Everyone will experience the death of a loved one at some point in their lives. Talking about death and dying can be difficult, and it can be hard to know how to best support someone through a loss. Bereavement research conducted with adults with intellectual disabilities and with neurotypical children can provide suggestions on how we can support people with ASD through the grieving process.

It is important to recognise that individuals with intellectual disabilities who may not fully understand the concept of death still experience the emotions of grief, and still require support through the grieving process (Dodd, Dowling, & Hollins, 2005). In addition, support people in the bereaved individual’s life need to be aware that the person’s reactions may be delayed and that expressions of grief may be different from what is seen in neurotypical individuals, and may include changes in the individual’s behaviour (Meeusen-van de Kerkhof, van Bommel, van de Wouw, & Maaskant, 2006; Sormanti & Ballan, 2011).

The literature reviewed suggests that we can best support grieving individuals with an ASD in the key ways listed below. (Note: It is important to remember that as with any intervention for an individual with a developmental disability, considering a person’s level of cognitive functioning is crucial to developing appropriate supports and must be taken into account when providing support for an individual with ASD who has been bereaved).

Some of the key things parents and other support people in the bereaved person’s life can do include:

- **Preparing the individual with ASD as much as possible about death and grief.** Educating the individual with ASD about death and dying can help reduce the anxiety that unexplained changes may produce for them when someone does die (The National Autistic Society, 2014; Read & Elliott, 2007). In addition, helping someone to understand the abstract concept of death - whilst not a necessary factor in experiencing grief - is also considered to help the bereaved individual through their grief and loss (Dodd, Dowling, & Hollins, 2005; Ryan, Guerin, Dodd, & McEvoy, 2010). It is suggested that carers explain death in concrete, practical, visual ways, for example, through using a life-cycle approach with animals (McEvoy, MacHale, & Tierney, 2012; Ryan, Guerin, Dodd, & McEvoy, 2010). For some people with ASD it may also be appropriate to explore situations of grief and loss when naturalistic opportunities arise in the broader context of life (e.g., when a character in a movie dies) (Read & Elliott, 2007).

- **Use clear, accurate, simple language** when talking about death and when answering any questions that the individual with ASD might have. Avoid using metaphors (e.g., “he went to sleep”), as individuals with ASD may take literal interpretations of language which can result in confusion and anxiety (Meeusen-van de Kerkhof, van Bommel, van de Wouw, & Maaskant, 2006; Wong, 2014). Consider also using visual supports to aid the individual’s understanding of death and grief (e.g., a social story may be appropriate in some situations) (Read, Frost, Messenger, & Oates, 1999).

- **When an individual with ASD has experienced a loss, maintain routines as much as possible,** as this will help alleviate stress and anxiety, and will reduce the impact of any ‘secondary losses’, which are those subsequent losses that can occur as a result of the death (e.g., an individual who no longer goes on weekend camping trips as his father who used to take him has died) (Sormanti & Ballan, 2011).
• Include the bereaved individual in the rituals surrounding death, such as the funeral and viewing of the deceased’s body, if possible (Meeusen-van de Kerkhof, van Bommel, van de Wouw, & Maaskant, 2006; Wong, 2014). Support their understanding of what happens in these social situations by preparing them beforehand, for example, through the use of social stories giving explicit and clear information of what to expect (Sormanti & Ballan, 2011).

• Assist the bereaved individual to learn appropriate coping strategies to help them through their grief (Read & Elliott, 2007). For example, developing and using a ‘feelings chart’ may be helpful for some individuals to identify how they are feeling and then what they can do when they have those feelings.

• For some individuals, therapeutic interventions such as individual counselling or a bereavement support group can also be beneficial to assist with their grief and loss (Read & Elliott, 2007; Sormanti & Ballan, 2011).

Keeping the above things in mind when supporting an individual with ASD who has experienced a bereavement is likely to assist them in the grieving process.

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References


