

Anticipatory Grief: A New Educational Resource for Health & Social Care Staff

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Abbreviated abstract: Anticipatory, or 'living' grief, is when someone experiences feelings of loss before the time of a death. This is often found following a diagnosis such as dementia, other terminal conditions, or in families of children with a life-limiting, or life-altering condition. We explore the development of a new short animated video resource for health and social care professionals on anticipatory grief with advice on how to support those experiencing this.

References:

- A Bereavement Charter for Adults and Children in Scotland, (2020) <https://scottishcare.org/bereavement/>
- A. Coelho *et al*, Current Opinions in Supportive and Palliative Care.12(1),52-57(2018)

Background

Anticipatory grief is a significant and under-recognised experience affecting a wide variety of people.

Scotland's **Bereavement Charter** highlights the need to recognise that grief can begin before a death and can be lifelong.

To **identify themes**, we interviewed experts from different backgrounds including Health Board Bereavement Leads, Spiritual Care Leads, Specialists in Palliative Care and Medicine for the Elderly, and third sector organisations. These themes formed the basis for an animation script which was then developed into a film that follows the story of two fictional families.

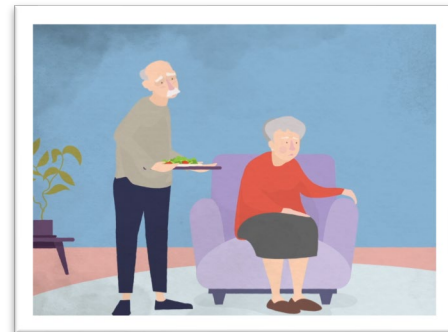
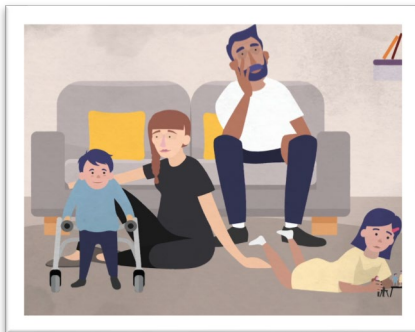
This resource has joined other short films developed by NES which provide a **suite of materials** (>72k views to date) that are quick to view for busy frontline health and social care professionals and aim to enhance their preparedness to manage care and communication related to themes of bereavement.



Animation

The film follows the family of a child with a life-limiting neurological condition, a lady with dementia and her husband.

The motif of a **road** is used to represent the journey of anticipatory grief.



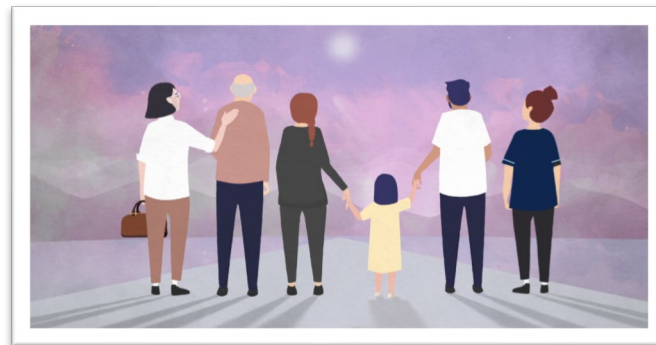
A significant diagnosis can change an individual's path completely. They may need to leave their hopes and dreams aside.

They may grieve for the loss of their own identity, especially if they have taken on a caring role.

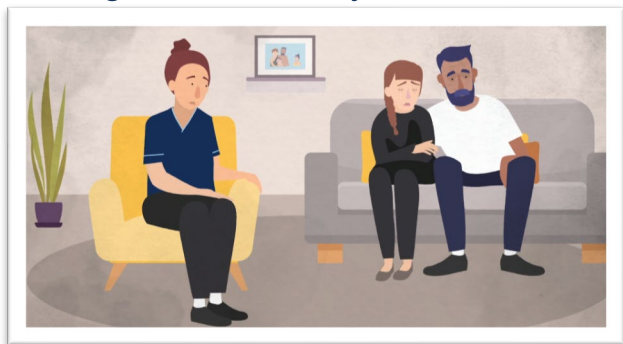
Uncertainty, fear and loneliness can often be experienced.

Key Messages

- Anticipatory grief can be long-lasting and multifaceted
- A prolonged time of anticipatory grief does not usually lessen feelings of grief at the time of death
- Certain phrases such as '*at least they are still alive*' can be very unhelpful
- Anticipatory Care Plans can help families and carers to navigate uncertainty



As professionals, it can help to think of our role as accompanying individuals for a small part of their journey



Sometimes all that is needed is to stay quiet and listen

We are developing additional materials to accompany the video for use in small group teaching settings

Watch the film: the full animated video can be viewed on [NES' Support around Death website](#) alongside other resources on bereavement and grief for health and social care professionals.