

Anticipatory grief and unpaid carers

Richard Meade, Director Carers Scotland



Carers Scotland

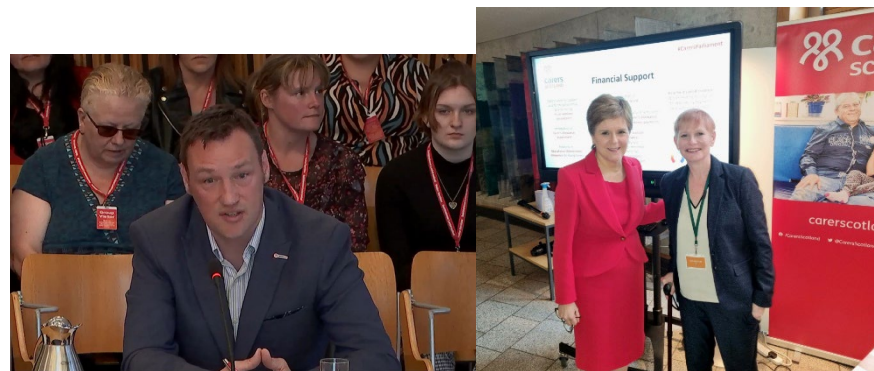
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9am-6pm, Monday-Friday on
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What is a carer?

Is someone who provides care to ill and disabled family members, friends, partners, or neighbours, they are unpaid, and they are often family members, friends, partners or people in the community. They support a person with daily activities who wouldn't be able to manage if they didn't have help. This could be someone who is seriously ill, disabled or who needs extra help as they grow older. Carers are normally described as unpaid, informal carers or family caregivers



What is anticipatory grief

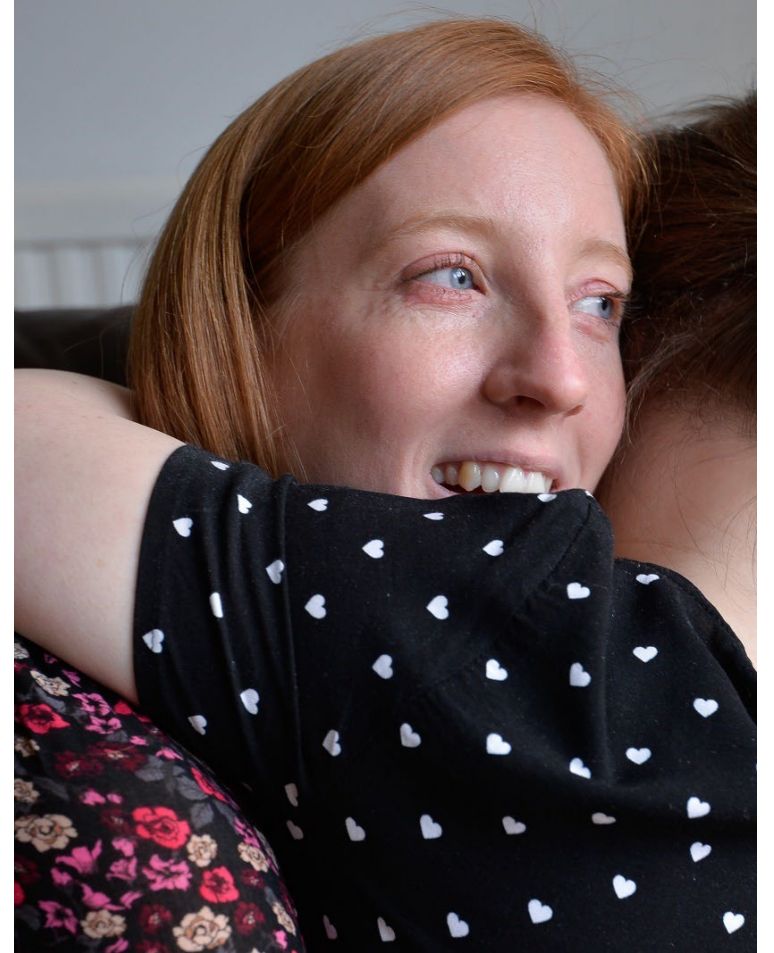
“is an emotional response to an expected and inevitable loss which occurs before the actual loss”.

- Can occur at any point – many years before a person has died or in the days before death.
- Carers experience stages of grief.



What does it look like for carers?

- Can take many forms and be experienced in different ways.
- Loss of intimacy and companionship.
- Changes in behaviour and personality.
- Sense of loss, despite being physically there.



What does it look like for carers?

- Can be constant and consistent.
- Can fluctuate.
- Accumulates over time.
- Significant impact on carer's sense of burden.
- Can lead to many emotions.
- More intense than conventional grief?



Anticipatory Grief – carers reflection

“I think what people don't understand is it's a very lonely place to be a carer, because you're no longer part of a, in reality, you're no longer part of a couple. [...] because the person I'm looking after now is a shadow of the person that I married [...] Its sad to see the life you had.” A carer of someone with MS

“[...] but it can be quite difficult, especially when you no longer have the same relationship with the person. You know, he's not my husband anymore. We don't go to bed together, we don't cuddle the same, you know, we don't snuggle up together [...]” A carer of someone following a severe stroke



How common is it?

- Hard to say precisely but is common.
- May vary between disease of cared for person.



Recognising anticipatory grief

- People may not recognise anticipatory grief.
- Anticipatory grief can be mistaken for other health problems
- A taboo?



Unresolved anticipatory grief

- Significant impact on mental health.
- Lead to complicated grief post-death.



Addressing anticipatory grief

- Recognise anticipatory grief in unpaid carers.
- Training and support for professionals.
- Support carers experiencing anticipatory grief.
- Raise awareness of anticipatory grief.
- More research.



Thank you

TWITTER: @richardmeade13

EMAIL: richard.meade@carerscotland.org

