

Anticipatory, or 'living' grief is where someone experiences feelings of loss before a person dies – possibly long before the actual time of death. Health and Social Care professionals need to be aware of anticipatory grief and alert to situations where it may be affecting people or families in their care. This could be the partner of a person with dementia, the child of someone with a terminal illness or parents whose child has a life-limiting or life-altering condition, such as a lifelong learning disability.

People may experience anticipatory grief in different ways. Some may feel guilty about the way they feel, while others may not recognise, they are experiencing a grief response at all.

Anticipatory grief can be thought of as a journey. The path someone thought they were on now looks very different, and they must navigate a new and unfamiliar way. This can be a frightening, uncertain or lonely experience. People may feel grief for the person who's changing in front of them. They may grieve the loss of their own identity, especially if they have taken on a caring role. They may also grieve for the loss of the future they had imagined together or the hopes and dreams they held for their child.

Anticipatory grief may last for many years. Although there may be times of stability where life feels more manageable, events, like a change in a person's condition, an admission to hospital or a move to residential care, can reawaken feelings of grief. When supporting someone in this situation, it can be helpful to think of it as accompanying them for a short part of their journey. It can be difficult to know what to say. Saying things like "at least they're still here" is generally not helpful. Sometimes it's appropriate not to say anything at all, but just be with them, giving them a safe space to talk, cry or just 'be'.

Affirming with people that how they are feeling is a natural response to grief or loss, or simply acknowledging their thoughts and feelings can also be an important first step. People may also appreciate being directed to sources of support. Meeting with others who are going through a similar experience can be a comfort. Finding ways of connecting with a person with dementia, through music or by sharing happy memories, can be helpful.

For parents, making memories with their child, and any siblings, can be very valuable. Supporting the wider family is also important. Helping relatives feel more prepared and making an Anticipatory Care Plan can help them navigate this time. This can help with some of the fear or uncertainty before and around the time of death. When an adult or child dies after a long illness a new wave of grief is usually triggered in those close to them. Families say that it can feel as though they lose the person twice. It's important for health and social care teams to recognise this. It's unhelpful to make comments about the death bringing 'relief'. People may be comforted knowing their relative is no longer suffering, but it's still likely to be a very painful time and can come as a shock. Often a simple acknowledgment of their loss is most appropriate.

Experiencing a long period of anticipatory grief doesn't necessarily lessen feelings of grief at the time of death. The sudden loss of a caring role and contact with people such as nurses or carers can also be isolating. Be sensitive about the removal of aids and equipment from their home and ask the family about their wishes. Try to affirm the important role they had in caring for the person who has died. Small acts of sympathy are often important to families. This may be as simple as a letter of condolence, or a phone call. A meeting with the healthcare team may also be appropriate but consider where best to do this. Returning to a hospital or care setting might be a painful experience soon after a person has died.

Anticipatory grief can be a long and lonely journey. People might find they come in and out of periods of grief over a sustained period of time. But each person's experience of grief, and their response to it, will be unique.

As health and social care professionals, we have the opportunity to recognise anticipatory grief, and come alongside people on this journey to help and support them find their way through.

The short animated film was produced in October 2021 and can be found at <http://www.sad.scot.nhs.uk/> or <https://vimeo.com/629251076>

For more information visit www.sad.scot.nhs.uk or contact supportarounddeath@nes.scot.nhs.uk

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