



Mental Health
Equity Project



Autism
AIM

Strategies and Resources

Autism, Loss and Grief

What is Loss and Grief?

Loss is a universal human experience. It is a significant change where something we value or is a part of our lives is taken away. Grief is the feeling of pain that comes from loss but can be expressed by many other emotions.

The most known type of loss and grief is caused by death, but it is not the only type, including others such as loss of friendship, relationships, marriage breakdown, job or financial loss.



This guide will discuss the lived experiences of autistic people relating to loss and grief.

We will explore some of the ways that autistic and mental health needs can be met, and look at ways to help manage emotions in this time.

Processing and Expressing Grief

When we experience loss, you may express grief in many different ways. Some of these include:



Anger



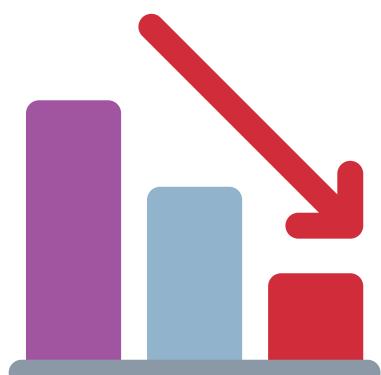
Feeling restless



Sleeping differently



Eating differently



Skill regression



Increased meltdowns / shutdowns

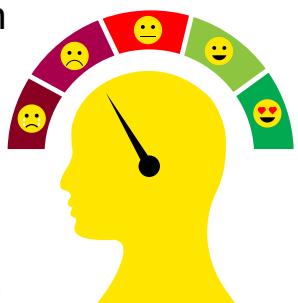
Experiencing Grief

There are lots of reasons why someone may grieve. Many autistic people find change and adapting to it to be particularly difficult and stressful experience, and may struggle with loss, or need additional support during these times. Autistic people may process grief in different ways due to:

Emotional Processing Differences

Grief may feel delayed, overwhelming, or difficult to express in 'expected ways'. You may not know how you are supposed to feel or behave in this time.

You may also show some feelings that others aren't expecting, such as: not feeling grief or sadness, feeling grief and sadness after other people do, or feeling more angry than you usually do.



Need for Routine and Predictability

Loss can disrupt stability. It can be difficult when this takes away something that was part of our regular routine or interactions. This can cause distress and difficult emotions.



Sensory Overload and Emotional Exhaustion

Grief can intensify sensory sensitivities, making our surrounding more overwhelming. Trying to process and communicate emotions can be difficult, and lead to increased meltdowns or shutdowns.



Other peoples Expectations and Misunderstandings

Other people may not understand how grief presents in autistic people. Reacting differently to how they expect can lead to difficulties with communication, seeking support, and increased isolation. It may also mean support offered is untailored, or limited.



Types of loss

Loss can happen in many different ways, including:



Relationship breakup

The end of a relationship, even amicable, brings major change, and may affect finances, living situation, and friendships.

Mourning and processing the loss, especially after difficult circumstances, will take time.

Financial and Property Loss

Loss of property or financial stability can affect all areas of life, and can have serious emotional impact while you are adjusting to this.

Examples may include losing a job, losing access to finances, losing access to accommodation.



Identity Loss

Identity loss can be a source of trauma for some people. Examples of this include realising past making behaviours, struggling with self-acceptance, or processing a new diagnosis.

Losing a friendship



Loss of friendships can happen for many reasons, disrupting emotional and social stability, and potentially affecting support networks. This can be difficult, and you may take time to rebuild friendships or gain others.



Loss of Health

Decline in physical fitness or health, or diagnosis with a long-term illness can significantly impact mental wellbeing, daily life, and executive function.

Anticipatory Grief

Grieving in advance for something that hasn't happened yet can be just as challenging as grieving after a loss, such as when a loved one is ill.

Types of loss



Loss of Support

Changes to support, formal or informal, can disrupt daily life and long-term planning, and add additional barriers to access that were previously removed.

For example, if you have Universal Credit, or Access to Work funding that is lost when switching employer, or working hours, then this could be detrimental to the accessibility of your workplace.



Loss of Ability

Long term illness and loss of ability in areas that you may previously not have struggled with can have a profound effect on mental wellbeing and, work, and routine; you may need time to adapt to these changes and they may prevent you from fully engaging in activities you used to.

An example could be a loss of ability due to autistic burnout and needing time to recuperate.



Loss from Death

Grief from bereavement is commonly understood and will have a major impact on mental wellbeing, and time will be needed to mourn and process the loss, and this can be the case whether it is the loss of family, friends, colleagues, or pets.

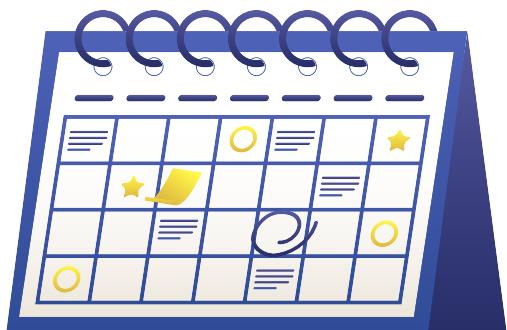


Types of Grief

Grief may be expressed and processed in many different ways, and will vary from person to person; many find they experience grief suddenly and acutely, while others will have different experiences.



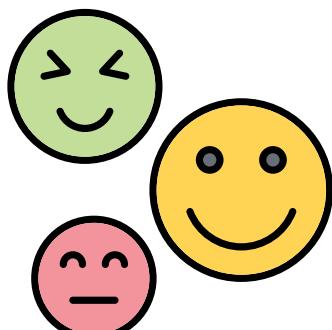
Some people find that grief stays with them over a long period of time, or that it isn't felt until months or even years after the fact, as you become able to process the emotions and weight of the loss.



It is also important to reiterate that grief can be felt, or emotionally expressed in numerous different ways, whether that is sadness, frustration, relief, denial, risk-tasking, numbness, creativity, guilt, or anxiety



Autistic Lived Experience with Grief and Loss



Autistic people can process loss in many ways, and loss can add additional stress of change, along with the difficulty recognising emotions and possible delays in emotional response to loss. This can sometimes be known as alexithymia, which is struggling to recognise words or put to words our own emotions.



Autistic people may also exhibit grief in ways that differ from Allistic / Neurotypical people, which has potential to lead to misunderstandings or lack of needed support. For example, you may show little outward expression of grief to others while struggling to manage it or may engage in more self-soothing behaviours and have greater occurrence of sensory overload, meltdowns / shutdowns, and emotional dysregulation.



You may also find that you struggle to manage emotional responses, that you are more irritable or angry, and experience physical responses of stress and grief such as difficulty sleeping, attending social engagements, or managing self-care tasks e.g., brushing your teeth. Autistic people can also experience emotional mirroring.

Autistic Lived Experience with Grief and Loss

Many autistic people report feeling differently about grief to people who are not autistic. Some common ways this is shown include:

- Reacting differently to how other people expect them to.
- Finding it hard to understand the loss and the emotions that are being experienced.
- Not crying or behaving in ways that people expect.
- Showing delayed and extreme emotional responses.
- Experiencing an increase in autistic traits, like sensory differences, meltdowns and shutdowns.
- Finding it harder to organise, plan and concentrate on tasks. This is also known as executive functioning.
- Difficulty understanding what to do in social situations such as hospital visits and funerals.
- Difficulty knowing what to say and asking for support from people.

“With grief, my emotional responses feel like they are delayed by a few days. When the initial incident happens, I often feel numb and then annoyed that I am not more upset. A few days later, I am grieving and mourning, struggling a lot with my emotions”.

“As someone who processes things externally, I find that people get annoyed that I am talking about it too much, and don't understand that this is how I process grief”.

Coping with Loss

There are many ways that people may find best to grieve and deal with loss, and these will vary on the individual, how one person manages may not suit another, and this must be recognised and respected.

The feelings of pain that come from loss can be difficult to manage. Finding healthy ways to cope with these emotions can be helpful. It is good to find coping mechanisms that work for you. Here are some examples of ways you can cope with loss.



Peer Support:

1-1, Online, or in a group setting where lived experiences are shared, and you can find ways to process your own emotions through discussion with others who have related experiences of loss.



Formal Counselling or therapy:

Which could be autism specific if available, or with specific adjustments made to existing therapy to meet autistic needs.

Crisis support and Phonelines:

These can offer a short-term and immediate support service in times of crisis, someone to listen to your needs or feelings and sometimes they can help you be signposted to relevant local support networks.



Mental health and support resources:

Accessing support and resources can be helpful to manage emotions that come with grief. See page ____.

Coping with Loss



Creative outlets:

Art, music, writing and other forms of creative expression can be a non-verbal way for you to externalise your feelings.

These practices can be soothing and mindful; however, it is important to note that people may disengage from hobbies during times of loss.



Adjustments or Compassionate Leave:

If you are processing a loss and are in education, or employment then it may be important to discuss the implications with your relevant organisation and seek support via adjustments, or compassionate leave.



Talking to someone close to you or a professional:

Expressing how you feel can help you feel understood and can take some of the load off you. It is better to talk to someone who isn't directly affected by the loss, as they may be grieving in their own way. If you

do want to talk to someone who is affected by the loss, it is important to check they are in the right headspace for the conversation.



Structure and Routine:

When you have experienced a loss, it can feel like everything is out of balance. This is why it can be important to try and keep a good routine. The structure can provide comfort and help you keep up with practical tasks, but please do not feel pressured to keep a routine or know that you can update yours to need specific needs at the time.

Coping with Loss



Special interests & sensory support:

Engaging in safe, familiar activities can help you to regulate emotions. Try to meet your sensory needs when you can, and please know it is okay if you cannot engage in special interests at the moment.



Give yourself permission to grieve:

However your emotions show up, they are valid. It is okay to allow yourself time to grieve. You may want to try limit overwhelming situations, and remember, it is okay if your grief looks different to how others expect.

Taking time to understand your feelings:

Allowing yourself to feel whatever emotions you have without judgement can be an important step.

While this can be harder for autistic people for a number of reasons, such as Alexithymia and differing expressions of grief, allowing yourself the time to experience and recognise those feelings may prove helpful in processing the loss.

Supporting someone through

Grief and loss is something all of us go through, but there is limited understanding about how this might differently affect autistic people - they may process grief differently, and their needs may not align with your expectations. Autistic people may also find it difficult to express their own feelings around loss and grief.

Validate their grief

- Avoid assumptions about how they should grieve - some people may show intense emotions, while others may not.
- Acknowledge their feelings, even if they express them differently.
- Let them know its okay to grieve in their own time and way.



Help them with daily tasks if they are struggling

- It can be hard to stick to routines and perform self care / daily tasks when grieving. Offering physical support, such as helping the person cook their meals, offer to go food shopping or helping with house work can be helpful.
- Helping keep daily routines consistent can provide comfort.



Offer alternative ways to express grief

- Verbal expression can be difficult, doing things such as writing, art, music, or movement can help process emotions.



Supporting someone through

Reduce sensory and social overload

- Grief can heighten sensory sensitivities, so offering low-demands environments can help reduce overwhelm.
- Large gathering (such as funerals), can be overwhelming due to crowds, emotions, and uncertainty. Offering options like attending for a short time, having breaks, or engaging in home rituals can provide comfort. Preparing them with information and visit to the venue beforehand can also ease anxiety.



Be patient

- Grief isn't linear, and autistic people may revisit their feelings over time.
- Non-linear grief may look like alternating between engaging in interests and then reflecting on their loss. Creating a safe space for this process is essential.
- Check in regularly, even after the initial period of loss, as they may still be processing.



Respect processing styles

- Some people may have delayed or unexpected responses - grief can surface weeks or months later, and some may focus on facts rather than emotions. This does not mean they aren't grieving.
- If they need to externally process the loss, offer a listening ear, but also prioritise your own well-being and seek support if needed.



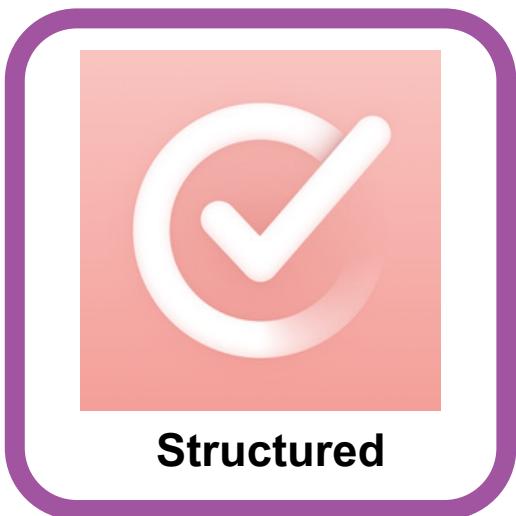
Apps



Grief Refuge



Good Grief



Structured



How We Feel



Headspace



Finch

App Descriptions

Grief Refuge



A free app to help you through your grief journey and offers a space to explore grief related feelings. Offering guidance, self care tips, journaling, daily reflections, intention setting, stories from others who have found healing in their grief, and a tool for tracking 'progress'.

Good Grief



A free social network for loss, where people can connect privately and support each other in finding a new normal. Fill out who you lost, when and what to. You do need to be approved before you start so know that it might take a few minutes - an hour before you can use the app.

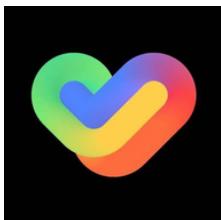
Structured



Daily planning tool to help you keep on top of routines and plan for days ahead.

App Descriptions

How We Feel



A free app to help people understand and regulate their emotions. Over time, logging your emotions can help to spot trends and patterns. You can also access mini lessons on coping strategies, including meditation and positive affirmation.

Headspace



Guided meditation and mindfulness app, with over 1,000 guided meditations for relaxation and stress management. There are also tools to help manage anxiety, depression and stress and has specific grief tailored courses / meditations. The grief specific is available on the paid for subscription plan which is £12.99 per month.

Finch



A self care and planning tool app. This app offers some extra in app purchases but has many free tools, including a first aid kit to help with grounding, journaling options and reflections that can be guided or unguided.

Additional Resources

Local Organisations and Support

Leeds Mental Wellbeing Service – Offer a range of services and support for people struggling with mental health, such as anxiety.

Further sources of support can be found in Leeds Autism AIM's Mental Health Guide: <https://leedsautismaim.org.uk/wp-content/uploads/sites/7/2023/04/Leeds-Autism-AIM-Mental-Health-Guide-v6-April-2023.pdf>

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This guide was produced by the Mental Health Equity Project, part of The Advonet Group. We are a free service co-led by and run for autistic adults (aged 18+) in the West Yorkshire area.