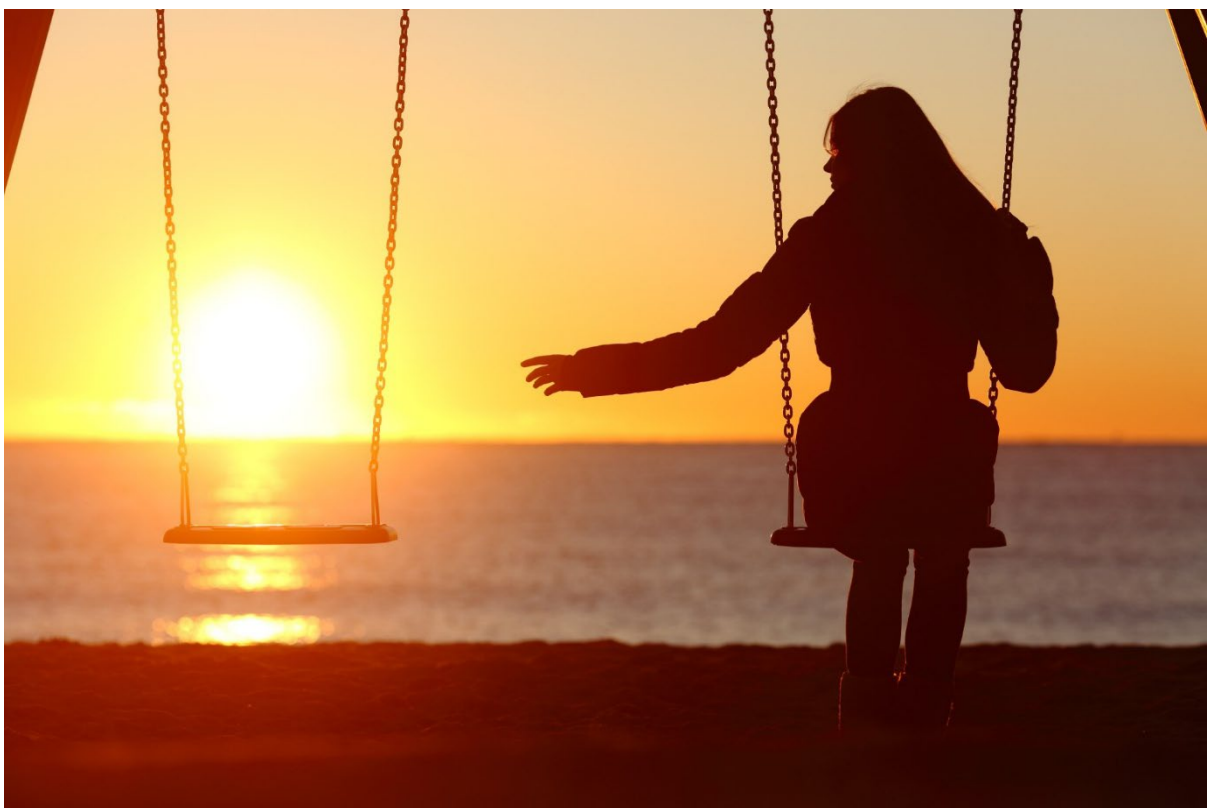


Autism and Bereavement:

A social-model concept, centring autistic voices

Understanding grief through neurodiversity affirming perspectives

By Dr Lisa Alcorn



Bereavement is a universal human experience, yet the ways people process grief are shaped by their identities, communication styles, and environments.

For autistic individuals, the challenges surrounding bereavement often arise not from autism itself, but from social barriers, inaccessible environments, and rigid expectations about how grief 'should' look. The social model of disability reminds us that people are challenged not by their neurology, but by the structures around them. When we apply this lens to bereavement,

we see clearly that autistic people do not struggle because they are autistic; they struggle because society is not designed to support neurodivergent ways of grieving.

Autistic people themselves consistently express that their grief is deep, real, and often misunderstood. Many describe feeling judged, excluded, or pressured to perform grief in ways that do not align with their natural communication or emotional patterns. By listening to autistic voices and removing social barriers, we can create environments where autistic people can grieve authentically and safely. That is a world we could all benefit from!

Understanding grief through the perspectives of autistic people

Grief is felt deeply, even though it may look different

Autistic people often say that others assume they are 'not grieving' because they do not cry or express sadness in expected ways. One autistic adult described feeling devastated after a family member's death, but being told they 'didn't seem upset' because they were quiet and focused on a familiar object during the funeral. Their grief was real; the misunderstanding came from neurotypical expectations.

Another autistic person shared that they felt overwhelming sadness but could not express it verbally. Instead, they spent hours engaging in a comforting routine, something that helped them process emotions safely.

At SJOG, a private social network has been developed where autistic people come together to share their experiences. What is clear is that these neurotypical expectations are widespread and deeply rooted, as the stories shared within this community echo the same themes of being misunderstood.

Autistic people often grieve differently not because their feelings are any less real or meaningful, but because the way they process emotion, sensory input, communication, and change is wired differently. Grief interacts with these differences in very specific ways, creating expressions of mourning that may not match neurotypical expectations. When you look closely, the differences make perfect sense; they reflect the autistic nervous system, autistic communication styles, and autistic ways of understanding the world. These are not deficits; they are simply different ways of expressing emotion. As I've already said, we all grieve differently, the problem isn't the grief itself, but the narrow expectations placed on how it should look.

So let's look at some of the reasons how grief may be expressed differently for autistic people so that we help communities understand better:

Alexithymia: Strong emotional reactions paired with challenges in recognising or naming what those feelings are.

Difficulty identifying emotions can make grief especially disorienting for many autistic people, because the internal signals that usually help someone recognise sadness may feel muted, jumbled, or physically uncomfortable instead of clearly emotional. For some autistic individuals who experience 'alexithymia', often find that grief is turned into a puzzle: the body reacts; tight chest, heavy limbs, stomach tension but the mind can't easily translate those sensations into words or categories.

"I feel emotions like weather inside my body, but I can't always tell what the weather is. I just know something is happening, and I have to wait until it makes sense."

This can create a sense of distance from the loss, or even self-doubt about whether one is grieving 'properly,' despite feeling deeply affected. Instead of a clear emotional wave, grief may show up as irritability, fatigue, anxiety, or a vague sense that something is wrong without knowing why. That confusion can be distressing in its own right, adding an extra layer of overwhelm to an already painful experience.

Increased sensitivity

Increased sensory sensitivity during grief can make the world feel harsher and more intrusive for many autistic people, because emotional stress often amplifies the nervous system's baseline reactivity.

"When I'm grieving, my senses turn up to maximum. Every sound feels sharper, every light feels brighter, and the world becomes so loud that I must retreat just to breathe."

Sounds that were merely irritating before may become physically painful, lights can feel sharper or too bright, and even gentle touch might register as overwhelming. This heightened sensitivity isn't simply discomfort; it can drain energy, reduce tolerance for social interaction, and make everyday environments suddenly unmanageable. As a result, someone might retreat to quieter spaces, rely heavily on noise-cancelling headphones, dim lights, or familiar sensory tools, not because they're avoiding grief but because their sensory system is overloaded by it.

The emotional weight of loss and the sensory intensity feed into each other, creating a cycle where grief magnifies sensory overwhelm, and sensory overwhelm makes it harder to process grief.

Abstract concepts and use of language

Struggling with abstract concepts like death can make the grieving process especially confusing for many autistic people, because figurative language and symbolic explanations don't always translate into something concrete or meaningful. When others use metaphors such as 'passed on,' 'gone to a better place,' or 'watching over us,' the autistic mind may interpret these phrases literally and find them illogical or misleading.

“When people talk about death in metaphors, it feels like they are giving me a riddle instead of an answer. I need clarity, not poetry, to understand what’s happened.”

This can create a disconnect between what is being said and what is actually understood, leaving the person unsure how to make sense of the loss or how they are expected to feel. The emotional weight of death is still very real, but the language surrounding it can become an additional barrier to processing grief.

Communication differences

Communication differences can shape how an autistic person expresses grief, often leading others to misunderstand their emotional state.

“When I am grieving, people expect tears or the ‘right’ facial expression, but my feelings don’t always show on my face. I wish others understood that just because I don’t express grief the way they do, doesn’t mean I am not feeling it deeply.”

Someone might not cry, show the expected facial expressions, or use the social cues typically associated with mourning, which can cause people to assume they are unaffected even when they are grieving deeply.

These examples highlight that autistic grief is not absent; it is simply expressed differently.

Barriers created by society, not autism: the impact

Society often assumes that autistic people struggle with grief because of their autism, but in reality, many of the hardest parts of bereavement come from environments, expectations, and communication styles that aren’t designed with autistic needs in mind.

The barriers they encounter are not internal flaws; they are external pressures created by unclear language, sensory-intense rituals, rigid social norms, and sudden disruptions to routine. Autistic people frequently describe how these expectations make grief heavier and more isolating. One person shared:

‘Everyone kept saying my mum had ‘gone to sleep,’ and I spent days terrified she might wake up somewhere. No one realised the words they used made everything more confusing.’

Another explained how sensory-unfriendly funerals pushed them away from the very support they wanted:

“I wanted to stay for the whole service, but the noise and the crowd felt like knives in my ears. Leaving wasn’t a choice, it was survival.”

Social judgement adds another layer of pain, as one autistic adult put it:

“People told me I didn’t look sad, but I was grieving so hard I could barely breathe. I just don’t show it on my face.”

And when routines collapse after a loss, the impact can be profound:

*'When my dad died, my whole world changed overnight. I wasn't just grieving him,
I was grieving the structure that made me feel safe.'*

These voices make it clear that the real obstacles come from a world that doesn't yet understand or accommodate autistic ways of grieving.

Supporting autistic grief: what society needs to change

Supporting autistic people through grief starts with recognising that the biggest challenges they face are often created by the environment around them, not by autism itself. When society shifts its expectations and makes space for different ways of processing loss, autistic people can grieve with dignity, clarity, and genuine support. Here the focus is on simple ways to change:

1. Concrete language

This begins with communication. Many autistic individuals rely on direct, concrete language, especially during emotionally overwhelming moments. Using clear terms like 'died' instead of euphemisms such as 'gone to sleep' or 'passed on' removes confusion and allows the person to understand what has happened without having to decode metaphorical language. Families, professionals, and communities can make a profound difference simply by choosing clarity over comfort phrases.

2. Sensory accessible environments

Another essential area of support is creating sensory-accessible grieving environments. Funerals, memorials, and gatherings are often loud, crowded, and emotionally intense conditions that can be unbearable for someone with heightened sensory sensitivity. Offering quiet rooms, allowing the use of headphones, dimming harsh lighting, or even providing alternative ways to participate (such as watching a recording later or via virtual means, or even attending a smaller ceremony) can ensure autistic people are included rather than overwhelmed. These adjustments don't diminish the meaning of the ritual; they make it accessible.

3. Acceptance rather than the 'social norm' of grief

Social understanding is equally important. Autistic people may not cry, speak, or display facial expressions in the ways others expect, and this can lead to unfair judgements about their level of care or emotional depth. Society can support autistic grief by letting go of rigid ideas about what mourning 'should' look like. When people respond with acceptance rather than criticism, autistic individuals feel safer expressing their grief in their own way, whether that means talking factually, staying quiet, or showing emotion through behaviour rather than words.

4. The importance of structure during autistic grief

Maintaining or gently adapting routines can provide stability during a time of upheaval. Many autistic people rely on predictable structure to feel grounded, and the loss of a loved one often disrupts daily patterns. Offering help to rebuild routines, providing visual schedules, or ensuring consistent support can reduce distress and create space for emotional processing. Grief is already destabilising; preserving familiar anchors can make it more manageable.

When society embraces clear communication, sensory accessibility, flexible expectations, and routine support, autistic people are not forced to fight through unnecessary barriers. Instead, they are given the understanding and conditions they need to grieve fully, authentically, and safely.

Conclusion

Grief is a profoundly human experience, and autistic people feel its weight just as deeply as anyone else but the way they process, express, and navigate that grief is shaped by a world that often isn't built with their needs in mind. When communication is unclear, rituals are sensory-overwhelming, social expectations are rigid, and routines collapse without support, grief becomes far more complicated than it needs to be. What looks 'different' from the outside is, in reality, a valid and meaningful expression of loss filtered through a distinct neurological and sensory landscape. Autistic people are not grieving incorrectly; they are grieving within the conditions they've been given.

The insights shared above from emotional overwhelm and alexithymia to sensory sensitivity, communication differences, and the impact of disrupted routines, highlight a simple truth: the barriers autistic people face in bereavement are largely societal, not intrinsic. When we offer clear language, accessible environments, flexible expectations, and stable support, we remove those barriers and allow autistic grief to unfold naturally and authentically. In doing so, we affirm that autistic ways of grieving are not lesser or lacking, they are simply different, and deserving of understanding, respect, and accommodation.

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