

# 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 need individualised support. I need open communication.**

**I may need your encouragement.**

**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**

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

## Emergency contact

<b>Name</b>	
<b>Relationship to me</b>	
<b>Phone number</b>	

# 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			7

# Things I may experience in times of grief

<b>Shutting down</b>		<b>Feeling a loss of support</b>	
<b>Difficulty communicating my feelings</b>		<b>Difficulty expressing emotions</b>	
<b>Difficulty accessing appropriate support</b>		<b>Difficulty understanding and processing grief/changes</b>	
<b>Experiencing shock/numbness</b>		<b>Difficulty letting go of situations and/or people/things</b>	
<b>Over/under eating</b>		<b>Difficulty understanding how others are feeling/behaving</b>	
<b>Struggling with rumination</b>		<b>Lack of/too much sleep</b>	
<b>Feeling guilty</b>		<b>Feeling physically ill</b>	
<b>Uncertainty about the future. It being different to what you expected</b>		<b>Feeling isolation/deterioration of mental health</b>	
<b>Difficulty understanding changes can be permanent</b>		<b>Overwhelmed or demand avoidance of certain events</b>	8



# Things I may find helpful from others

<b>Clear communication and information. Specific, logical giving time for questions</b>		<b>Others finding ways to engage with me. Guidance and encouragement to use coping strategies</b>	
<b>Space, time and opportunity to talk</b>		<b>Support me to keep a routine</b>	
<b>Time to process thoughts and feelings. Permission to manage this in my own way.</b>		<b>Support me in finding opportunities to socialise with others when I am ready</b>	
<b>People being patient and not putting pressure on me</b>		<b>Support to maintain my independence by encouraging me to complete my self care/household tasks</b>	
<b>Validation and acceptance of my feelings and how I manage them</b>		<b>Support me with daily tasks. Such as admin, appointments, phone calls, finances</b>	
<b>Develop a clear plan of ongoing support</b>		<b>Ensuring I maintain control &amp; understanding of my choices</b>	9

# **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:**

<b>Becoming mute</b>		<b>Appearing anxious</b>	
<b>Being tearful</b>		<b>Appearing distant</b>	
<b>Appearing hyperactive</b>		<b>Becoming angry</b>	
<b>Appearing apathetic</b>		<b>Showing a lack of emotion</b>	
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## 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/>
- 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
<b>Adult Help Desk Gloucestershire County Council</b>	<b>01452 426868</b>	<b><a href="https://www.gloucestershire.gov.uk/health-and-social-care">https://www.gloucestershire.gov.uk/health-and-social-care</a></b>	<b>socialcare.enq@gloucestershire.gov.uk</b>
<b>Cruse Bereavement Support</b>	<b>0808 808 1677</b>	<b><a href="https://www.cruse.org.uk/">https://www.cruse.org.uk/</a></b>	
<b>Carers Hub</b>	<b>0300 111 9000</b>	<b><a href="https://gloucestershirecarershub.co.uk/">https://gloucestershirecarershub.co.uk/</a></b>	<b><a href="mailto:carers@peopleplus.co.uk">carers@peopleplus.co.uk</a></b>
<b>Mind</b>	<b>0300 123 3393</b>	<b><a href="https://www.mind.org.uk/">https://www.mind.org.uk/</a></b>	
<b>National Autistic society</b>	<b>0808 800 4104</b>	<b><a href="https://www.autism.org.uk/">https://www.autism.org.uk/</a></b>	
<b>Suicide Crisis</b>	<b>07975 974455</b>	<b><a href="https://www.suicidecrisis.co.uk/">https://www.suicidecrisis.co.uk/</a></b>	<b>contact@suicidecrisis.co.uk</b>
<b>Your Circle</b>		<b><a href="https://www.yourcircle.org.uk/">https://www.yourcircle.org.uk/</a></b>	<b>yourcircle@gloucestershire.gov.uk</b>