autism
wellbeing

Supporting an autistic child or young person to deal with grief.

Grief is a complex experience and every person responds differently when someone dies. There is no set pattern of grieving to follow, or right and wrong way to go through the process of bereavement. People may react in different ways and how we feel and respond to our experiences can change from minute to minute as well as over the months and years following a bereavement.

The Covid-19 pandemic dominates the news, and sadly many people have died from coronavirus. Many people have died from other causes too, and your child may have lots of questions and feel confused, scared, or distressed.

Sometimes when children don't show the emotions that are expected, adults can assume the child is unaffected. This could lead to less support being offered, or fewer explanations being given.

We know from personal accounts of grief written by autistic people, that the effects of a bereavement can be as intense as for any other person, but these effects may show in a different way.

- Some children may have a very logical approach towards death and ask questions that may appear inappropriate or insensitive to others. This may be because they are needing to understand what has happened in order to process their loss.

- The language used around death and bereavement can be difficult to understand – particularly if a child takes things literally. Words like "loss" or "passing" or "going to a better place" can all mean different things when taken out of the context of death. Children may find it more helpful if we use very frank language that describes exactly what has happened.

- Self-care for everyone involved in the bereavement is essential. It may feel extra distressing when coping with your own loss, whilst trying to support someone who is reacting in an unconventional way.

- Sometimes autistic people experience delayed emotional responses. Instead of feeling upset, sad, or angry at the time of the death, they may show no emotion and then experience these emotions much later. Some children may not show any emotion, and some may show emotions that are not usually associated with grieving.

- A child's sensory processing may be affected by their experience of grief. Some children may experience visual disturbances, acutely sensitive hearing, an aversion to touch, or other sensory responses during times of stress. This may show in their behaviour – perhaps they'll want to put things in their mouth or sniff objects, or seek proprioceptive input by bouncing or being squeezed.

- A lack of response may not mean a lack of understanding. Death is a complex subject that requires a lot of processing to understand. A quiet child may be taking everything in and could even be feeling overwhelmed by the amount of information they need to process, alongside all their feelings, and the confusion about why their loved ones are acting differently or have disappeared.

- It is natural that we want to protect our children from distress. We may decide to shield them from hearing about the death, or feel anxious about them attending a funeral, or wonder whether they will ask a question that appears insensitive or act in a way that looks like they don't care. Our children may well pick up on our own sense of grief and notice small changes in how we are speaking or behaving. This may feel confusing, unpredictable, and distressing for them. As families we need to be aware that the child is likely to be affected by the bereavement, regardless of how they show this, and we need to decide how to involve them in the grieving process.

- Funerals can be distressing for autistic children. Not just because of the typical upset and sadness because of the loss; but because they are complicated social occasions with expectations for behaviour. The pandemic means that funeral services may need to be conducted differently. Some families have found that watching the service via video-link is helpful. Others have conducted their own ceremony at home to commemorate the person who has died and they have conducted their own tribute and rituals and the autistic child has joined in in a way that is meaningful for them. This could be by making something, lighting a candle, singing a song, or saying a prayer.

- Your child may need lots of reassurance because they may feel scared that other people will inevitably die too if they contract coronavirus or experience the same illness that the person they have lost had.

- Time for self-regulation and co-regulation is essential. There is no typical way of coping with a death and the current pandemic situation complicates the grieving process. There are sources of support listed at the end of this pack.