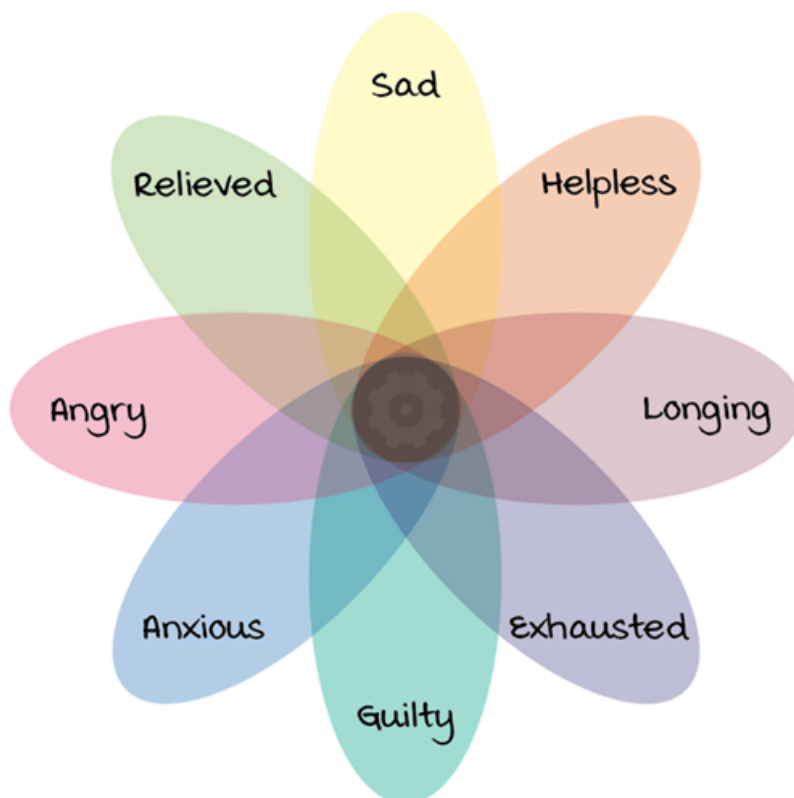


Grief & Feelings of Loss Passport



Grief and feelings of loss affects us all in different ways. It's important to remember there is no 'normal' way to grieve. Age, culture, additional disabilities and individual needs should be considered, in order to provide appropriate support.

It is also important to remember that grief can present differently in neurodivergent individuals compared to neurotypical people. This booklet aims to give you information about how autistic grief may be different to neurotypical grief and to help you think about how grief affects you individually.

After experiencing loss, for example through death or divorce, some people may have a strong sense of that persons presence and this feeling can be very powerful. It is really important to talk about what you are experiencing and how you are feeling when going through these periods, in a way that feels comfortable and safe.

Autistic individuals may cope with grief differently, this doesn't mean there is a lack of understanding or empathy. You just have a different way of communicating our thoughts and feelings. Grief is also a difficult concept for some because death and loss can feel quite abstract, feelings about an absence of something can be confusing.

Grief responses

These are a few ways grief may affect you

No change in behaviour or emotion

Physical symptoms - such as nausea, gastro issues, headaches

Increased self soothing behaviour

Anxiety and stress - due to feeling new or different emotion, or not feeling as expected

Regression to childhood behaviours

Anxiety about social rituals surrounding death. Such as expectations at funerals and how to respond to emotions

Alexithymia - inability to express or identify emotions

Meltdowns or sensory overload

Struggling to maintain normal routines

Sleep disturbances

Remembering your loved one

There are many different ways to remember your loved one. Memories of your loved one will always stay with you and these can help give you comfort in times of loss.

Listen to their favourite song

Draw a picture of them or things you enjoyed doing together

Eat food that you both enjoyed together

Keep special objects of theirs such as a piece of jewellery, a book or a blanket

Create a memory box of things that remind you of them

Look at photos of them and remember happy times

Visit places that you went to together

Visit the cemetery where they are buried or a place of remembrance

Things that autistic people want you to know

I need to have conversations about death, dying and loss in general. Not just when something happens.

I would like to thrive not just survive!

I need you to have the correct knowledge about me in order to reduce the impact of burnout.

I may need your encouragement.

I need individualised support. I need open communication.

I may need you to maintain consistency. Ensuring my basic needs are being met, safe food/drink.

I need you to understand that I might react differently. I need you to support my emotional regulation.

I need you to acknowledge my sensory needs.

Grief passport

Use this document to help you communicate with others about your reactions to grief and how they might be able to support you in the best way

Name	
Phone number	
Address	
Email	
Preferred method of contact (Call/Text/Email)	
NHS number	
Allergies (Food/Medicines/Environment)	

Emergency contact

Name	
Relationship to me	
Phone number	

Sensory reactions

In times of grief or distress, you may experience more sensory challenges and it may be useful to record what you think these might be. We also have a more in depth sensory profile which you can fill out if you would prefer

	Under sensitive	Average	Over sensitive
Light			
Noise			
Touch			
Smell			
Taste			
Pain			

Things I may experience in times of grief

Shutting down		Feeling a loss of support	
Difficulty communicating my feelings		Difficulty expressing emotions	
Difficulty accessing appropriate support		Difficulty understanding and processing grief/changes	
Experiencing shock/numbness		Difficulty letting go of situations and/or people/things	
Over/under eating		Difficulty understanding how others are feeling/behaving	
Struggling with rumination		Lack of/too much sleep	
Feeling guilty		Feeling physically ill	
Uncertainty about the future. It being different to what you expected		Feeling isolation/deterioration of mental health	
Difficulty understanding changes can be permanent		Overwhelmed or demand avoidance of certain events	

Things I may find helpful from others

<p>Clear communication and information. Specific, logical giving time for questions</p>		<p>Others finding ways to engage with me. Guidance and encouragement to use coping strategies</p>	
<p>Space, time and opportunity to talk</p>		<p>Support me to keep a routine</p>	
<p>Time to process thoughts and feelings. Permission to manage this in my own way.</p>		<p>Support me in finding opportunities to socialise with others when I am ready</p>	
<p>People being patient and not putting pressure on me</p>		<p>Support to maintain my independence by encouraging me to complete my self care/household tasks</p>	
<p>Validation and acceptance of my feelings and how I manage them</p>		<p>Support me with daily tasks. Such as admin, appointments, phone calls, finances</p>	
<p>Develop a clear plan of ongoing support</p>		<p>Ensuring I maintain control & understanding of my choices</p>	

Things I can do to support myself

Managing emotions

It can be difficult to manage your emotions in times of grief or distress. It may also be hard to express what you are feeling to others. People manage difficult experiences in different ways and that is okay!

Emotions can be varied and difficult to identify.

I may display my emotions in the following ways:

Becoming mute		Appearing anxious	
Being tearful		Appearing distant	
Appearing hyperactive		Becoming angry	
Appearing apathetic		Showing a lack of emotion	

Useful Links

- NAS, bereavement guide
<https://www.autism.org.uk/advice-and-guidance/topics/mental-health/bereavement/autistic-adults>
- Sue Ryder, how to look after yourself whilst grieving
<https://griefguide.sueryder.org/support/coping-with-bereavement/taking-care-of-yourself/>
- Samaritans
<https://www.samaritans.org/how-we-can-help/contact-samaritan/>
- Be Well, counselling options in Gloucestershire
<https://www.bewellglos.org.uk/category/counselling/>
- Cruse, understanding the stages of grief
<https://www.cruse.org.uk/understanding-grief/effects-of-grief/five-stages-of-grief/#:~:text=The%20five%20stages%20%E2%80%93%20denial%2C%20anger,one%20stage%20to%20the%20other>
- Thinking autism guide, experiencing grief and loss as an autistic adult
<https://thinkingautismguide.com/2012/08/autistic-grief-is-not-like-neurotypical.html>

Useful Contacts

	Phone Number	Website	Email
Adult Help Desk Gloucestershire County Council	01452 426868	https://www.gloucestershire.gov.uk/health-and-social-care	socialcare.enq@gloucestershire.gov.uk
Cruse Bereavement Support	0808 808 1677	https://www.cruse.org.uk/	
Carers Hub	0300 111 9000	https://gloucestershirecarershub.co.uk/	carers@peopleplus.co.uk
Mind	0300 123 3393	https://www.mind.org.uk/	
National Autistic society	0808 800 4104	https://www.autism.org.uk/	
Suicide Crisis	07975 974455	https://www.suicidecrisis.co.uk/	contact@suicidecrisis.co.uk
Your Circle		https://www.yourcircle.org.uk/	yourcircle@gloucestershire.gov.uk