**Bereavement – What Helps? Additional Q&A from the webinar**

This list of Q&A was created from the unanswered questions posed by audience members at the webinar hosted by Open Thanatology and the WELS Faculty at The Open University on December 7, 2022. The panellist (Andy Langford, Jane McCarthy, Kerry Jones and Korina Giaxoglou) and facilitator (Erica Borgstrom) have dedicated time outside of the webinar to respond the to questions below. In some cases, questions have been modified and/or combined in order to present them clearly and to maintain audience members anonymity. If you asked a question and do not see it answered here, this may be due to the specific nature of the question and/or it being beyond the scope of the session. Please note that recommendations to services are UK-focused and are not exhaustive of all services available.

**Q: What can we do to ensure our society and the statutory sector is better able to support the Death and Bereavement agenda?**

A: Panellists suggest taking a look at the recent report from the UK Bereavement Commission – as they've given this a lot of thought. <https://bereavementcommission.org.uk/>. They also suggest that people encourage conversations within their own social networks, starting small to help normalise death and bereavement.

**Q: What 24/7 support is available?**

A: For children, Winston's Wish offers 24 hour crisis support <https://www.winstonswish.org/crisis-messenger/>

Samaritans are open 24/7 for anyone who needs to talk (Tel: 116 123). You can [visit some Samaritans branches in person](https://www.samaritans.org/branches). Samaritans also have a Welsh Language Line on 0808 164 0123 (7pm–11pm every day).

Other support lines, such as CRUSE, tend to operate during working hours.

**Q: What other sources can we signpost people to?**

A: There are a wide range of sources and organisations that provide bereavement support. Here are some additional links beyond what has been mentioned in some other answers.

For bereaved adults and children: <https://www.thegoodgrieftrust.org/> and <https://childhoodbereavementnetwork.org.uk/>

Website with lots of signposting: At a Loss - <https://www.ataloss.org/>

Who to contact after a death: <https://www.gov.uk/after-a-death/organisations-you-need-to-contact-and-tell-us-once>

**Q: Is there any advice about ‘unfinished business’, such as if a bereaved person feels they have ‘unfinished business’ with the deceased?**

A: Several panellists commented on this in detail –

Kerry: Previously, I have encouraged individuals to write a letter to the person who has died and read it aloud if they can, where they can express the emotions that are held whether it is anger. This can be carried out in a safe space with a counsellor/friend. It may take several letters as there may be a lot to digest and to be expressed.

Andy: There are a few ways of looking at this. What I would advise is to think about the matter of 'unfinished business', through the lens of 'continuing bonds'. It can be very challenging for someone if they feel there are things unsaid between themselves and the deceased. It can be even more difficult if the relationship when the deceased was alive, included tensions, brokenness and/or abuse. It's important to think about how the bereaved wants to interact with the memories they have of the deceased, and what bonded them together, even if this is negative. There may be things the bereaved needs to say or do to put these memories to rest. This can include letter writing, as Kerry suggests Ruminating about the relationship can lead to low mood an increase in what is experienced as 'unfinished'. Finding ways to essentially 'locate' these memories as past events and not memories that need to effect current behaviour is really important.

Korina: 'Unfinished business' may result in what is known as 'complicated grief'. The work of mourning in this case may be accompanied by mourning for the loss of the relationship while the person was alive and feelings of guilt on top of grieving their death. To cope with this type of loss it is indeed important to try and separate the two and work on one's affective positioning to the person before and after their death in any way one feels is appropriate (e.g. letter writing, journaling, talking, drawing, reaching out to other people who knew that person etc.)

**Q: How do you encourage someone to get support?**

A: It can be difficult to encourage someone to seek peer or professional support if they are reluctant to do so. Be ready to listen about why they may be reluctant to seek support if you talk about this directly – this can help you understand their situation and perspective better. Sometimes it can help if you can provide details of support groups (in person or online) or accompany them to supportive spaces. If it is impacting their health, you can recommend that they speak to their GP.

**Q: If someone is grieving after a miscarriage, what support is available?**

A: Andy - I can recommend content from the Miscarriage Association - [Counselling after a miscarriage or pregnancy loss - The Miscarriage Association](http://www.miscarriageassociation.org.uk/your-feelings/counselling-after-a-miscarriage/) (there's some useful information present, not just focused on counselling). Also, Tommy's has a range of resources on their website - [Support after a miscarriage | Tommy's (tommys.org)](https://www.tommys.org/baby-loss-support/miscarriage-information-and-support/support-after-miscarriage)

**Q: Do you know of any techniques to use on anniversaries/birthdays and the emotions that may come with those significant dates?**

A: Kerry – I would plan ahead, and do something that marks the date such as a favourite trip, walk, gather family together. Some go on a trip and purchase a memento that reminds them. Find a good listener who can be with you, if you don’t want to be by yourself.

A: Korina - Social media are often used as sites for remembering loved ones on calendar-important days such as birthdays, anniversaries or even deathversaries. This proves for many to be a source of support on such difficult days and provide an opportunity for talking about loved ones and sharing memories, alone and together.

**Q: Are you aware of bereavement support specific for ASD or ADHD?**

A: Panellist suggest a few websites –

Child Bereavement UK have some useful resources on their website - [Supporting bereaved children and young people with Autism Spectrum Disorders (ASD) | Child Bereavement UK](https://www.childbereavementuk.org/information-bereaved-children-with-asd)

The National Autistic Society also have some useful information on their site, with resources, that focus on adults (autism, not ASD, but has some practical tips) - [Bereavement - a guide for autistic adults (autism.org.uk)](https://www.autism.org.uk/advice-and-guidance/topics/mental-health/bereavement/autistic-adults)

Winston's Wish, another childhood bereavement charity, is imminently publishing a blog reviewing resources for children with ASD. <https://www.winstonswish.org/>

**Q: Can Jane explain more about how the Senegalese deal with death?**

A: Jane - There were some things that were simply not part of the way people talked about the death, but the death was very much a collective experience. How to respond to the death was also very strongly framed through religion, but there was very little discussion of emotions. Material hardship and emotions were not separate. More details here: <https://bereavementjournal.org/index.php/berc/article/view/1046>

**Q: Any thoughts on culturally competent bereavement support in a diverse community context - how to deliver nuanced and personalised support in an agenda where the individual’s path and experience is unique and as discussed today sometimes policed?**

A: Jane - That's a million dollar question! We made some specific suggestions in writing up the Senegal research in the last part of this article here: <https://bereavementjournal.org/index.php/berc/article/view/1046>

This is what bereavement support services currently may find difficult to engage with. Knowledge of particular death rituals and immediate mourning customs is a start, but only a very first step. Beyond that the next step might be to ask the person or family concerned about their previous experiences of a significant death in their families, their relations and communities. In coping with a death, what is expected, and what they've experienced, amongst those they're close to, and have they found that helpful or not.

But I also think it's important not to underestimate the key value placed upon shared community relationships, and expectations. But also how for some, that may also be constraining. or at least, a mixed blessing perhaps. As the question says, such nuances are difficult to appreciate, so lots of respectful listening I think, with humility. And then, alongside that, there's the impact of having experienced life with a skin tone that is not white.

**Q: What advice do you give to someone who can only take two weeks’ for bereavement leave from work?**

A: Panellists recognise that for many two weeks may feel very short, especially if there are also practical tasks to do following the death. One suggestion is to speak with your line manager about options such as taking annual leave/ phased return/ alternative tasks for the job if possible. You can also discuss with them about what you need when you return in terms of if the bereavement should be spoken about or not, in terms of what would be most supportive for you. You can read short article by Kerry Jones about supporting colleagues when they return to work: <https://www.open.edu/openlearn/health-sports-psychology/mental-health/grief-during-covid-19-supporting-our-colleagues-return-work-and-thrive-following-loss>

**Q: Is there a time when someone should stop grieving?**

A: The panellists agree that there is no set time for when grief ends, and that often people learn to live with grief and loss. They note that thinking in ‘should’ terms may be unhelpful for people. They encourage people to recognise the importance of the loss. If someone is experiencing that their grief is continuously making it difficult to maintain aspects of daily living, they recommend contact bereavement support services and/or one’s GP.

**Q: While prolonged grief is a controversial term, does it require unique treatments and/or support and are these effective?**

A: Andy - There's some evidence for the following being useful in cases where PGD has been identified: Discussing positive memories of the deceased and giving time for the bereaved to express distress in a managed and contained way; Developing emotional regulation and ways in which the bereaved can build coping skills; Help the bereaved to understand the nature of their attachment to the deceased and how this effects current relationships (and then supporting the bereaved to work out how they want their relationships to be like both now and in the future) - people can become incredibly lonely in response to the debilitating effects of PGD. Also, check out the following website - [Treatment Manual & Tools | Center for Complicated Grief (columbia.edu)](https://prolongedgrief.columbia.edu/professionals/manual-tools/) Dr Katherine Shear is an international authority on complicated grief. The materials on the site offer a particular set of protocols. Whether you choose to take them as a whole or consider using elements, the materials are well grounded in research.

**Q: Prolonged grief disorder was added to DSM-5, in trauma- and stressor-related disorders chapter. What is your opinion on this? Is grief getting more medicalised?**

A: Jane - This is a controversial area, much debated. There are certainly different ways of looking at grief, and Dennis Klass argues that the 'Western' model of grief has been exported to the rest of the world. But even within affluent 'Western' countries, writers like Granek argue that grief has indeed been medicalised. An alternative view is to understand a significant death as a life event for those affected, primarily experienced through everyday lives and relationships.

**Q: Are there positive transformational effects of mourning for mourners?**

A: Kerry - Yes, there are plenty of examples from people setting up their own support groups; lobbying government for changes in the law; raising money for charity in memory of the person who has died.

**Q: Does CRUSE have many male clients?**

A: Andy - Yes Cruse does help thousands of men each year. However, at any one time, around 80% of Cruse clients are women. We do not know the proportion of people who define themselves as non-binary. How information is gathered on protected characteristics is going to be reviewed as part of the organisational Equality, Diversity and Inclusion strategy.

**Q: How is bereavement and grief perceived in other minority cultures and backgrounds?**

A: The panellists recognised that this is a large question with a response that requires lots of nuance. Jane provides a brief response to note two key aspects: That is a very big question! And people who are from minority ethnic backgrounds in the UK are of course in the majority in the rest of the world. But two key aspects are that bereavement is much more likely to be experienced collectively, and for those affected by the death, their life experiences are more likely to include a difficult history of inequality and discrimination, leading to little trust in mainstream bereavement services. We need a lot more research on this topic.

**Q: What about the dying person? Might they have grief before death?**

A: Several panellists have responded to this and note that wide range of emotions that people may experience. Kübler-Ross’s famous stages of grief model was actually written about the experiences people go through when they know they have a terminal illness – it has long been recognised that someone may go through a range of emotions prior to their death as they confront their mortality.

A: Kerry – A range of emotions and feelings will be experienced and more. This is why it is important to spend time with loved ones, reminisce on the good memories and also reflect on what has been achieved.

**Q: What is anticipatory grief and how might someone be supported when they are experiencing it?**

A: Anticipatory grief is when someone begins the grieving process before someone else dies. Some people describe this when they know someone has a terminal illness or in the context of someone having dementia, although it is not limited to these examples. People may experience a series of losses ahead of the death. CRUSE offers a range of advice on this topic: <https://www.cruse.org.uk/understanding-grief/effects-of-grief/anticipatory-grief/>

**Q: When is the right time to reach out to someone who has been bereaved?**

A: The panellists acknowledge that there is no one single answer that will apply to all people: things like your relationship with the person, what the content of the contact will be, and their own personal preference may influence this. Researchers typically wait three to six months after a death before approaching a bereaved person to be part in a study. Social support and signposting to services can happen earlier than this time. You can also take your cue from the bereaved person – they may have posted on social media about wanting to talk or not or they may bring up the topic in conversation. If you are offering social support, naming practical tasks or what you are offering can be helpful for the person to be able to understand your offer of support and determine if they want to take you up on it.

**Q: Can we join your Open Thanatology group?**

A: Open Thanatology membership is currently open to Open University (OU) students, staff, and affiliated faculty. You can follow what we do on Twitter (@openthanatology) to hear about updates and join future events. If you want to be emailed about future events, please email Erica Borgstrom (see below); please note that we will only use your contact details to share information about our events and resources. If you are affiliated with the OU and would like to join, please contact Erica.Borgstrom@open.ac.uk.

If you want to know more about Open Thanatology, you can visit our site here: <https://wels.open.ac.uk/research/open-thanatology>

If you want access to free resources linked to topics about death, dying and bereavement, you can see them here: <https://www.open.edu/openlearn/health-sports-psychology/open-thanatology>

If you want to watch any of our past events, you can access them on [ORDO](https://ordo.open.ac.uk/projects/Open_Thanatology_Resources/93488#:~:text=Open%20Thanatology%20is%20the%20OU's,of%20our%20events%20and%20resources.). Recording from this webinar is also available on ORDO: <https://ordo.open.ac.uk/articles/presentation/Bereavement_-_What_Helps_/21689027>