

JOHN PENDAL: Coaching For People Who Feel Like Outsiders

Autism and Grief

A common topic on coaching calls is the subject of bereavement, grief and funerals – and how autistic folk can experience these differently. *(I'd also like to acknowledge that anyone can experience grief differently, not just autistic people.)*

For example, autistic people might experience grief on a different timescale. It might take weeks, months or years before we process a loss. This can lead to the situation where an autistic person is asked to give the eulogy because we're seen as stoic or unemotional – we might even be praised for how we get through a funeral offering other people support – but when we need support in turn it can feel that everyone else has moved on.

We might experience the feeling of grief differently. Whereas others can be seen openly expressing "sad" emotions, we might experience grief as exhaustion, burnout or a mystery illness. We even might be told off for not showing the right level of distress!

There can be a social rule in some cultures to *"not speak ill of the dead"*, which means that all of sudden someone is being described in glowing terms when that wasn't the case when they were alive. That can be really challenging for autistic people. We may want to share our honest, authentic memories and as a result get told off for being disrespectful. Meanwhile other people appear to be openly lying about the deceased and being praised for it.

We might struggle to know how we're feeling in real time, or unable to name our feelings at all. Then we are thrust into a situation where all anyone seems to do is talk about their feelings – or ask us how we are feeling all the time. *(One of my clients decided to answer feeling questions at a funeral with "I'm still processing" – which was accepted by everyone else as being a very wise answer.)*

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There are other possible energy costs on an autistic person at this time:

- Changes to your routine
- Guests staying in the house
- Social gatherings where you are expected to talk to new people
- Uncertainty over plans
- If folk are talking about the past that might bring up childhood trauma
- Coping with the difference between other people's experiences and yours
- Feelings of exclusion, or that your voice isn't being heard
- You might feel more pressure to mask to fit in (*following conventions of tone of voice, body language etc.*), but this might also be seen as faking your grief

I've heard from many people that it helps to know that they aren't alone. Here are some results from a web search on "autism and grief". I've included excerpts from each page, along with a link to the full account:

FROM THINKING AUTISM GUIDE

(This was my favourite page as it combined a first person account with practical ideas)

Autistic Grief - Things to Think About

- Autistic people may or may not cry or overtly show emotions. Alternatively, emotions may be delayed or very extreme when they do come.
- Grieving will very possibly manifest itself via increased autistic symptoms (*increased sensory processing issues, shutdowns, meltdowns, decreased social abilities, etc.*)
- May be unable to articulate what is wrong or talk about feelings.
- And have an increased desire to be alone to work things out.

<https://thinkingautismguide.com/2012/08/autistic-grief-is-not-like-neurotypical.html>

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FROM THE NATIONAL AUTISTIC SOCIETY

When grieving over the death of someone or something important to them, autistic people may show typical grief responses, such as anger, increased restlessness, changes to their sleeping and eating patterns, an increased dependence on others, or a loss of previously displayed skills and confidence.

For some autistic people, the death of someone or something close to them may be overwhelming. Their grief will need to be recognised and understood. They will need time and space to express their feelings.

Be aware that when an autistic person is experiencing grief, their autistic traits may become more apparent. This is something autistic people highlight in their personal accounts of going through a bereavement.

<https://www.autism.org.uk/advice-and-guidance/topics/mental-health/bereavement/professionals>

FROM THE INDIANA RESOURCE CENTRE FOR AUTISM

It is important to anticipate some of the cognitive effects (*of grief or loss*) listed below and realize support is needed. For example:

- May have a hard time processing information
- May be very confused
- May be unable to express feelings and/or ask questions
- May talk a lot: repeatedly asking questions, wanting reassurance, etc.
- May have increased executive functioning problems (*i.e., organizing, remembering things, paying attention, getting started on tasks*)
- May feel like they have lost control of their life

<https://www.iidc.indiana.edu/irca/articles/supporting-individuals-on-the-autism-spectrum-coping-with-grief-and-loss.html>

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The **Thinking Autism Guide** also had some strategies that may help:

1. Taking care of the physical part of the body (*nutrition, sleep and exercise*)
2. Alone time
3. Learning about autistic traits (*increased awareness about sensory issues and taking care to avoid triggers*)
4. Time spent with obsession(s)
5. Getting involved in viable projects (*focusing on helping others*)
6. Setting realistic goals/expectations for recovery (*grieving symptoms can last for longer than 1 year*)
7. Discovering/exploring new areas of interest or special interests. Many autistic people are avid explorers or wanderers. Take some time to explore or wander. Take up an instrument or new language, etc. Learning helps to calm and to process feelings
8. Understanding that your way of grieving is not like everyone else's and that your way is just as valid

<https://thinkingautismguide.com/2012/08/autistic-grief-is-not-like-neurotypical.html>

Another resource is the **Autism & Grief Project**: <https://www.autismandgrief.org/>

They offer an online toolkit for adults with autism offers a validating grief experience through personal and social stories, animated videos and other tools. Families, friends, professionals, and faith leaders can also find materials to help them understand autism, grief, and ways to offer support.

I hope that helps. Please send me a message if you'd like to chat further.

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