

‘Alive, but just a shell’ – the grief that haunts dementia caregivers

It’s called pre-death grief and it afflicts caregivers even before the physical loss of their loved one.

Chetna Malhotra

Dementia is a condition that robs individuals of their cognitive functions, eroding over time their personality and changing their behaviour.

As the disease progresses, families and friends of those affected grapple with the sadness and helplessness of losing the person they once knew, while also anticipating the inevitable physical loss.

This unique form of grief, experienced while the loved one is still alive, is known as pre-death grief. It is a complex emotional journey for caregivers and can be as challenging as mourning the physical loss of a person, warranting attention and compassion.

For a long time, the common belief was that this pre-death grief would help prepare caregivers for the eventual loss they would experience. But, as with other forms of loss, it turns out that denying these feelings

has far more harmful consequences.

Consider the story of Alex*. Alex’s relationship with his mother, Madam Tan*, was fraught with conflict for years. Madam Tan was known for her domineering personality and had strong opinions about almost everything in Alex’s life, including his spouse.

Her disapproval of his marriage was so intense that she threatened not to attend Alex’s wedding and caused significant strain on his young marriage. For a time, Alex found himself caught between a domineering mother and a strained marriage, leading him to live separately from Madam Tan.

Years passed, and the fractured family dynamics gradually healed. However, as Madam Tan’s dementia progressed, the once vibrant matriarch became a passive shell of her former self. The sharp arguments and daily phone calls that once punctuated Alex’s life were replaced by silence.

One particularly poignant moment for Alex occurred when he visited his mother at her home. Now, Madam Tan sat quietly, rarely speaking more than a few words throughout the evening. The forceful, assertive woman he

remembered was gone, replaced by someone who barely engaged with him. He found himself mourning the loss of his mother in a new way, and he struggled to reconcile the stark contrast between the mother he had known and the one she was now.

This shift in their relationship left Alex feeling guilty and helpless. He found it difficult to share his feelings with others, leading to a sense of isolation. Unlike traditional post-death mourning, which garners sympathy and support, pre-death grief can be harder for friends and acquaintances to recognise and validate, leading caregivers to feel unsupported.

And Alex is not alone. We found that about 35 per cent of caregivers of individuals with

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advanced dementia experience high levels of pre-death grief. In our study, those caring for individuals exhibiting changes in their behaviours and those living with their loved one are more likely to experience this form of grief.

This study, initiated in 2018, surveyed 215 family caregivers of community-dwelling individuals with advanced dementia. It currently follows these caregivers every four months, gathering insights into various aspects of their caregiving journey.

CAREGIVER BURDEN OR PRE-DEATH GRIEF?

What makes pre-death grief difficult to identify is that it is often confused with caregiver burden.

Caregiver burden typically refers to the physical, emotional, financial and social stresses associated with caregiving. While caregiver burden is well recognised as a very real and pressing issue in the context of dementia, pre-death grief is a distinct emotional experience. While higher caregiver burden may also contribute to pre-death grief, many caregivers experience it even in the absence of significant burden.

But pre-death grief doesn’t just affect the caregiver experiencing the loss.

In another study carried out by the Lien Centre for Palliative Care at Duke-NUS Medical School, we found that pre-death grief increases the risk of hospitalisations and emergency department visits for the person with dementia. We speculated that caregivers’ pre-death grief reduces their ability to cope with older adults’ deteriorating condition at home and possibly leads them to seek more hospital-based care including life-prolonging treatments.

So, rather than serving as a protective factor, our recent research indicates that higher

levels of pre-death grief can increase the risk of prolonged grief during the bereavement period, highlighting the importance of early recognition and support for caregivers.

HELPING THE CAREGIVERS

Pre-death grief often goes unrecognised, so addressing it requires societal awareness. This involves an understanding that the grieving process begins before the physical loss of a loved one, and that feelings such as guilt, anger and sadness are normal reactions during this time. Certain events, like birthdays or anniversaries, may intensify these emotions.

Just as in traditional mourning, it is important for communities, families, friends and acquaintances to validate and acknowledge these emotions, providing appropriate emotional support. Caregivers themselves should recognise their emotions as grief and seek ways to honour and preserve the remaining connections with their loved ones and celebrate the life that remains.

Over time, with support from social networks, most caregivers adapt to the loss. Some may require additional help from community support groups. If grief remains unresolved, caregivers should seek help from a healthcare provider.

By recognising and validating pre-death grief, we can offer more comprehensive support to our caregivers and ensure that every facet of the caregiving experience is acknowledged and respected.

• *Pseudonyms were used in this commentary.

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