

**Virtual Autism Team Wales**

**Advice Sheet**

**Loss and Bereavement**

Loss and bereavement will be experienced by all of us at some time in our lives but since Covid 19 has been in the news we hear a lot more about it. When someone or something that we care about dies, we use the term “bereavement”, and we talk about grief and grieving.

This last year (2020/21) has been very difficult for people everywhere, in different ways. Some people have lost their jobs and others their homes. Some relationships have come to an end e.g. divorce. A lot of people have died, some because of Covid-19 and others for different reasons, such as cancer or heart failure. The news broadcasts tell us regularly how many people have died because of Covid-19. As well as the death of many people, there have been other losses and it is not easy for anyone to know what to do as life changes.

Grief could be described as a way of adapting to the loss, or the death of a person we cared about. Some people talk about loss and grief after the death of a pet, and this can be very sad for them. Sometimes, the end of a relationship may make us feel loss, or losing our jobs, or moving to a new place; the loss can be described as grief. Grief is the natural reaction to the death of *someone* to whom you felt connected or attached, or the loss of *something* important in your life. Loss occurs as a significant change that alters your life as you know it. Life will not be the same for you again.

For someone who is autistic, feelings of loss and grief may be hard to identify and describe. Some autistic people are alexithymic, which means that typically they are unable to identify, understand or describe their own emotions. The reaction of an autistic person to loss or death may be different to those of a neurotypical person. Indeed, it may be the opposite response to what other people are expecting you to express or feel. The important thing to remember, is that this is ok, but you may need some help to recognise and describe how you are feeling and coping and to communicate this to someone you trust.

What is very important to remember is that every individual’s experience of grief is unique and personal. There is no timeline and no right or wrong way to grieve.

Someone may, or may not, experience what have been described as the “stages” of grief (see references below for more detail):

* Denial - a means of coping with the shock and confusion of the loss
* Anger - a masking mechanism which might be directed at yourself, or those around you, or the person or pet who has died
* Bargaining and questioning - asking “what if?” or “if only…”
* Depression - you may feel numb or confused and you may want to isolate yourself from others
* Acceptance - you may understand what changes the loss now means to your life

The cycle is not the same for everyone and you may experience some but not all of this. Some individuals may go through these stages several times or very differently.

Autistic people have told us that sometimes they do not cry or behave in an emotional way and other people might not understand this. Their response might be delayed, or they might focus on what has to be done practically. They might experience more autistic behaviours such as meltdowns or shutdowns, or an increase in their sensory differences, or a deterioration in their physical wellbeing. They may not be sleeping so well.

People often might not know what to do in unfamiliar social situations like hospital visits, or funerals. Covid-19 has made grief and loss particularly difficult because many of us have been unable to say “goodbye” to the person before they have died. Saying goodbye to a person is often an important part of the grieving process for many people. For some people, the opportunity to see the person who has died can help with the processing of the experience. Equally for others, seeing someone who has died can cause distress; once again, we are all different and our responses differ.

There could be a short, or long delay in processing the grief. Other people’s expectations of what grief is can give the appearance of the autistic person coping, or not being affected (for example, remaining calm and practical) and the delayed processing of grief can lead to autistic fatigue, or burnout [[1]](#footnote-2) at a later date.

We know that anxiety is a common condition for autistic people, and this may increase as a result of loss or a bereavement. Some people feel more isolated because of loss.

Autistic people can struggle with identifying and describing emotions, this is known as “alexithymia” This means it can be even more difficult to process feelings of loss and grief also making it harder for those around you to understand as well and to respond appropriately to you.

**What people can do to help**

* Use specific and straightforward language (e.g. ‘the person has died’ not ‘the person has passed away’)
* Be reassuring but do not give false reassurances, be honest.
* Listen to their concerns and worries, do not dismiss these
* Remember, an autistic person’s reaction to death in particular might be very different to a neurotypical person. For example, someone might laugh nervously; not talk at all; or stim [[2]](#footnote-3) at the funeral; or indeed at the news of someone’s death. These responses are often due to anxiety.
* Help the autistic person look to the future, life continues.
* Acknowledge any religious/cultural conventions
* Understand that anxiety is a very common feature of autism and therefore autistic people might need that extra bit of care or reassurance to help sooth or calm.
* Be aware that incidences of suicide are higher across the autistic community and it’s important to be able to support and sign post someone who is feeling that low and unable to see a way forward, to appropriate advice and support.

**More information is available:-**

* National Autistic Society

[Bereavement (autism.org.uk)](https://www.autism.org.uk/advice-and-guidance/topics/mental-health/bereavement)

* MIND

[Helping someone who is experiencing grief | Mind](https://www.mind.org.uk/information-support/guides-to-support-and-services/bereavement/for-friends-and-family/)

* Purple Ella

[Autism and Bereavement - Purple Ella](https://www.purpleella.com/2018/03/01/autism-and-bereavement/)

* Cruse Bereavement Care Helpline: 0870 167 1677

<http://www.crusebereavementcare.org.uk/index.htm>

For young people freephone 0808 808 1677, e-mail: [helpline@cruse.org.uk](mailto:helpline@cruse.org.uk) [https://www.cruse.org.uk/#](https://www.cruse.org.uk/)

**Information for autistic people**

We have talked to autistic people who have experienced loss and bereavement and we have asked some people who have experience of working with autistic people. We have come up with a few things which might help you to come to terms with loss and bereavement. There are many sources of professional help available too and this is a simple guide about what you might find useful.

**Things you can do to help cope with loss or bereavement?**

* Understand that grief is a process and take “one day at a time”. If you were very close to the person who has died, it could take a long time to “recover”
* If you want to say “goodbye” to the person who has died (meaning, if you want to visit the person who is no longer alive and speak to them, knowing that they cannot respond), then ask the funeral director and they should be able to make the arrangements.
* You may need to develop some new routines and alter the structure of your day
* Do things that may help you feel better – for example sleep, relaxation, gentle exercise
* Write down how you are feeling, keep a journal. Use pictorial symbols or numerical scales to record if writing is too hard
* Talk to someone you trust
* Remind yourself that these feelings of emptiness, or sadness will pass. Write yourself a social story or script or a “mantra” (a phrase to repeat to yourself) to remind yourself of this and what you need to do to help yourself.
* Make sure that you eat a healthy diet if possible.
* Try to maintain a regular sleep pattern
* Try not to make yourself feel better through drinking too much alcohol or using drugs
* Be kind to yourself.
* If you are unsure what is expected with funeral arrangements, ask someone who knows and ask for their help in preparing for this. The professional people involved in arranging funerals will help you too.
* Remember things that help ease your anxiety and use these tools
* Making a ‘memory box’ or ‘scrapbook or journal’ of the person who has died can be helpful. It is okay to talk about them if you want to.
* **Remember, what you are feeling is what you are feeling**

**and that is fine.**

**Appendix A**

**References**

* **Childline:** when someone dies Helpline: 0870 167 1677 For children and young people to the age of 19 to be able to discuss worries and concerns

<http://www.childline.org.uk/whensomeonedies.asp>

* **Ted Hughes’** memorial poem (part)

<http://www.guardiancentury.co.uk/1990-1999/story/0,6051,112762,00.html>

* **Association of Child Psychotherapists**

<https://childpsychotherapy.org.uk/> Tel: 020 7922 7751 e-mail [admin@childpsychotherapy.org.uk](mailto:admin@childpsychotherapy.org.uk) will help provide caller with child psychotherapist within the NHS in their area.

* **British Association for Counselling and Psychotherapy** (BACP)[www.bacp.co.uk](http://www.bacp.co.uk) 01455 883300 [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)
* **Child Bereavement Trust** <https://www.childbereavementuk.org/>

0800 02 888 40 [support@childbereavementuk.org](mailto:support@childbereavementuk.org) online chat via the website.

* **Child Death Helpline** This is not a counselling service. It is manned by bereaved parents and professionals.

[www.childdeathhelpline.org.uk](http://www.childdeathhelpline.org.uk) [contact@childdeathhelpline.org](mailto:contact@childdeathhelpline.org) 0800 282 986 from a landline, or 0808 800 6019 from a mobile.

* **Compassionate Friends,** Tel: 0345 123 2304.

Support for parents who have experienced the loss of a child. [www.tcf.org.uk](http://www.tcf.org.uk) Online support also available.

* **Gingerbread Association for One Parent Families,** Tel: 0808 802 0925.

Support and information for one-parent families of both sexes. [www.gingerbread.org.uk](http://www.gingerbread.org.uk)

* **Grief Encounter**, Support for children and young people who have been bereaved.

<https://www.griefencounter.org.uk> / 0808 802 0111 weekdays, 9am – 9pm.

* **Mental Health**, this is an extensive site offering comprehensive data and advice. [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk).
* **Mind Infoline** [www.mind.org.uk](http://www.mind.org.uk) 0300 1233393 Information on all aspects of mental distress. Does not give medical advice. Weekdays 9am – 6pm.
* **PAPYRUS, (Prevention of Young Suicide)**, support for those under 35 who feel suicidal, or have concerns about another young person. call 0800 068 41 41, text 07860039967, email [mailtopat@papyrus-uk.org](mailto:mailtopat@papyrus-uk.org), <https://papyrus-uk.org/> 9am – 10pm weekdays, 2pm – 10pm weekends and bank holidays.
* **The Samaritans,** Tel: 0845 790 90 90, e-mail: [jo@samaritans.org](mailto:jo@samaritans.org), [www.samaritans.org.uk](http://www.samaritans.org.uk)  Confidential emotional support for anyone in crisis.
* **SANE,** a national organisation dealing with mental health. [www.sane.org.uk](http://www.sane.org.uk) SANELINE: 0845 767 8000 12.00 – 2.00pm.
* **SOBS (Survivors of Bereavement by Suicide),** Support for those over 18 bereaved by suicide. Tel: 0300 111 5065, email: [email.support@uksobs.org](mailto:email.support@uksobs.org) uksobs.org, 9am – 9pm weekdays.
* **Trauma Pages,** [www.trauma-pages.com](http://www.trauma-pages.com) these trauma pages focus primarily on emotional trauma and traumatic stress, including PTSD (post traumatic stress disorder) and dissociation, whether following individual traumatic experience(s) or a large-scale disaster.
* **Tommy’s,** [www.tommys.org](http://www.tommys.org) Tel: 0800 0147 800 e-mail: [mailbox@tommys.org](mailto:mailbox@tommys.org) Tommy’s is determined to end the heartache caused by premature birth or miscarriage.
* **WAY Widowed and Young,** An organisation that acknowledges the needs of men and women widowed young. Can offer support for members’ children: <https://www.widowedandyoung.org.uk/>
* **Winston’s Wish** supports bereaved children and families. Helpline 08088 020 021 9-5 weekdays , [www.winstonswish.org.uk](http://www.winstonswish.org.uk)
* **Youngminds,** national charity committed to improving the mental health of all children and young people. [www.youngminds.org.uk](http://www.youngminds.org.uk) Parents helpline 0800 802 5544 Young people can text YM to 85258 for support.
* **Youth Access,** Helpline: 020 8772 9900 e-mail: [admin@youthaccess.org.uk](mailto:admin@youthaccess.org.uk)  [www.youthaccess.org.uk](http://www.youthaccess.org.uk) Provides young people with access to a counsellor nearest them, UK.
* [**Beyond Words** booksbeyondwords.co.uk](https://booksbeyondwords.co.uk/) offers a range of resources for those with a co-ocurring learning disability.

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| **Helen Etherington**  Senior Educational and Child Psychologist, Carmarthenshire County Council  **Willow Holloway**  Director, Autistic UK  **Dr Helen Matthews**  Consultant Psychiatrist  **Anne Marie McKigney**  Professional Advisor & Chartered Psychologist  **Sara Harvey**  National Strategic Lead Autism, WLGA |

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1. [Autistic fatigue - a guide for autistic adults (autism.org.uk)](https://www.autism.org.uk/advice-and-guidance/topics/mental-health/autistic-fatigue/autistic-adults) [↑](#footnote-ref-2)
2. [Stimming - a guide for all audiences (autism.org.uk)](https://www.autism.org.uk/advice-and-guidance/topics/behaviour/stimming/all-audiences) [↑](#footnote-ref-3)