurance more than normal.

Be mindful some people with intellectual disabilities may keep things compartmentalised and attempting to talk about home life when at school or adult placement may leave them confused and agitated.

Also time out from grieving can be very important. Doing something unrelated may provide the rest the mind needs from all the changes in life, which can be exhausting.

There is a very good booklet called 'Supporting people with Disabilities Coping with Grief and Loss' put out by Scope.