

Death and Grieving

Autistic people may grieve and respond to death differently to non-autistics. Sometimes this can be perceived as heartless, unempathetic or selfish. Other times it might be seen as prolonged and overly sensitive. This all comes down to the way we process and understand the world around us.

What it might look like

Expression of emotion

Autistic people often express emotion differently to non-autistics. So, we may not cry or behave in the way that is expected of us, when it is expected of us. Some may laugh or tell jokes which may just be a way of coping but can be interpreted as lack of care for the loss or those around them. Some may insist on carrying out their normal routine as if nothing has changed. This can be because death is a huge change, which can be incredibly difficult to manage and having any more changes than necessary will only make things harder for them. Some may also not know how they are expected to react.

Identification of emotion

Autistic people often struggle to identify or describe their emotions so if you ask them how they're doing or if they're okay, you might not get the expected response.

Prolonged emotional responses

Sometimes autistic people can have strong emotional responses or changes in their behaviour for longer than you expect them to. You might expect them to have a period of time where perhaps they're more distracted, angry, shutdown, crying, acting out or having meltdowns but then it ends up going on for months with no sign of easing.

It can sometimes take autistic people longer to process and adjust to changes, especially when they're sudden and unexpected. They may also need support in different ways to neurotypical individuals.

Delayed response

Some autistic people may take some time before showing any change in their behaviour or emotions. It may take some time to process what's happened, or they may start noticing the loss throughout their routines.

Translating to everyday life

For some autistic people, hearing the news itself is hard to translate into real life. It's not really until that loss is seen through changes in routine or regular interactions that it might start to sink in. That's not to say that the autistic person only sees people for the role they play, or how they're personally impacted. It's not necessarily a matter of being selfish but rather that those moments that have changed will be what helps translate an abstract concept into something more tangible.

Relationship status

While it may seem cold hearted, some autistic people may be unmoved by deaths of individuals whom they do not know personally, or who are not connected to their personal relationships.

However, they may still hold sympathy towards those who are affected by the loss.

Pre-prepared

Autistic people often like to be prepared. So sometimes, if they know someone hasn't got much time left, they may already be preparing for that. This can mean that by the time the person passes, they've already done a lot of their grieving.

Matter of fact

Sometimes autistic people are just very matter of fact. Death is a part of life, that's just the way it is. Some may be quite content with accepting that and moving on.

Anxiety

Some autistic people may experience increased anxiety as a result of loss. They may become concerned about losing others or even dying themselves.

Reduced masking/regression

Grieving takes a huge toll on anyone's capacity. This can mean that autistic people may be less inclined to mask or may show signs of skill regression. They may go into shutdown, have more meltdowns, talk less, etc.

Inanimate objects

Autistic people can sometimes form deep attachments towards inanimate objects. With some items, they become almost alive to the autistic person. Other items become a part of their routine or ability to cope with daily life. Losing these items can trigger a grieving response.

Ways to help

Why?

Give information to help them understand why this happened. Why do people or animals die? Why now? This can help them grasp the concept and (depending on the nature of the loss) have less concerns about losing others in the immediate future.

How?

For some people it can be helpful to give an explanation as to how a particular life ended or if it was not a living thing but rather the loss of something special, then how that happened (for example, how a favourite toy was destroyed). Some people can find that if they don't have the information and they're trying to figure it out, they replay the possible situation over and over again. This can ultimately only drag out the situation longer.

Transition

If you have the time (as you might in the case of items or animals), create a transition period. With items that are starting to reach the end of their life, you might try to find a replacement before then and start slowly introducing it while slowly reducing how much the old item is used. With animals, you might start explaining that they'll have to say goodbye one day and explain that maybe they're looking sick or they're getting old. This reduces how sudden the loss is when it happens.

Identify emotions

Autistic people often struggle to identify or describe their emotions so asking how they're feeling or if they're feeling okay, might not generate a response that accurately portrays how they're doing. It can be helpful to describe different emotions and what they feel like (you could use the book 'How do I feel'*) to try increase vocabulary around emotions. Otherwise, you might try letting them find and show you videos or photos that match how they feel. Keep in mind if they're feeling sad, these might not just be videos or photos of people looking sad. It could be a particular colour they associate with it, an energy level, a facial expression, an activity etc. If you get them to put multiple pictures or videos together, it might give you a better overall idea. You could also get them to draw, act, dance, choose TikToks to make with you, etc. These can all give you insight into how they might be feeling.

Keep active

Do something active regularly. Keeping active keeps the mind healthy. Staying in a slump too long is not good for anyone's mental health.

Have routines

Try to stick to some kind of routine and schedule. If possible, have the autistic person help set the routine or make choices about what goes into it each week.

Alone time

Let them be alone if that is what they want (within reason. If their mental health is declining significantly and there are concerns about wellbeing or safety, then that is a priority. However, being alone can be good for some autistic people).

Sensory sensitivity

Take extra care around sensory sensitivities as these may increase or the autistic person may have less capacity to regulate without tools like headphones or fidget toys.

Funerals and saying goodbye

Don't force them to participate in neurotypical grieving rituals (including in the event that it's not possible to attend the funeral and alternative events are arranged). They may not say goodbye in the same way as those around them and may end up feeling judged for not reacting how they're expected to react.

*How do I feel: https://www.wildlingbooks.com/collections/how-do-i-feel?utm_campaign=gs-2020-02-19&utm_source=google&utm_medium=smart_campaign&gad_source=1

This resource was written by an autistic author (2024)