

Bereavement experiences of older people

Dr Caroline Pearce

Research Fellow

University of Edinburgh

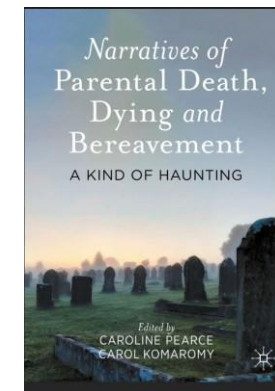
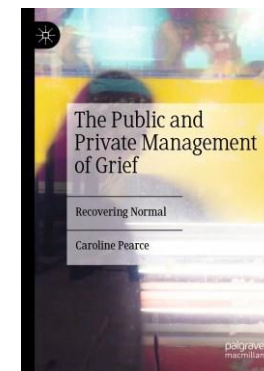
caroline.pearce@ed.ac.uk

About me

- I am currently a Research Fellow at the University of Edinburgh based at the **Advanced Care Research Centre** which aims to improve the care people receive in later life
- **'Environmental support for flourishing in older age'** explores what supports older adults to spend time outdoors and enables them to flourish in later life
- Conducted over 90 interviews with people aged 50 and over living in Scotland during 2021-23.

I have worked on/led a number of bereavement studies including:

- a survey of UK bereavement care practitioners during the pandemic
- a realist review of complicated grief support in primary care
- PhD study of recovery following bereavement – including interviews with bereaved people and bereavement counsellors
- Edited book on experiences of parental death, mostly in later life



Setting the scene...

- Advancements in health care has meant that for many people, particularly in developed countries, death most commonly occurs in later life (after age 65)
- Older people are more likely to experience bereavement– grieving for contemporaries such as partner/spouse and friends, as well as parents

Yet older people are often not seen as a priority for formal bereavement interventions

Negotiating societal assumptions around bereavement and death in later life

Bereavement in older age is part of natural order

"They had a good run"

Bereavement in later life is less problematic or emotionally intense

Older people are better equipped to deal with death

"a good innings"

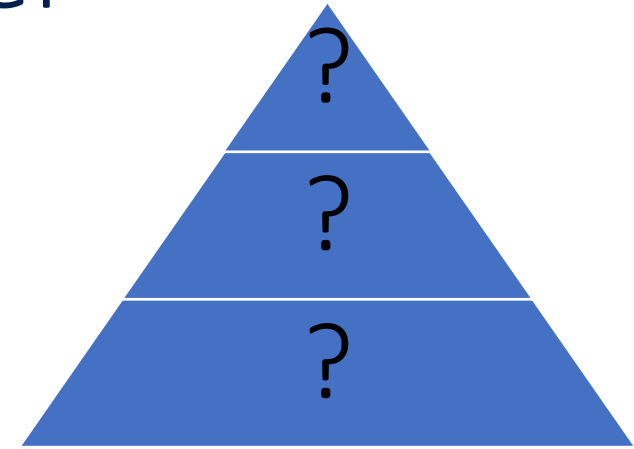
Easier for older people to adjust to losses

Older people's grief is therefore less important?

Social and cultural norms inform grief experiences at any age

- Normative hierarchies of grief
- Timely and untimely deaths
- Feelings of deserving and who has the 'right to grieve'
- Sense that grief has been 'disenfranchised' or unrecognized

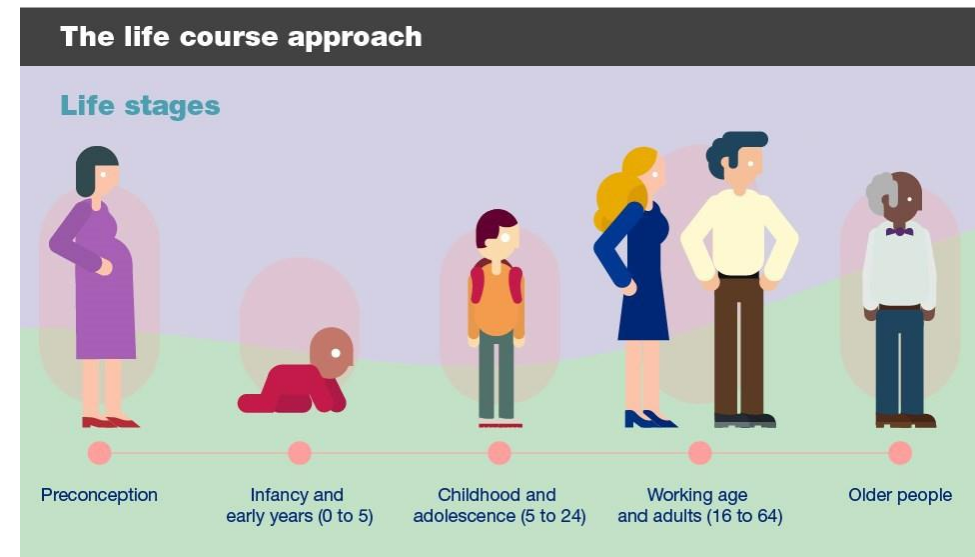
The relationship a person had with deceased tends to be key factor in how people grieve – but this expands far beyond familial or societal roles and obligations



Perceptions of the life course also inform attitudes to bereavement experiences

- Later life viewed as period of decline with increasing physical inactivity
- Narrowing of life possibilities: assumption that older people less likely to change behaviours or try new things
- Limited potential for growth and living beyond loss: identity becomes 'fixed'

... Later life can be and is full of changes and transitions



<https://www.gov.uk/government/publications/health-matters-life-course-approach-to-prevention/health-matters-prevention-a-life-course-approach>

Lack of broader understanding of bereavement experiences of older people

"Majority of the studies that do exist have focused on two narrow but important issues: the health consequences of bereavement; and the impact of spousal loss. Consequently, there remain significant gaps in our knowledge about the bereavement experiences of older people (O'Hansson and Stroebe, 2007)."

- Croxall, J. (2016). Bereavement Support in Later Life: An Emerging Social Problem for the Twenty-First Century. In: Foster, L., Woodthorpe, K. (eds) Death and Social Policy in Challenging Times. Palgrave Macmillan, London.

Ageist attitudes?

- Value placed on the lives of older people within different societies
- Significant bereavements in later life more likely to be deaths of other 'older' people (e.g. partner, parent, sibling), in other words, expected and timely deaths
- Perceived value of the life of the older bereaved person and value of the life of the older person who has died

COVID-19 and ageism

The Telegraph

News Sport Money Business Opinion Ukraine Royals Life Style Travel Culture Puzzles

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'Ageism' is to blame for Britain's high covid death toll, Age UK boss suggests

By Gabriella Swerling, SOCIAL AND RELIGIOUS AFFAIRS EDITOR
16 January 2021 • 6:00pm

<https://www.telegraph.co.uk/news/2021/01/16/ageism-blame-britains-high-covid-death-toll-age-uk-boss-suggests1/>



Covid: Boris Johnson resisted autumn lockdown as only over-80s dying - Dominic Cummings

🕒 20 July 2021

<https://www.bbc.co.uk/news/uk-politics-57854811>

Who is defined as 'older'?

- Increasing retirement age – later life shifting
- Research studies tend to focus on 65 and over
- Acknowledging geographical inequalities in life expectancy
- In Scotland: increase in premature mortality (death under 65) in recent years
- Since 2011 mortality rates have stalled across UK and inequalities deepened
- Not just about biological age



An ageing global society: Implications for bereavement in later life?

- Across the world, people are living longer, especially in high income countries
- In 2021, the World Health Organization estimated that by 2030 one in six people will be aged 60 or older.
- Increased life expectancy in western countries has meant first experiences of death tend to come later in life
- More people in need of care and for longer
- But also more older people involved in caring for others for example grandparents more involved in care of grandchildren, looking after parents etc



Types of bereavement experienced in later life

- Death of spouse or partner – most researched bereavement experiences (widows in different sex relationships)
- Death of siblings
- Death of friends and peers
- Death of parent
- Death of an adult child or grandchild
- Death of a pet
- Anticipatory grief – caring for person with long term illness such as dementia

Increased risks? Physiological and psychological

Physical health impacts

- Morbidity and mortality - risk of death significantly higher after the death of a cohabitee - greatest in the first three months of bereavement (King et al. 2017)
- 'Broken heart' – increase in heart disease/cardiovascular events
- Existing health conditions that are exacerbated by bereavement or that make managing grief more difficult

Mental health impacts

- Social isolation and loneliness
- Existential crisis- loss of sense of self and identity (Fang and Carr 2021)
- Reflecting on own mortality
- Complicated or prolonged grief

Complicated grief: research from The Netherlands

- Newson et al. (2011): 'The prevalence of complicated grief in older adults in the general population was noteworthy'.
- Time since bereavement and relationship to deceased, particularly when the source was a spouse or child, were predictive of complicated grief.
- People with complicated grief were older, had a lower level of education, and more cognitive impairment.
- Bruinsma et al. (2015): Preexisting conditions such as depression more important in explaining the occurrence of complicated grief than circumstances of death.

Figure 1 Overview of identified psychological and physical effects of grief on older people.



Wider socio-economic impacts

- Caring responsibilities – chronic illness, long periods of ill health before death
- Moving home and downsizing – practicalities of managing household and finances
- Losing peers and social networks
- Constructing a new identity/finding meaning e.g. after death of long term partner
- Loss of shared past/identity rather than future
- Accumulation of losses

Experiences of bereavement: Spotlight on the Advanced Care Research Centre (ACRC) project

- The ACRC is a multi-disciplinary research centre at the University of Edinburgh focussed on ways to improve care in later life.
- Research is not about bereavement specifically.. But we found bereavement experiences were interwoven into the lives of many of the participants
- Following extracts are from interviews where people were not asked about bereavement but the topic came up organically
- Focus of interviews was on understanding what supports people to spend time outdoors
- Participants aged 51-88 living in different parts of Scotland

End-of-life caring experiences



Photo taken by researcher on walking interview with participant

I go down there, along the beach path [...]. **I did that quite a lot last year after I lost the wife, just to get out the house**, because I had six months where I couldn't leave her. I was looking after her 20 hours out of 24 hours a day. [...] I always remember she died in the early hours of the Saturday morning, and on the Sunday I was sitting here and I thought, I'm needing to get out the house.

And I put my coat on, I went across the road there and **I thought, I don't need to hurry back today. That was a strange feeling.** After being so intense focus within the sort of the four walls, and I walked all the way into the [local area] and all the way back. I didn't have a wallet with me, didn't have my bus pass, didn't have money with me, I just walked in, all the way into the [local area], turned round, came back by the road there.

(Male, 79)

Cumulative losses



“But this is what happens when you’re older, your friends die. I had three brothers and they’ve all gone. Well I don’t have many relatives now...So, you know, as you get older people vanish in your life.

I thought, what’s happening to me, you know, and it all happened around about the same time. So that’s quite difficult when everybody that you know seems to have left you, you know.”

(Female, 84)

Photo taken by researcher on walking interview with participant

'Losing your person': Death of a spouse



“It’s a big, big loss and it’s...I said to people, we’re all lost people very, very close to us. **But it’s a different feeling from the person you chose to be with.** You’ve made that choice and that’s the difference... it’s just a different feeling altogether. I was a daddy’s lassie and I miss my dad greatly but it was in an entirely different miss for [R].

I think that’s what you can’t get over, because nobody can understand unless they’ve been there. It’s something that nobody can understand, **because I’ve sympathised with people in the past, for losing their person. But never realising just what it was.**

(Female, 83)

Losing social networks

“I don’t go far now. ...because I’m alone. Unfortunately all my friends I did have locally have all died within the last year.

It’s quite hard going. But, you know, and we keep saying, it’s our age... we’re in that era. Because I’ll be 84 in July and they were all much the same age as I was. It was just an age, which, as I say, is difficult because **there’s no other way of getting friends like that, because you had these friends for so long.**”

(Female, 83)

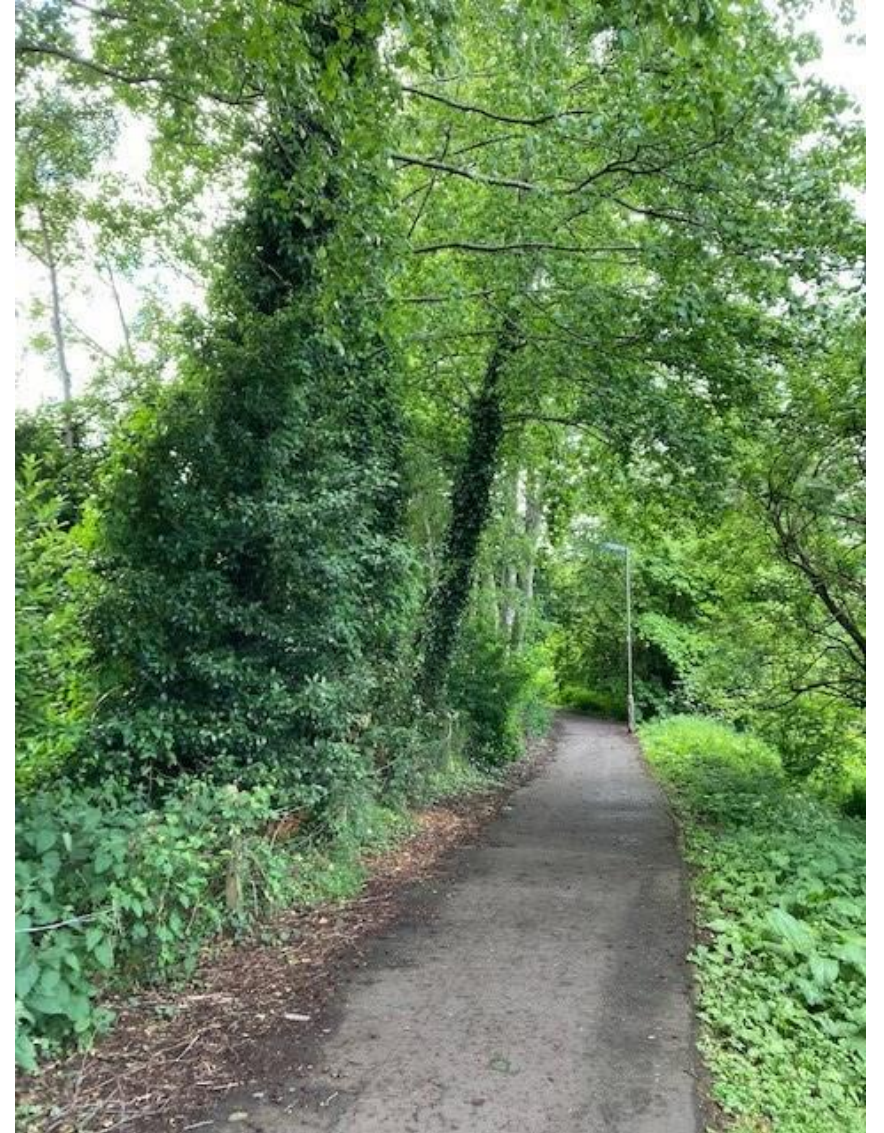


Photo taken by researcher on walking interview with participant

Losing social networks during pandemic



Photo taken by researcher on walking interview with participant

I: And how long is it that you've had difficulties in getting out and walking?

P: Quite a long time now. Well during the pandemic I think it got worse... And that's why I started joining clubs because I didn't know anybody to go out with, you know.

(Female, 84)

COVID-19 and accelerating ageing?

- Impact on individual routines and in turn physical and mental health
- Shielding and isolation – long term impacts
- Efforts to get out during lockdowns
- Ongoing concerns about going out and losing confidence
- Closure of vital community services and facilities

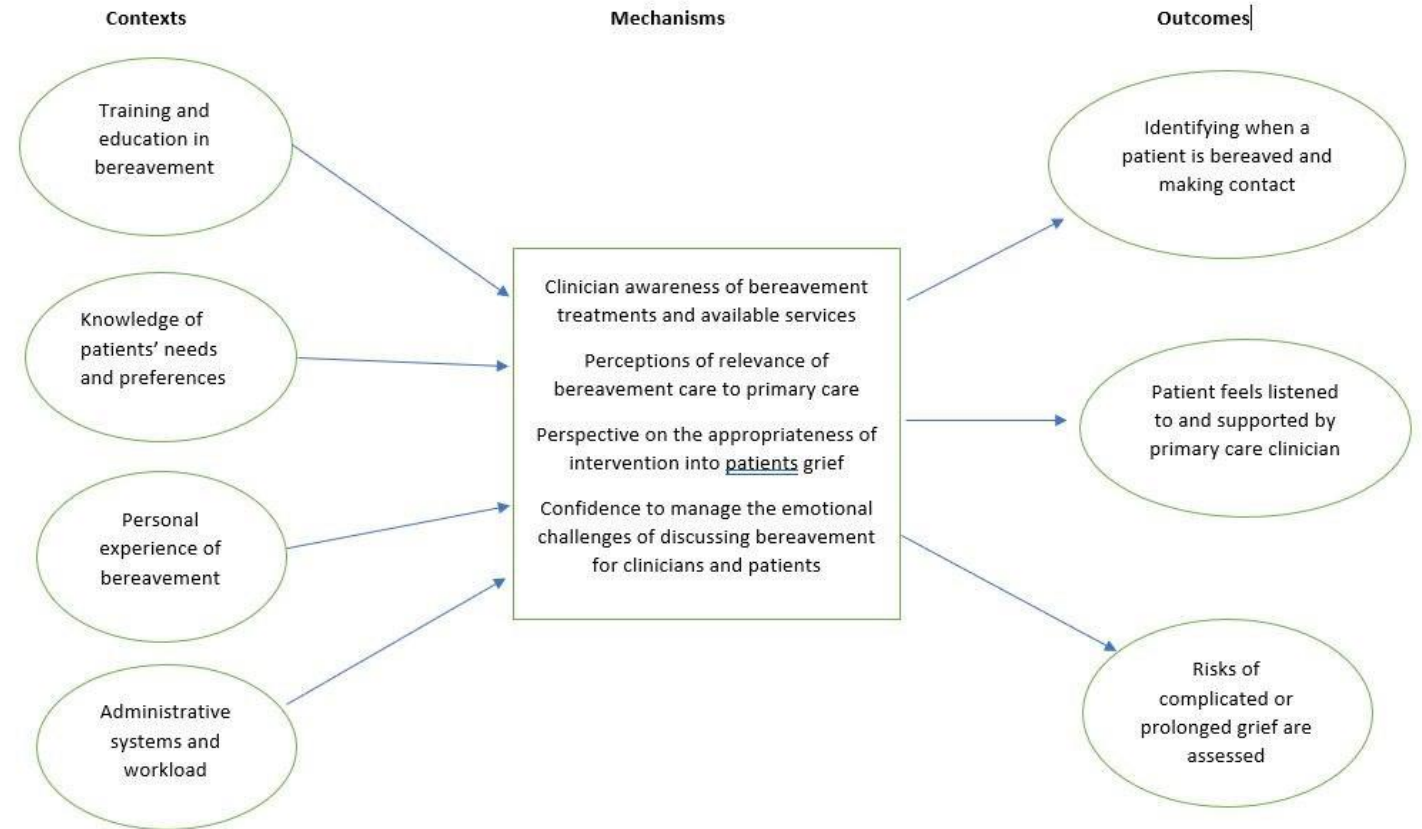
“I do think we, as a couple, have, sort of, quietened down a bit, you know, because of the lockdown and COVID. We don’t really go out as much. ...My husband, he was on the shielding list, so we were a wee bit more wary about it, and ...well, we got out of the habit of going out... We don’t go out to pubs or anything, now... You know, we’ve got into that age, we don’t need it, you know.” (Female, 70)

“...I was shielding for all that time, I was shielding for seven months. So, [my daughter] said, you need to get out and go somewhere. I started going round the block and then I ventured into the park and I just go to the park now.” (Female, 84)

Forms of support: formal care

- Role of primary and community care
- Social prescribing and link workers
- Voluntary organisations

Figure 2. Final programme theory based on CMOCs displaying ideal outcomes



Supporting bereavement and complicated grief in primary care: a realist review, Caroline Pearce, Geoff Wong, Isla Kuhn, Stephen Barclay BJGP Open 2021; 5 (3): BJGPO.2021.0008.

Older adults less likely to seek support

Stephen et al. (2013) – support provided to older people can be opportunistic, preparation for death doesn't mean preparation for bereavement

Independent Age (2021) - Older people less likely to seek help

- 4% of people aged 65 and over who had been bereaved in the past five years sought extra support, compared with 9% of adults aged under 65.
- Asking for help seen as a weakness
- Unfamiliarity with counselling approaches
- Need someone to make suggestion – more than providing a phone no


Landscape since covid

- Increase in modes of support: telephone, online
- Reliance on online/digital may isolate older people further
- Shift to proactive rather than reactive approaches?
- Closure of community groups and centres
- More reliance on volunteers

Open access

Original research

BMJ Open 'A silent epidemic of grief': a survey of bereavement care provision in the UK and Ireland during the COVID-19 pandemic

Caroline Pearce ¹, Jonathan R Honey,² Roberta Lovick,¹ Nicola Zapiain Creamer,³ Claire Henry,¹ Andy Langford,⁴ Mark Stobert,⁵ Stephen Barclay^{1,2}



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'Being there' is what matters: Methodological and ethical challenges when undertaking research on the outdoor environment with older people during and beyond the COVID-19 pandemic

Caroline Pearce^{*}, Sara Tilley, Catharine Ward Thompson

OPENspace Research Centre and Advanced Care Research Centre, University of Edinburgh, United Kingdom

The role of social support

“I go to the folk club on a Thursday night. I used to go with my husband a long time before he had the stroke. .. [R] died four years ago come June. And I was beginning to feel I wasn't doing anything at all... I plucked up the courage and went to the folk club which was a bit daunting, going on your own the first time. But I'm glad I did, because I've been made welcome by the people that go.”
(Female 83)

Last October I was as low as I could go, and I walked in and the reception I got was brilliant. It's banter, non-stop banter. The kettle's never cold. We all help each other.” (Male, 79)

- Local community groups
- Places to connect: emotional support and rebuilding social networks
- Support with future bereavements
- Not necessarily badged as bereavement support

How to support someone?

- Avoid minimising even if feel inclined to focus on positive e.g. 'at least...'
- Reflect on own ageist attitudes – related to own fears around getting older?
- RCGP Compassionate bereavement response: Acknowledge, Ask, Advise, Act



Freedom in later life following bereavement

"...I was just always a wife and mum, you know what I mean. That's it. That was who you were. You know, sometimes you didn't get even get your name. You know, are you [G]'s mum, or, are you [T]'s mum, or...you know what I mean. Are you [H]'s wife... you didn't really have an identity... I feel freer because I can go to a club...sounds...I mean, it's not anything exotic, but I can go to a club. ... Whereas before you couldn't have done that. Your life was needed elsewhere."

(Female, 76)

Summary

- Older people are more likely to experience bereavement, yet older people's bereavement experiences are often overlooked or not prioritised in research and in practice
- As the population gets older, and as we come to experience bereavement at later stages in life, attention to the broad and varied nature of bereavement in later life is required (i.e. widening out from narrow focus on health impacts)
- Formal health and social care staff and informal community networks have a key role to play in addressing issues such as social isolation and loneliness which can be caused and/or exacerbated by bereavement

Thanks for listening!

- Have you faced any challenges when supporting bereaved older people?
- Anything not covered in the presentation you would like to highlight/mention?

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